

Consultation with children and young people accessing Child and Adolescent Mental Health Services (CAMHS) and their parents, about how their need to access a service and the treatment they receive supports them in their mental, emotional, social, intellectual and physical wellbeing.

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Abbreviations

NHS: National Health Service

CAMHS: Child and Adolescent Mental Health Service

ASD: Autism Spectrum Disorder

OCD: Obsessive Compulsive Disorder

TS: Tourette's Syndrome

AN: Anorexia Nervosa

HYV: Highland Youth Voice

ASN: Additional Support Needs

NICE: National Institute for Health and Clinical Excellence

SLG: School Liaison Group

Introduction

Recently there has been a move from the focus of mental health services on the treatment of ill-health to a wider focus on the promotion of positive mental health (Jane-Llopis & Anderson as cited by SE 2006). The Mental Health of Children and Young People A Framework for Promotion, Prevention and Care (SE 2005) recognised that mental health services were not just about providing a service to people who had a mental health problem, disorder or illness (mental ill-health as defined by British Medical Association (BMA) 2006), but about all services who work with children recognising the need to promote good mental health, work preventatively with

groups of children or young people who are vulnerable to developing mental health issues as well as ensuring that when a child or young person has a mental health need that they receive the right care and support for their mental health and wellbeing.

The Scottish Needs Assessment Programme Report on Child and Adolescent Mental Health (Public Institute of Health 2003) recognised the benefits of listening to and involving children and young people in consideration of mental health and wellbeing. This was reflected in the subsequent framework for promotion, prevention and care (S.E. 2005). The benefits of such participation are two fold, firstly to inform the development of Child and Adolescent Mental Health Services (CAMHS) and secondly the process of being listened to can contribute to the child or young person's feeling of wellbeing. This study has been carried out to ensure the views of young people are included in the review of the implementation plan for CAMHS in Highland.

The focus of social research internationally (Organisation for Economic Cooperation & Development (OECD) 2007) has moved from looking at objective measures of socio-economic or health status to consideration of the more subjective area of people's wellbeing, recognising the significance of wellbeing in childhood as a predictor of outcomes in people's lives.

There is recognition that the mental health and wellbeing of individuals will have a profound impact on their personal life journey but also there are serious implications for the mental 'capital' of the nation, and consequently for the economy. (Bed-dington et al 2008)

Certain pressures on people's wellbeing, risk factors, make them more vulnerable to mental health problems

(Equally Well SG 2008; Towards a Flourishing Scotland, SG 2009) and having a mental health need impacts on wellbeing and quality of life. (Bastiaansen as cited in Storch et al 2007). Mental health and wider wellbeing are interdependent.

There has been an increasing body of research considering the wellbeing of children and young people over the last decade some of which have listened to children and young people to gain their self-assessment of wellbeing (Children's Society (C.S.) 2006, Counter Point Research 2008). Children and young people identified a range of issues which contributed to their wellbeing and in the "Good Childhood? A question for our times" study (C.S. 2006) ten themes were identified as being important in having a good life.

The consultation project with young people for the CAMHS review in Highland is divided into three pieces of work; one study working with young people in universal services to inform the promotion of wellbeing amongst young people, one study working with young people with additional support needs who may be vulnerable to mental health issues to understand how wellbeing and resilience might be supported to prevent development of mental health problems and one study working with young people accessing mental health services to find out how their need to access a service and the treatment they receive supports their mental health and wellbeing across the identified 10 themes (CS 2006).

Due to the subjective nature of wellbeing, and in recognition that not all young people would identify exactly with these themes, participants were asked in the first instance to consider what makes a good life for any young person. If young people did not include any of the ten themes these were offered as suggestions of things that might be important, which young people could agree to include or not.

Sometimes young people had additional themes. This allowed young people to develop their own themes which might overlap but not be identical to the 10 themes. Young people could then consider their own wellbeing compared to their self-identified priorities.

The ten theme basis allows for comparisons to be made between the views of young people with different levels of mental health need whether promotion, prevention or care considering both their idea of what 'wellbeing' is as well as their own experience of wellbeing.

The views of young people can be examined to consider what integrated children's services can do to promote good mental health and wellbeing, how services can support strengths and reduce pressures to help prevent mental health problems developing in vulnerable young people and how the care provided to young people with mental health needs which require input from a specialist Child and Adolescent Mental Health service can improve their mental health and support young people in maintaining their broader wellbeing.

This report is from the study consulting young people who access child and adolescent mental health services in NHS Highland to ascertain how services can best support both their mental health and their wellbeing. Where young participants agreed, their parents were also asked for their views about how having a mental health need and the health services their son or daughter was receiving was affecting his or her wellbeing.

Method

Participants

The participants were sought from young people who were currently or had been recently accessing a service from the Phoenix Centre for Child and

Adolescent Mental Health Services for NHS Highland.

The proposal had been for professionals to give young people invitations to the study when they came in to the Phoenix Centre. In practice, professionals found this difficult to do in the context of a therapeutic session. The Phoenix Centre then posted invitations and information about the project to young people, but there was conflicting information about who to contact if they were interested in participating. This resulted in willing participants responding directly to the Phoenix Centre rather than to the consultation worker and then the contact details not being passed on. The Phoenix Centre contacted young people again inviting them to come in to the Phoenix Centre and meet the Children's Consultation Worker to discuss the project and decide if they wished to participate. Although 12 participants were sought, only 4 young people came forward. All four young people consented to taking part and to their parents being invited to participate as well. One of the parents had a second young person who also had experience of mental health services. While that young person did not wish to participate, they consented to the parent contributing her experience.

