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An exploration of the experience of attending the *Kidstime* programme for children with parents with enduring mental health issues: Parents' and young people's views.

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Abstract

The Kidstime programme is an innovative attempt to address the particular needs of children and young people who have parents with mental illnesses. It comprises a monthly psycho-educational workshop involving discussions about the meaning of mental health, dramatizations of stories constructed by the children (often filmed), and concurrent parents' groups, as well as joint seminars and review sessions (Cooklin, Bishop, Francis, Fagin, & Asen, 2012). This paper presents a qualitative analysis of interviews with young people (n=6) and parents (n=5) attending the groups and interviews with former service users

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(n=9). Five themes emerged from the thematic analysis: initial engagement, sharing with others, learning about mental health, opportunity for fun and impact on family relationships. Areas for further development were identified including the formation of a distinct adolescent Kidstime workshop, to better meet their age-specific needs and adjustments to the system for introducing new families to established workshop groups. Given the positive experience of the groups by those attending, a rigorous evaluation of the approach is suggested.

Introduction

It is estimated that across the UK two million young people under 16 are currently living with at least one parent with an enduring mental health issue (Parrott, Jacobs, & Roberts, 2008). The impact on the child can be severe. A child with a parent who has a mental disorder has about a 70% chance of developing at least minor adjustment problems by adolescence, and with two mentally ill parents, there is a 30-50% chance of that child becoming seriously mentally ill (Cooklin, 2006, 2010). The presence of mental illness in a parent has been shown to negatively affect the cognitive and language development, attention and concentration span, educational achievement, and the social, emotional and behavioural development of children (Falcov, 1998). Some additional challenges found to be experienced by these children and young people include high levels of anxiety, a sense of personal blame and

responsibility, and in severe cases, suffering from neglect or abuse from the mentally ill parent (Weir & Douglas, 1999; Yule & Williams, 1990). In addition, many such families become isolated through the stigma of mental illness - they experience a lower standard of living and financial hardship and the children are more vulnerable to rejection and bullying in school.

There is evidence that children can sometimes overcome the effects of extreme adversity, provided they can understand what is happening to them (and, as far as possible, why), and that they have at least one reliable and impartial adult with whom they can achieve a more objective perception of events (Dyregrov, 2001, 2010; Falcov, 1997, 1998; Shachnow, 1987). It may be crucial, therefore, for these young people to be offered a convincing and understandable explanation of what is happening to their parent, what is likely to happen and why, the possible impact on their own lives, and what part they can play in their parent's recovery. It has been argued that this should take priority over any suggested form of counselling or other therapy, which many children and young people actively oppose as they perceive this as placing them in a similar category to their ill parent/s. In addition, the children and parents may need specific help in how to manage their relationships, which may have been significantly distorted by parental mental illness.

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The needs of these children and young people have been traditionally over looked, falling as they so often do between adult mental health services (which focus on adults and often do not even enquire about the impact on children) and child mental health services which these children often do not access. Moreover, although there are now a growing number of 'Young Carers' groups (funded either directly by local authorities or by non-governmental organisations) that offer after-school 'fun' groups where children can have time out from home worries, participate in activities and talk to each other, these groups do not tend to involve parents, and are limited in regard to the specific needs of children who are affected by parental mental health issues.

The current programme described here is an interactive programme of monthly 'Kidstime Workshops' (Cooklin, 2013) which consists of a series of innovative psycho-educational workshops which involve dramatizations of stories constructed by the children, which are often filmed, and parents' groups, as well as joint seminars and review sessions. Kidstime attempts to address the particular needs of children and young people who have parents with mental illnesses, by bringing them together, along with their parents, around the issue of mental health.

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Drawing on the multi-family approach has now become an effective and recognised intervention for relapse prevention in major mental illness and schizophrenia in particular. It provides a new social context for the family, and as a result offers new and positive ways in which family members can think about and respond to the person with the illness. It also effectively addresses social isolation and stigma (Bishop, Clilver, Cooklin, & Hunt, 2002; Leff et al., 1990; Leff, Kuipers, Berkowitz, Eberlein-Vries, & Sturgeon, 1982; McFarlane, 1994; McFarlane, Link, Dushay, Marchal, & Crilly, 1995).