One young person provided the imaginary story but later withdrew from the project. The other three were young females, aged between 15 and 17. Their mental health issues included Anorexia Nervosa (AN), Tourette's Syndrome (TS), Autistic Spectrum Disorder (ASD) and Obsessive Compulsive Disorder (OCD).

Although this was a smaller number of participants than planned, it was agreed to proceed. While the views of 3 young people and their parents can not be extrapolated to a wider population of young people with mental health issues, they are valid

testimony in themselves of the experience of these young people. These stories can also contribute to the wider picture of mental health and wellbeing developed from all three parts of the consultation project, looking at promotion, prevention and care.

The three participants had all taken part in previous unrelated health consultations with Highland Children's Forum and so had met and worked with the consultation worker. The trust that they already had in the CCW may have been a significant factor in their willingness to participate.

Participants were given pseudonyms beginning with sequential letters of the alphabet, Anna, Beth and Chloe. The young person who did not participate but agreed to parental participation was given the name 'Lesley' as this is non-gender specific.

Consultation

Each participant was asked to contribute two stories, one about an imaginary young person to consider the question "What makes a good life for a young person?" and a second story about their own experience asking "How does your need to access a service and the treatment you receive support your wellbeing across the areas in your life (as identified in the first question)?"

To consider the first question, participants were invited to draw a stick young person and to give him/her a name and an age. They were then asked to think about this imaginary person and consider what would be important for that person to have a good life. As the young person chatted about these, they would write down things they thought were important in a Mind Map style around the stick person drawing. The consultation worker (CCW) encouraged this by reflecting back what young people were saying, checking what was

important to them and asking open questions to expand their thinking.

For example if a young person said that a good school was important the consultation worker would ask "What might a good school be like?"

Once the young person had run out of suggestions, if any of the ten themes were missing the CCW would provide the theme and ask if this was something important to a good life. Sometimes the young person did think it important and would write more, sometimes they didn't and that theme would not be included.

The young person with ASD found it difficult to make up an imaginary young person, and felt she could only tell her own story.

Young people were then given a choice about how to tell their own story to ensure the media chosen suited the young person's self-expression style and was attractive and interesting as recommended for health consultations with young people (Madge et al. 2005, Laws, S. 1998). The media offered reflects some of the media used by other studies considering wellbeing; photography, Gabhainn, S.N. and Sixsmith, J., (2006), drawing and writing, Wetton, N (1998), focus groups and interviews, Garcia I, Vasiliou C and Penketh K, (2007), visual maps or symbols, MENCAP, (2001).

Young people could opt for

- face to face interviews
- virtual interviews over the internet (MSN)
- writing in a journal or other
- drawing and writing/telling what the drawings signify
- Photography making up a photo album and writing/telling the story around it
- through the use of visual 'maps' using symbols and

stickers to demonstrate emotions at different places/with different people

It was explained to the young people that the CCW would take the story and put it in to a Mind Map format and the journal or photo album would be returned to them. No photos would be copied.

One participant chose to have a face to face interview. The others opted to write their story in a journal. Journals were supplied and young people given a month to complete them.

Each of the stories was put in to a Mind Map around the themes considered important by the young person. The Mind Maps were sent to the young people for editing and they could change or add anything.

Parents of the remaining participants were contacted and the three mothers consented to take part. The mothers were offered interviews at a time and place which was suitable for them. The project was explained to the parents and consent sought.

Parents were asked the following questions:

"Consider your son/daughter's need for a mental health service. How has that affected him or her in all areas of her life?"

"Consider the treatment your son/daughter has received for his/her mental health needs. What has that been like for him/her?"

"How do you feel the service received has affected his/her mental health and wellbeing across all areas in his/her life?"

"Are there any other comments you would like to make?"

These interviews were recorded, transcribed and then the audio

recordings deleted. The interview notes were then put under the headings of the wellbeing themes and experience of mental health services. Another heading around 'concerns being raised' was given as this was the starting point of the story for parents. In consideration of services received parents included reference to social work and education. These comments were considered under experience of integrated services. The stories were sent to parents to be edited.

Although pseudonyms were used, the small number of participants means that professionals working with these individuals might recognise them. It was especially important therefore that all participants, young people and parents, were able to both view and edit their stories in the knowledge that they might be recognised by health staff in the Phoenix Centre or other professionals.

Results

The Good Childhood Study (C.S. 2006) 10 themes for wellbeing are:

- Family
- Friends
- Leisure
- Learning
- Behaviour
- Local Environment
- Community
- Money
- Attitudes
- Health

Imaginary Stories

What is wellbeing?

In the imaginary young person stories, most of these themes were included.

Family:

The things identified as being important for a good life was a family that spent time together, both social time and meal times. Personal space was also important. Family should be supportive and accepting.

Friends:

Close friends who accepted you and were supportive were mentioned along with friends who were a good influence and who had shared interests.

Learning:

A good school with good teachers and pupils ('not nerdy'), good subject choices and a good reputation was important. The need for the young person to work hard was also noted.

Health:

Good health for the imaginary young people was about having good underlying health as well as choosing a healthy lifestyle.

Apart from the consideration of whether or not it was good to have a part time job while still at school, there was general agreement about what would be important for a good life for a young person.

Leisure:

Sport was identified as an important leisure activity along with hobbies, cinema, music and dance. The benefit of leisure was that it was relaxing, a distraction from problems and a way to meet new people.

Attitudes:

The young people did not say anything which specifically referred to attitudes. However, it was mentioned that family and friends should be supportive and caring. One young person thought that being confident was important.

Behaviour:

Behaviour was not mentioned by the young people as being important.

Money:

'Financial security' or 'enough to live comfortably' was what young people considered to be important. One young person thought a good life would be not needing to work, just asking for money if needed; another young person thought that working and understanding the importance of

earning money was needed for a good life.

Local Environment and Community: Living in an area that was 'nice' and 'safe' was mentioned as important. Good public transport was also raised.

Real Stories

Under each theme the young person's view is presented first and then the parent's. Where a young person had an additional theme this is included. The parental story of concerns being raised and the experience of services are under their own headings.

Anna's Story

Anna is a 16 year old young woman with ASD.

Concerns raised

Anna's mother had known there was something different about Anna but her needs developed and she now shows some complex Autism Spectrum symptoms, although she has never been given a formal diagnosis. Although Anna has been recognised as having additional support needs since primary, her need for a mental health service is more recent. She was first seen by a psychologist, which her mother felt was not helpful as Anna does not have insight and is not able to work out her own solutions. She was then seen by a psychiatrist and was put on medication. This has helped certain symptoms such as anxiety.

Family

Anna lives with her mother and sister. She shares a room but would prefer to have her own space. Personal storage space, even in the fridge, is important to Anna so that knows what she has.

Anna's mother explained that she had recently divorced. While she is at work now, Anna's younger sister takes on the role of young carer. There has been no follow up from social work or anyone about the effect the divorce

may be having on Anna or the rest of the family.

Anna also needed to know the comings and goings of others; she did not feel safe if people could just arrive at the door of her home, even if they are family friends.

Friends

Anna does not mention friends as being important in her life.

Anna's sister is her social world according to Anna's mother, although this expands a bit in summer time when her brother is home.

Learning

Anna needed help to know how much she should study. Having a schedule was really important to Anna, knowing where she should be when and also what she should be working on.

Anna's need had initially been seen by the school as behavioural, according to Anna's mother. However, once they understood, the primary school was supportive. Anna has difficulty socially in school and this affects her attendance.

In secondary school Anna's support has not been well planned. Anna is now coming up to transition and there is no plan for her.

Guidance staff have been 'brilliant' to talk to, but nothing seems to happen as a result. School staff complain about Anna's poor attendance but do not look for solutions or suggest ways around it.

Health

Anna felt there was a lot of emphasis on diagnosis rather than understanding that *"not everything about me fits under a name. People are complicated and I am one too!"*

Anna's mother raised the issue of the 'Red Flag' system when particular support needs are flagged up at any

presentation to a health service such as Accident and Emergency. Not all medical staff seem to be aware of the system and so it does not work.

Medication is not always followed up and repeat prescriptions can continue unchecked long after the review date.

Leisure

Anna said that she would like someone to go with her shopping, not just a 'general' support worker but one who specialised in ASD.

Attitudes

Anna is aware that sometimes she has difficulty understanding and sometimes she has difficulty in being understood.

Anna felt that people didn't listen to what it was that made her feel the way she does. Anna had difficulty attending one class; the school suggested she drop that subject. Actually there was an issue with the way others in the class treated her. This sort of 'bullying' could be experienced by anyone, but Anna felt that it was all put under the label of her ASD and seen as her problem rather than a class one.

Anna's mother felt that there was a lot of misunderstanding of mental health and people still think of it in terms of the old institutions. She felt the information about it was poor and that services were not well signposted. Anna's mother also recognised there is a problem about diagnosis. In one sense it is not the label that matters, but in another sense it is the label that sometimes brings recognition and support.

Behaviour

Anna did not mention her behaviour in her story. Anna's mother did report that Anna suffered from anxiety but is now on medication which is helping this. Her anxiety could be reduced by things like a fast ticking clock or digital watch which act to calm Anna down.

Money

Anna was concerned about learning how to manage her money. To learn how to be independent, she would like to know how to budget to ensure she has enough money left for bills.

Local Environment and Community

Anna did not mention the local environment or the community in her story.

Independence (additional theme)

Anna is keen to develop independence. She knows to achieve this she will need support from people who understand her needs.

Anna would like tools such as clear schedules which say exactly when things are due to happen both start and end times. She needs to have a list of useful phone numbers she can call if she needs help. She needs help with budgeting and managing money.

It is important to Anna that she has control of her things, that she knows where things are, that they are not moved or other people's things put amongst them.

Experience of Phoenix Centre

Anna is receiving a service from the Centre which is helping her anxiety although her mother feels that other issues such as sensory and social difficulties are overlooked.

Communication from the Phoenix Centre about follow up appointments is not consistent; either follow ups don't happen or notification of appointments is too late for arrangements to be made to attend.

Experience of integrated services

Anna's mother is not aware of a Child's Plan. There are School Liaison Group meetings (SLG) which she receives the minutes of, but actions don't seem to happen in between. There is no input to these from psychiatry. Dates are set without consulting families about what might

be suitable. There does not seem to be any input from the Phoenix Centre to the school.

Previously Anna has not been involved meaningfully in SLG's, but her new Social Worker takes great care to enable Anna's views, meeting her beforehand to prepare her. Anna's mother feels the principles of Getting it Right (S.G. 2011) but it is not experienced in practice.

Beth's Story

Beth is a 15 year old young woman with a diagnosis of TS and OCD

Concerns raised

Beth's mother reported that Beth's needs were recognised at a pre-school stage, although she was not diagnosed until in primary school. Her symptoms had been occasional and it was when they became consistent that she was referred to a paediatrician who then referred her on to the Phoenix Centre.