Kidstime workshops were originally called 'What Shall We Tell the Children?' and began in 1999, partly as a result of the experiences of similar workshops for adults and their relatives, over the previous 10 years (Bishop, et al., 2002). Prior to this the predominant approach towards providing interventions for families of patients with mental illness was exclusively concerned with the adults. This often meant that the most vulnerable members of the family – the children - were largely ignored. More recently the workshops were renamed 'Kidstime' with both children and parents participating in the production of one training film (Cooklin, 2004) and the children participating in an 'explanatory' short internet film (Cooklin & Njoku, 2009).

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Aims of the Kidstime programme

The overall purpose of Kidstime is to reduce the likelihood of children of parents with mental illnesses developing emotional difficulties later on in life.

Specifically, its aims are as follows:

- To help the children and young people benefit from understandable explanations of their parents' mental illness and the parental behaviour which may be associated with this.
- To address the children and young people's various fears, confusion, and lack of knowledge about mental illness and its treatment.
- To help the parents who suffer from mental illness to find a medium within which the illness and its impact can be discussed between themselves and their children.
- To help the parents to access or rediscover their pride, confidence and competencies as parents.
- To help the children and young people to experience their parents responding in a more positive manner.
- To encourage the children and young people to feel free to engage in pleasurable age appropriate activities.

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This is the first evaluation which explores service user experience of this approach. Ethical approval for this evaluation was granted by NHS Ethics (ref 09/H0808/57).

Method

Methodology

Qualitative interviews were undertaken with a purposive sample comprising: young people currently attending groups (n=6), parents currently attending groups (n=5), former service users who had finished coming in a planned manner after long attendance (n=2) and former service users who had come only once or twice and then ceased to attend groups without this being planned or discussed (n=7) (see appendix 2 for structure of interview).

Sample population

Children and young people who attended the Kidstime workshops involved in this evaluation ranged from 4 -16 years. Adult attendees were parents with mental health problems, ranging from severe and persistent psychotic disorders such as schizophrenia, bipolar disorder through chronic depression and anxiety disorders or personality disorders.

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Referrals were made by mental health workers, children's social workers, voluntary workers (particularly those concerned with 'young carers'), psychiatrists, family therapists and psychologists, general practitioners, and by recommendation from other families who have attended.

Intervention

Kidstime workshops included in this evaluation took place in two London boroughs. These are open ended groups meeting monthly, each lasting 2.5 hours after school and open to parents and young people to attend as fits their needs.

The workshops were delivered by a core team comprising mental health and social care professionals, a Drama Practitioner and voluntary workers. The workshops began with a short seminar for the children and parents together, in which some aspect of mental illness, or questions about it, were discussed or demonstrated. This was followed by separate groups for the children and for the parents. The children's group started with games and warm-up exercises, and then the children told stories about family life, perhaps prompted by the seminar. They were helped to dramatize these stories and the resulting plays filmed. The parents and children then came together for the remainder of the

workshop. They had pizza together, followed by a group discussion of what the children had produced as well as issues raised in the parents' group.

The workshop delivery teams met before each session to discuss the workshop theme and any concerns or issues brought forward from the previous session. If appropriate this included updates on families currently attending the workshops. This was also the time when the team learnt about new families joining the workshops including a brief history of their current situation and a report on the mental illness of the parent and why they had been referred. At the end of each workshop the team met to debrief each other and discuss any successes and challenges experienced and to brainstorm plans for future workshops from any issues that had arisen (see appendix 1 for typical workshop example).

Aims of evaluation

The purpose of this evaluation was to investigate the Kidstime Workshop experience from the perspective of young service users, their parents, and professionals involved in the referral pathway and workshop delivery. By exploring the value of the workshops for all those involved, and identifying areas for improvement, this evaluation set out to provide a foundation from which to assist with the refinement and development of a training programme that will

support national rollout of the Kidstime intervention, in voluntary and statutory settings, as well as to establish a basis for further research.