Family

Beth lives with her parents, sister and pet dog. What is important to Beth is that her family accept her as she is. She likes that they have time together especially eating together, but also that she has personal space.

Beth's mother said that relationships were generally good in the family although Beth and her sister didn't always get on.

Friends

Beth has a mixed gender group of friends who accept her and don't try to change her. She appreciates their support and that they are a good influence.

Beth's mother said that most of Beth's friends know about her TS. To begin with at school Beth chose which friends to tell, but late in primary her condition was explained to the whole class. This did not cause Beth difficulty. There has been the odd

episode in secondary school when someone has said something about it which has upset Beth, but on the whole it has been fine.

Learning

Beth liked being at a school that had a good reputation. She thought the teachers were good and she liked the support for learning base. Beth liked the other pupils. Altogether she felt it was somewhere she could work hard.

Beth's mother reported that Beth had been supported in primary school and the transition in to secondary was well planned and managed.

There are some subjects that are problematic; Beth has a compulsion to touch things that are harmful such as something straight out the oven or the flame on the Bunsen burner which makes science and home economics difficult. Also her spasms affect her ability in music and in PE.

Beth's attendance is low. She often gets sent home when she has tics or migraine.

Health

Beth has been attending the Phoenix Centre for some years. There had been a time where Beth had felt unable to attend the Phoenix Centre and the nurse had visited her at home instead. Beth had a good relationship with her nurse because the nurse accepted Beth and some of her idiosyncrasies such as sitting upside down in her chair sometimes. The communication between the nurse and Beth is really good as the nurse listens and does not rush so Beth feels she can tell her anything. But also the nurse knows how to speak to Beth and explains things checking that Beth has understood.

Beth's mother reported that she has physical health issues as well as her TS. She gets injured very easily and has had fractures of shoulders, arms and legs. Her mother feels this may be

that the tics make her lose concentration. For example, one fracture occurred when Beth let go of the Flying Fox and fell.

She suffers from migraine which can be triggered from Aspartame which Beth craves. She has sensory issues with smells, sounds, texture, and taste which are all capable of triggering tics.

Beth has a poor appetite and her parents are now concerned that her low weight and appetite could tip her in to more serious health issues.

Beth's parents have found the Phoenix Centre enormously helpful and have been able to contact them to discuss things. Beth is seen weekly and there are 6 weekly reviews which the parents find helpful.

Leisure

Beth enjoys music and has been playing fiddle since she was 3. Music helps her calm down. Beth also enjoys movies and the cinema as it takes her mind off things.

Beth's mother said organisations such as Brownie/Guides and Scripture Union Camps have been brilliant for Beth. They have known about Beth's condition and have been supportive. Beth was participating in some sport, dance, gym and swimming but she does not have the energy now. She is a poor eater and her tics use up a lot of her energy and spasms interfere with doing sport. She has become anxious about swimming which she was not before.

Attitudes

Beth emphasised how important it was for her that people accepted her for who she was. This included her family, her friends and her nurse.

Beth's mother felt that because Beth had grown up with her condition she had adjusted well to it. She felt that although teachers had received some training, there still seemed to be a

misunderstanding about the condition. If Beth does not have any obvious tics in class then they do not believe her to have a problem. But it might be taking all of Beth's concentration and energy to contain the tics.

Behaviour

Beth did not mention her behaviour.

Beth's mother reported that Beth is addicted to screens and can be paying attention to her phone, Ipad, laptop and TV at the same time. She becomes anxious and distressed if asked to put them down. Sometimes when anxious, Beth sits wrapped in a blanket with the doors and curtains closed. Beth does not like to move from one room to another without someone accompanying her.

Beth also self-harms. There is something about the sensation of pain her mother feels she is unable to resist. Touching hot things from the oven, cutting herself with a knife and putting her fingers in a closing door are amongst the things she has done.

Money

Beth has enough money to be comfortable.

Beth's mother is concerned about the changes in Disability Living Allowance and does not know if it will affect Beth.

Self-confidence (additional theme)

Beth felt that self-confidence was important for happiness but that this was something she lacked and needed help with.

Things I like (additional theme)

Beth had things that she liked which were important to her having a good life. One of them was lists and so she made a list of the things she liked.

Experience of Phoenix Centre

Beth's mother said that over the years Beth has attended the Phoenix Centre on the whole the service has been fantastic. There was one time when a

relationship with one member of staff was difficult and trust had been broken. However that was dealt with and otherwise relationships have been good.

For a while Beth was seen at home. This was better for Beth but also provided an opportunity for her mother to catch up with the practitioner once a month about how things were doing. Once the appointments moved back to the Phoenix Centre, that opportunity was lost.

Beth's parents are not sure what the different professional titles mean, but Beth is now seen by a 'drama therapist' and has done drawing and modelling which has been helpful.

There have been difficulties with change over of medication which was not monitored well to start with and there were side effects which were difficult.

Experience of Integrated services

Beth does not have a Child's Plan as far as the family are aware. The lack of integration between mental health services and education is a concern for the family as Beth approaches transition in to adult services.

Currently the family would contact the Guidance teacher for any concerns about school and the Phoenix Centre for any concerns around her mental health.

Chloe's story

Chloe is a 17 year old young woman with a diagnosis of AN.

Concerns raised

Chloe's parents had been concerned about her loss of weight and behavioural changes for a while. Her weight loss would not trigger a referral to mental health services until her Body Mass Index (BMI) was 19 or under. However the signs of anorexia were there before this. The parents did

pay for some private counselling which was helpful but did not prevent Chloe from developing AN. Once referred to the Phoenix Centre things moved on. As the signs had been there earlier, Chloe's mother wondered if therapeutic help could not have been initiated earlier, perhaps avoiding the dangerously low weight Chloe reached.

Chloe's mother suggested that instead of a particular BMI acting as the trigger, a range of behaviours could also be a trigger for additional support.

Family

Chloe thinks her family are "*extremely important*" in making her life good. She enjoys spending time with them and building up happy memories. When things are good at home she feels safe and relaxed.

Chloe's mother said that the family had always enjoyed meals together and so they did not expect an eating disorder in their family. Chloe had always had a tendency for anxiety but became dissatisfied with her body image as she moved in to secondary school. At this time she began to withdraw from family eating and made herself tiny amounts of particular food and would not eat anything else. This led to tension around family meal times which was stressful for everyone.

The family had some family sessions at the Phoenix Centre which had been helpful and had enabled a younger brother to express his feelings too.

Chloe's mother felt that Chloe had made huge progress and now usually eats the family meal.

Friends

Chloe says she has boys and girls as friends, girls for 'sympathy' and boys for 'comic relief'. She has a big group of friends she can relax and socialise with. She also has friends she can trust and confide in.

Withdrawal from friends was one of the things Chloe's parents had noticed before she was diagnosed. When she was getting ill, Chloe didn't really go out at all. Gradually friendships and social life are being restored.

When Chloe was really ill and withdrawn, some of her friends shared their concerns with their parents and through them to Chloe's parents. Two friends turned up with daffodils once to show Chloe they cared.

Chloe had a boyfriend who she had previously been supporting through issues of his own. Then it turned around and he was supporting Chloe.

Learning

Chloe thought her school was a good school. She summed up the culture there as being 'calm, enjoyable and fulfilling'. Where she has a 'sound' relationship with teachers she found it easier to pay attention. When she didn't get on with a teacher it was stressful and the work became a chore.

Chloe talked about her guidance teacher and the support she had offered. Chloe felt this had been 'life saving'. She felt the teacher had been very understanding and had done her 'absolute best'.

Chloe's mother also reported the support they had received as a family from the Guidance teacher. Chloe at one point had become obsessive and anxious about school work. Now this is more balanced and Chloe is coping well.

At one point when Chloe was very ill she was not allowed to go on a school trip she had been looking forward to. This was a bitter blow to her but Chloe's mother felt it might have served the purpose of making her realise how her condition could affect things she wanted to do.

Health

Chloe said she now had a focus on good health, eating a healthy diet and being active. She thinks people do not understand enough about the foods which should not be eaten excessively and the effects of not eating enough.

Chloe and her parents hit a low spot when it was thought that Chloe was such a low weight she would need to be admitted. However the way this was handled by the psychiatrist and staff was wonderful and helped the family through that time. In the end Chloe narrowly avoided being admitted. Chloe's parents feel a huge sense of debt toward the Centre and know without the service they provided; Chloe might not have been with them today.

Leisure

Chloe mentioned an active lifestyle as making her happy and helping her to relax, but only referred to taking part in sport at school.

Her mother had commented that Chloe was back to socialising with her friends.

Attitudes

Chloe had a lot to say about values rather than attitudes. She had learned the value of money, and of developing an active lifestyle. She valued living in a safe neighbourhood and the support she had from people around her. Chloe now understood the consequences of not eating healthily. She felt that learning these things was important for all young people, but did not feel this was something that was always covered well in school.

Behaviour

Once treatment began, the parents had to insist certain food was eaten which was a battle at times. However, they felt hugely supported by the Phoenix Centre and were in regular contact throughout that difficult time.

Money

Chloe has a part time job and felt there was *“nothing better than money earned”*. She was also able to ask for money from her parents if she needed to. Chloe also felt there was a need to learn about money, so that you could realise what it is worth. She thought it was sad if people grew up expecting something for nothing.

Local Environment and Community

Chloe felt glad that she lived in a safe family, home and town. But she recognised that if someone had a worrying home life it would be important that they had someone to offload to.

Experience of the Phoenix Centre

Chloe’s parents have found the support from the Phoenix Centre tremendous.

Experience of Integrated Services

Chloe’s parents were not aware of a Child’s Plan. They can speak to guidance at the school or the psychiatrist at the Phoenix Centre.

Chloe’s mother noted the difference in the approach by professionals to breaking the news to Chloe about missing the school trip and breaking the news that she may need admitted in to hospital. In the first instance this was handled abruptly which had been distressing to Chloe. In the second case it had been handled very sensitively which had been really helpful.

Lesley, a mother’s story

Concerns Raised

Lesley’s mother had noticed the signs of Lesley’s additional support needs since the start of primary school but it was not until secondary that things escalated and Lesley was seen and diagnosed. Lesley is on the autism

spectrum and has some additional difficulties.

Experience of the Phoenix Centre

Lesley’s mother does not have much communication with the therapist at the Phoenix Centre and so finds it hard to both keep the therapist up to date with changes in behaviour, as well as with finding out how Lesley is responding. The parents have shared information about Lesley’s behaviour deteriorating, including drinking and violence, but have not been able to discuss this with Lesley’s current therapist. There is a generic email address which the parents can use to make contact, but there is no reply so the parents can never be sure the message has been forwarded to the therapist. It may be that Lesley has not provided consent for the therapist to discuss her case with her mother.

Experience of integrated Services

There have been difficulties between professionals from health and education including over whether or not to use medication. This is not yet resolved.

The school have not always understood Lesley’s needs. Although Lesley has difficulty with eye contact, one teacher insists on it. Lesley’s mother reported that Lesley can spend hours and hours on a homework project, redrafting and redrafting but then fail to hand the work in because it is not ‘perfect’. Some teachers have not made any allowances for this.