Analysis

The interviews were analysed using thematic networks analysis (Attride-Stirling, 2001). Thematic analysis was selected as the best approach to cluster the way participants talked about different issues into 'themes'. The analysis sought to examine the meaning of Kidstime events to participants, barriers and opportunities for participating in the events, positive and negative impact of participation. The aim of the analysis was to generate hypotheses about the benefits and limitations of the Kidstime events.

Results

Five themes emerged from the qualitative analysis:

1) Initial engagement

2) Sharing experience

3) Learning about mental health

4) Opportunity to have fun

5) Impact on family relationships

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The differential and common experience of children attending Kidstime (both current and young adults who had attended in the past) and parents (both current and past) are commented on under each theme

1. Initial engagement

Parent experience. For all parents interviewed (both past and current attendees) the decision to attend Kidstime for the first time was an anxious experience and many report taking some time before they finally decided to take the first step and attend a workshop. Several of the parents talked of having a sense of guilt over the burden their illness can place on their children in terms of them having to worry about their parent, the stigma and the bullying they may have to endure. A few also reported the distressing concern that because of having a mental illness their children may be at increased risk of developing a mental illness themselves.

In addition to managing parental responsibilities with their mental illness, several parents also reported going through additional stressful life experiences such as divorce, separation, loss of job, or loss of economic stability as a consequence of their illness which may also adversely impact on the children. It

was this guilt and this concern that seemed to be a key decision behind a family taking the first step and accepting a referral offer to join Kidstime.

I'm going back a bit now. I was worried about my children, I thought my children didn't really understand much about mental health and I was worried about what my ex-partner might be saying to them, because I thought he might be encouraging them to be prejudice against people with mental health problems. I worried about the attitude of the people that they might meet at school and in the community.

Parent past attendee.

Parents reported a key motivator to promote initial engagement was consideration of their child's needs.

I was worried about myself so I thought maybe it's good for my child, so we're going so that's what made me go, like think okay for kids, there's something for them if it makes them feel better, you know.

Parent current attendee.

Initial concerns included fearing stigmatisation and having concerns over what other attendees would be like.

The first time when I was going you know, even I got that past, I've still got that prejudice, as though oh my god I'm going to go there, there are going to be mad people if somebody, if I'm going to get upset, but there actually, there is, they're more like me.

Parent current attendee.

Child experience. Children did not report being the main decision maker about attending Kidstime. Generally they came after parental decision and were more likely than parents to report general shyness and worry related to fear of the unknown and not knowing what to expect.

I felt shy, I wondered what it was going to do, what it was about. Now I know. It is about having fun and mental illness so when mum or dad get ill, you can help them.

Young person current attendee.

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For both parent and child current attendees, engagement at the start of the session was noted as a potential problem for more regular attendees who reported finding the introductions irksome at times

I know they have to know our names but we can just introduce ourselves, you don't have to spend 30 minutes going round in a circle and telling our names. I'd prefer just um sort of like just do it in our own time like when, the workshop is taking place and just go up to them and say our names.

Young person current attendee.

Sometimes I get a bit, you know when we have to say our names but that's normal, it's not that I don't like it, I just get sometimes fed up of "say your name, you need to say where you are from" but then there are new people and they need to know and maybe, maybe it's good in the end really, because it's not a very big deal is it, sometimes if I'm a bit anxious and restless.

Parent current attendee.

Engagement could also be comprised by issues in terms of organisation of transport to the workshops. One parent who came once and then did not return reported feeling overwhelmed by the sheer size of the group she attended and

felt too vulnerable to manage that level of interaction especially with so many new people.

Of the families that had been longer term attendees one parent reported deciding to stop coming to the workshops with her family after it had been suggested to her by another service that she should try and mix more with people without mental health issues.

2. Sharing experience

Parent experience. Parents (both current and past attendees) commonly reported trying not to discuss their illness with their children at home for fear of overwhelming them or through fear of eliciting responses or questions they may feel unable to manage or answer. For most, one of the most useful aspects of the workshops was that they provided a safe environment for parents and children to discuss issues and problems in non-threatening, non-judgmental surroundings allowing both parents and their children to share experiences and feelings with each other that may be too uncomfortable to discuss one to one in the home.

I go there and I feel better actually I feel good but then you know I can go away and, but I think [my child] understands a bit better and they are not that worried or scared about me as they used to be

Parent current attendee.

Parents reported that the workshops helped them to put their experiences and feelings into context by enabling the families to share in and listen to the experiences of other families in a similar situation.

I know I'm not the only one that's got the, the illness and there's other people that's got the same complaints. So it has helped you know, to talk to other people about it.

Parent current attendee.

The normalising aspects of the experience were commented upon:

It does help because…I feel a bit normal, sometimes I do not feel good, I'm strange, I'm different it makes me feel normal and it makes [my child] more relaxed…..it makes us more relaxed about me, because when as well when [my child] just started to realize that I have some problems they were very scared because it is scary if you don't know what you deal with and somehow they put it in the normal perspective, normal like sort of it's okay.

Parent current attendee.

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We go and we speak to other people who've got mental health problem, and we talk about mental health problems a lot and the way that it's presented, children as well as playing they're learning to understand about mental health problems and with lots of mental health professionals who've got positive attitudes towards dealing with mental health, you know about mental health, it's a positive environment.

Parent current attendee.

Child experience. Sharing and meeting with other families was reported to help reduce the sense of isolation the children otherwise reported feeling. Current attendees focused in particular on being able to share problems

We come to Kidstime and we talk about it, talk about our problems

Young person current attendee.

Past attendees raised issues also of their fears of their own chances of becoming mentally ill and how these were addressed by the group:

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When I started the Kidstime project, I felt like I couldn't really express myself, because I know that people often thought that because my mum had mental illness I may have mental illness, so I didn't want to say anything, because I didn't want to seem odd or say anything inappropriate, so I kept to myself. So when I started coming to this project, you realise that, not necessarily, because when you know that other people have the same problem as you, and they look normal, they seem normal, that's it's okay to come out and just, you know, express yourself a bit more. So I just felt like I wouldn't necessarily, after learning about the illness I felt like I wouldn't necessarily become mentally ill, so it's okay for me to express myself.

Young person past attendee.

3. Gaining insight and knowledge about mental illness

Parent experience. Parents currently attending highlighted the psycho-education aspects as combining with the sharing of experience to reduce anxiety. Past parent attendees commented on the way the learning had stayed with them and helped them manage subsequent episodes and discuss issues with their children:

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He just explains how, or why people get a bit, why some people get mental illness and he says that the brain controls everything and sometimes the brain can get a bit… confused when it has a lot of things going into it, and some of us don't know how to control those impulses entering into the brain, so they get, so they start acting weird. … Its child friendly and normally a child will draw the brain

Parent past attendee.

One particular aspect commented on was the way knowledge was imparted in a non-stigmatising way.

That we all feel equal with them, we all feel, you know, you just all feel, well, not, obviously we're coming from different places, but we all feel respected I think, and easy to talk to them

Parent current attendee.

They just behave like normal, they don't seem to use many tactics because I used to go to therapy and I still go, there's always some sort of tactic that they try to work around, these people are more like, I don't know, have a very nice

approach, very relaxed approach and I like to be relaxed because I'm not often relaxed.

Parent current attendee.

Child experience. Young people currently attending reported valuing the opportunity to learn about mental illness in an accessible way including games.

I'd say, this is a bit silly but I like, I quite like the games and like the easier way of understanding it.

Young person current attendee.

Current attendees commented on their learning and how it impacted on their ability to understand their parents' behaviour

It's like they're helping young children to like just understand why their, their parents get ill.

Young person current attendee.

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I've learned a few more names of illnesses and I've learned some side effects of illnesses and how to know the difference between if a parent is, stroppy to know the difference if it's ill stroppy or normal stroppy.

Young person current attendee.

Past attendees reported that the increased knowledge helped them feel able to speak more freely with others and contrasted this with others in similar position that had experienced Kidstime.