Lesley has turned down a learning support auxiliary in school and has sometimes refused treatment from the Phoenix Centre. This is a challenge for the parents trying to get the right support.

Lesley’s mother experiences violence from Lesley but has been told that social work support could only be available if the child was at risk from the parents not if the child was being violent toward the parent.

Lesley did not have a Child's Plan at the time of the interview, but there has since been a full multi-agency meeting and the parents have subsequently been sent a copy of a Child's Plan.

Discussion

The two way interaction of mental health and wellbeing does come out through these stories. However, a much stronger thread that emerges is that these are first and foremost young people, individuals who are not defined by a diagnosis or state of mental health. This is summed up so well by Anna.

"..not everything about me fits under a name."

Across the three strands of this project, promotion, prevention and care, there were 100 participants; 30 young people with additional support needs, 65 Highland Youth Voice members from the general population and 5 young people receiving a mental health service two doing imaginary and real stories, one participant only contributing the imaginary story, one only their real story and one with only the parent perspective given.

All of these young people aspired to similar ideas of what wellbeing is for young people; what makes a good life. In consideration of how often each of the 10 themes was included as important in the imaginary stories, the 3 most popular themes across the 3 studies were family, friends and learning. Attitudes were the next most popular in the HYV study, and then health, money and leisure were the next most popular across the studies.

77% of young people from HYV thought attitudes were important, but for those with additional support needs whether mental health needs or other needs this was significantly lower (1 out of 3 for this study). One would expect that this group were more likely to be subject to discrimination in their real lives and would have rated this as

a higher ideal in the imaginary good life. Perhaps not having to think about the attitude of others was part of a good life.

Another surprising result was that the theme of behaviour which was mentioned by 38% of HYV and 52% of ASN was not mentioned as important by any of the 3 imaginary stories in this study. As mental health has such a large impact on behaviour it might be reasonable to expect young people with a mental health need would have included it.

The local environment and community were the least important themes for the HYV and ASN studies. In this study all three young people made some comment, two young people referred to the importance of feeling safe in the community.

When the real life stories of the young people in this report are considered one of the things that is striking is that while the mental health need impacted on their life the young people had the same concerns and issues of other young people. They were young people first, and young people with a mental health need second.

Family

In terms of the family, there is evidence that having a child or young person with ASD can be stressful to parents especially at times of transition (Meadan 2010). Anna's family have recently been through the trauma and transition of separation and divorce. Anna is now approaching transition in to adult services without a transition plan which creates stress for Anna and her family (Newman et al 2009).

Anna's younger sister now has a greater role to play in helping Anna when their mother is at work. There are mixed views on whether this has a negative or a positive effect on siblings (Meadan 2010).

Anna's need to feel safe at home by a restriction of visitors to those she has pre-knowledge of must have an impact on the family's social life.

TS and OCD together produce significant stress factors for parents regardless of the services received (Wilkinson et al 2007). The style of parenting is thought to influence the mental health of young people with TS, with benefits in parents who enable the young person to gain a locus of control (Cohen et al 2008). There are perceived benefits in offering the family, especially mothers, support and intervention (Wilkinson et al 2007; Schapiro 2002).

Beth's need for someone to accompany her each time she moves from one room of the house to another, her risk of self-injury, her obsession with screen time will affect other members of her family. Beth really appreciates that her family accept her as she is and accommodate her needs. Home is a safe place to be.

The NICE clinical practice guidelines for the management of AN (as cited in Bryant-Waugh 2006) emphasise the importance of involving members of the family, including siblings, in the treatment programme. Chloe's family had felt the support they received from the Centre had been helpful, especially when they had to go through a time of making Chloe eat things she did not want to.

Chloe, like Beth and Anna, mentioned the importance to her wellbeing of feeling safe at home.

Lesley's current disruptive behaviour and violence towards her mother was stressful for the family. While parents being violent to children would be a child protection issue and parents being violent towards each other would be a domestic abuse issue, children or adolescents being violent

to their parents does not seem to register with services.

The Phoenix Centre place importance on supporting the family as well as the young person with a mental health need and that is why this part of the study invited participation from parents as well as young people.

Friends

ASD is partly diagnosed on there being communication and social difficulties (Schall and MacDonough 2010). Anna's view that friends were not important for a good life perhaps reflects this. The onus on Anna's siblings to be her social world is a huge expectation from them. Peer training to build social skills can help people with ASD (Krebs et al nd). However, when someone like Anna has not been provided with a formal diagnosis, their communication and comprehension difficulties can lead to isolation and bullying as Anna has experienced (Portway and Johnson 2005).

Beth had good friends who accepted her and supported her. Her close friends had grown up with her knowing about her condition. The wider peer group in primary had not reacted negatively after they had been told. Woods et al (2003) suggests that peer education about TS does improve attitudes amongst peers, but this does not always translate in to being friends. Beth and her friends seem to have made a very good adjustment to her condition and this may have been helped by her early diagnosis.

Chloe withdrew from her friendships as she became ill. Her friends and boyfriend remained supportive and demonstrated concern for her at that time, although they did not seem sure what support to offer. Chloe recognises the benefit of having close friends you can trust and confide in. As self-consciousness is such a factor in AN, peer education may or may not be useful.

Learning

Anna had a different experience in primary where her needs were considered and secondary where there seems to be less understanding and support. Misunderstanding of the needs and behaviours of young people with ASD can lead to them being unhappy at school (Portway and Johnson 2005).

Beth has had a mostly positive experience of school, although her subject choices have been limited because of her condition and the likelihood of self-harm where there are hot or sharp things.

However, the perception by some teachers that Beth does not 'have TS at school' is not helpful. The effort of suppressing the tics may detract from Beth's ability to concentrate and she may become fatigued as the day progresses (Carter as cited in Schapiro 2002).

Beth misses a lot of school due to tics and also to migraine. She is susceptible to sensory triggers. Prestia (2003) suggests that a sensory profile in school could help the school realise how Beth receives and processes sensory information.

Chloe's mental health does not seem to have made an impact on her education as reported by her or her mother. The Guidance teacher has been helpful and understanding and this has been an important factor in Chloe managing at school.

A teacher insisting on eye contact from a pupil with a diagnosis of ASD demonstrates the lack of understanding that it is still possible for young people to come across in schools. Staff development to ensure understanding of the needs of pupils with ASD or other diverse needs is fundamental to an inclusive school (Lynch and Irvine 2009).

Health

Anna's physical health does not seem to be an issue, but her mother expressed concern that when there was an issue, that the 'Red Flag' system did not work. For people with ASD who rely on routine and require forewarning about any changes; something like an emergency trip to the doctor could be very stressful. Red Flag system should flag up key pieces of information about the person and their condition or any support needs they may have and the best approach to handle these.

Beth is prone to physical 'accidental' injury and this type of injury that is common in young people with TS has been associated with tic release (Prestia 2003).

There were issues around the follow up of medication with both Anna and Beth's mothers reporting that reviews do not happen when they are supposed to. In the case of Lesley, medication the parents received inconsistent messages from professionals about whether this medication was needed.

Chloe had shown signs of anorexia which her family recognised before she hit the measurable threshold for treatment of BMI 19. The medical view of body weight as a number does not resonate with the young person whose focus is on body image (Boughtwood and Halse 2007). Chloe was already behaving as an anorexic with a distorted self-image and fixation on being thin before she was physically deemed to be in need of treatment. Behavioural criteria as a threshold for receiving treatment may be helpful (Bryant-Waugh 2006).

Leisure

Anna's only reference to leisure involved shopping having a support worker with her. In the study with young people with ASN (Newman 2009), it was noted that young people with developmental disorders often

had a limited experience of leisure. This tended to be extracurricular school activities or specialist out of school provision, both of which are in the company of support workers.

Physical activity is seen as a 'positive step' towards mental health as it can improve mood, relieve stress, improve self-image, and help sleep (Friedle et al 2008). Anna and Beth do not mention taking part in exercise or physical activity and Beth's mother reports that she has recently given up sport due to her low energy. Chloe appreciates the importance of regular exercise but does not say if she takes part in any just now; there may be restrictions on exercise due to her body weight and energy levels.

Playing music helps Beth relax. Music featured as an important leisure pursuit in the wider responses from HYV. Beth also accessed Scripture Union and the Guides who understood her needs.

Chloe does not make specific reference to leisure except to say that socialising with her friends is important to her, the thing she withdrew from when ill.

Leisure activities can be therapeutic in improving self-efficacy and competency (Caldwell as cited in Trenberth 2005). Further, Juniper (ibid) suggests that leisure can also limit phobias or anxieties, promote positive feelings and limit destructive compulsions.

The limited leisure pursuits of these three young people may not be helpful to their mental health and wellbeing.

Attitude

Anna's experience of being bullied in class was dealt with by excluding Anna rather than by dealing with the bullying. Young people with ASD and other developmental disorders are more prone to bullying (Norwich and Kelly 2004).

There were mixed views about getting a diagnosis or a label and people's attitudes to that. Anna felt that labels were unhelpful, she was more complex than any label. Anna's mother felt that a diagnosis was often needed to get services. Portway and Johnson (2005) suggest that the diagnosis is useful in improving people's understanding of people with ASD and so improve acceptance of their difference. Lesley had experienced a lack of understanding from the teacher who insisted on eye contact who perhaps either did not know or did not understand the diagnosis of ASD. Beth's teachers did not realise the effort Beth had to make to not tic in the classroom.

'Authentic' inclusion in the classroom requires supportive teachers who understand the particular needs of the individuals, working in a multi-disciplinary way to plan appropriate individual learning and classroom strategies (Lynch and Irvine 2009). There does not seem to have been input from CAMHS to the schools and it would seem that some teachers have not understood the individual needs of these young people.

Behaviour

Some of the repercussions of mental health issues on the behaviour of the young people emerged from the stories but was not raised as a particular issue on its own.

Anna reported her need for personal storage and space of her own; clear boundaries between her and the rest of her world. Anna's mother reported that Anna has anxiety and depression.

Beth's self-harm is not unusual in young people with TS (Storch et al 2007). This type of self-injury has an element of compulsion and an element of complex tic (Jankovic as cited in Schapiro 2002).

Chloe's change in behaviour in her withdrawal from family and friends as

she became ill seems to be gradually reversing.

Lesley had been getting in to trouble with alcohol. It is not uncommon for young people to experiment with alcohol, but for young people with hyperactivity or obsession or tics, the temporary relief of symptoms with alcohol may be another compelling attraction (Schapiro 2002). Lesley's violence directed at her mother does not seem to register as a need for services to address. Presumably if the violence were towards anyone else it would.

Money

Anna's was concerned about how she might manage money independently. Beth's mother had concerns about loss of Disability Living Allowance. Chloe liked understanding the value of earning money.

These suggest that money is perhaps not much of an issue for these young people while they were still living at home, but when they become independent it may be more of an issue.

Local environment and Community

The community was mentioned in Beth's mother's reference to the uniformed groups which had provided a leisure opportunity for Beth.

Chloe mentioned that her town is safe.

Otherwise no comment was made about local environment or community. It might be that these young people are home based and do not go out much in their communities and environments or that their focus of wellbeing was within the boundaries of their homes where they felt safe or that they just did not consider their community or the environment to be important to having a good life.

Self-perception

Anna was aware that she was different, that people did not understand

her or grasp why she feels and behaves the ways she does. This growing awareness of difference, of not quite fitting in, can contribute to feelings of anxiety or depression (Portway and Johnson 2003 and 2005).

Beth was aware she had low self-confidence and needed help to rectify this. Cohen et al (2008) suggest that enhancing the locus of control in young people with TS and OCD improves their psychosocial state.

AN is a condition built around a distorted self-image. The message from the parents and professionals making Chloe eat calories to gain weight was the opposite message to those from the media about healthiness and attractiveness being about less calories and weight loss (Boughtwood and Halse 2007). This presents a struggle between the need to address the physical danger of low body weight while building up the young person's self-image (ibid).

In spite of these conflicting messages, Chloe now self-reports a good attitude to food and to exercise and thinks that these positive messages should be clearer in school.

Self-image is a key factor in a young person's psychosocial health and their relationships (Helseth & Mysaer 2010). Baumeister (2005) suggests that the solution is not so much about building up self-esteem in young people, as enabling them to have or develop a locus of control.

Conclusion

The young people who took part in this project had identified with most of the themes around wellbeing which the Good Childhood Study (CS 2006) had developed. However family, friends, learning and health were the key factors mentioned by participants.

The participants' mental health needs had impacted on each of these areas

of their lives; both by placing additional stresses and also providing strengths when relationships with others were good.

While attitudes, behaviour and leisure themes were not a specific focus for these young people; the gaps in their stories and the stories from parents would suggest that the mental health needs had impacted on quality of life in each of these areas.

Money, local environment and community were less important themes for these individuals, although feeling safe was important.

An additional theme for wellbeing from these young people was that of self-perception: feeling different, feeling dependent, lacking confidence or having a poor body image.

The Phoenix Centre service was, on the whole, supporting both the young person and their family as part of the therapy offered. Families were appreciative of this and felt that it had been helpful, even life saving. Where parents were able to contact the Phoenix Centre and discuss concerns, this was hugely beneficial. Review of medication has been an issue.

The Getting it Right approach to Integrated Services does not seem to be practiced. Neither parents nor young people were aware of a Child's Plans or of the Phoenix Centre working with the school. The participant's mental health need was impacting their education and often this was due to a lack of understanding by the school of the mental health need. Better integration may go some way to addressing this.

The mental health needs of the young people participating in this project had affected their quality of life. The opposite may also be true; the quality of their lives may be impacting their mental health. However, this was not as evident from the stories.

The service they received from the Phoenix Centre was making a difference and young people and their families felt that it supported their wellbeing. Their stories demonstrate that these young people are young people first, with many of the shared interests and concerns of other young people. Their mental health need was an aspect of their person which had some negative effects on areas of their life, while positive and supportive relationships with family, friends and professionals were fundamental to wellbeing. It was important that people accepted young people for who they are as well as understanding the condition they have.

As Anna says:

"People are complicated and I am one too."

Notification of interest

The study received ethical approval and was due to begin in 2010. Between applying for ethical consent and receiving it the author's own teenage daughter became a service user of the CAMHS in Highland. Ethical consent was given to continue on condition that this was made known in the report and that her daughter did not participate.

The Phoenix Centre

The Phoenix Centre brings together the services of Clinical Psychology, Psychiatry, Nursing, Family Therapy, Art Therapy and Social Work. They work with families, children and young people who need help in dealing with a variety of health and mental health problems and have expertise with children and young people with Learning Disabilities or Autism Spectrum Disorder.

The therapies offered include talking therapies, art therapy, medication, professional consultation and group therapies. Families along with professionals agree an action plan for treatment at their first visit.

Recommendations

These four case studies may or may not be typical of the experience of service users of the Phoenix Centre. The following recommendations which emerge from these stories are to address the issues these stories present in consideration of current policy.

Integrated services:

The Phoenix Centre did not appear to be collaborating with education or other services. Where the young person's mental health need has an impact on their education and or on their family life, then a multi-agency Child's Plan should be drawn up, whether the Lead Professional is from health, education or social work.

Wellbeing in the round:

Focus of the treatment sometimes seemed to be on a particular issue such as anxiety but overlooked other issues such as social difficulties in school. The benefit of a Child's Plan would be that these issues could be considered together as they may be interdependent.

Communication:

Communication between families and the Phoenix Centre seemed to depend on the practitioner involved with the young person. Communication routes should be clear from the outset so that families know who to get in touch with and how if they have issues or concerns.

Follow up of Medication:

When young people are put on medication there should be follow up from the prescribing doctor to ascertain if there are difficult side-effects being experienced. Repeat prescriptions should be reviewed at the time intervals given.

Information and pathways:

Parents did not seem clear about why a particular therapeutic approach was offered, whether it was the most appropriate or indeed what different approaches were available. Information about the different therapies available at the Phoenix Centre would be useful. Clear pathways to indicate how young people are directed to particular therapists would also be helpful.

Trigger for support for eating disorders:

The threshold of a particular BMI is not supported in current literature about Anorexia Nervosa as the best diagnostic criteria. Low BMI as well as a range of behaviours and attitudes is recommended. (Bryant-Waugh 2006)

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