I feel like I can talk about it easily, talk about mental illness without feeling embarrassed or feeling ashamed, because I now know that it's common, yes. If I didn't go to that project I wouldn't know that other people do have that illness, I don't feel scared or embarrassed to talk about mental illness.

Young person past attendee.

A friend of mine in secondary school, we were so close, we both had parents with mental illness but we didn't know, her mum had schizophrenia, my mum had bipolar depression, we didn't know at all. The only difference is, she never had any of these projects that she used to go to, so she would never speak

about it….I can't even go and tell her that I know your mum has schizophrenia, because you know, she didn't tell me that, it was the head teacher who told me.

Young person past attendee.

Past attendees commented that it helped provide strategies to manage difficult behavior.

When we know she's becoming ill, we kind of bring up strategies and things, you do this, you do that, and if you don't do this she's going to ... you know, we have to talk about it, yes, definitely. So we're both happy to talk about it, but talking about it to my mum.

Young person past attendee.

4. Opportunity to have fun

Parent experience. Whilst past and current parents stressed the learning and opportunity to share discussed above, current attendees also commented on the importance for their children to have fun at the workshops.

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[What I liked was] listening to other people who understand express things I have tried to say before but no one understood and watching the video of what my son was doing and how much fun he was having.

Parent current attendee.

It helps [my daughter] because she's meeting other kids that, you know, and just talking to them and she likes the drama facilitator.

Parent current attendee.

Child experience. Both current and past child attendees commented on how much they valued the opportunity to play and have fun.

We play games and we just talk about life and then if someone has an idea and then we talk about that.

Young person current attendee.

Home was sad, Kidstime was fun .That's what I looked forward to. I looked forward to having fun, you know being a child. But at home you have to be an adult, look after yourself, look after mum, look after the house, give her medication; at Kidstime you've having fun. You're being looked after and you're

not looking after others. …there are people there who are paying attention to you and you can go and speak to because you probably can't speak to your mum because you know she's not well she probably won't understand. But Kidstime was time for the kids; I think that's why it's called Kidstime.

Young person past attendee.

There were some issues raised by both past and current child attendees in terms of ensuring age appropriateness of focus, particularly for older young people attending.

I would like more people my age around.

Young person current attendee.

The only downside, what I was going to say before but I didn't want to say anything, was that, I felt more attention was paid to the younger kids than to the 15, 16 year olds.

Young person past attendee.

5. Impact on family relationships

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Parent experience. Parents current and past commented on the way attendance led to more open conversations although these were still acknowledged to be difficult and infrequent.

I've known that somewhere in there they sort of had the reinforcement of this explanation… I think it's had an impact even though you don't go home and think right, and find the time to discuss it, but obviously we answer questions from each other from time to time.

Parent past attendee.

Child experience. Children current and past commented on the impact of the workshops on facilitating discussion of topics that were not openly discussed elsewhere and reduce some of the strain and tension born out of misunderstanding or misinterpretation that may negatively impact on the parent - child relationship. This seems to be particularly effective in helping children and young people to understand their parents' behaviour, though it was noted by a number of children that actual discussion at home was no greater after the workshops.

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Young person current attendee.

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When we know she's becoming ill, we kind of bring up strategies and things. You do this, you do that, and if you don't do this she's going to ... you know, we have to talk about it, yes, definitely. So we're both happy to talk about it, but talking about it to my mum.

Young person past attendee.

Limitations

Participation was on an opt-in basis potentially leading to skews in the data, though it is to be noted that efforts were made to include interviewees who had chosen not to return to the workshops.

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Due to the vulnerable nature of client group, participation in the evaluation was undertaken on an opt-in rather than opt-out basis, resulting in a smaller sample size than otherwise might have been achieved. In addition, the young age of the children involved placed some limitations on the researcher's capacity to interview a larger number of children and young people.

As more interviews were conducted with parents than children, quotations within this evaluation may contain more insights from the parent interviews than the child interviews. It is worth noting, however, that several of the parental quotes also report their children's experience of the workshops, not just their own. The use of anonymous feedback forms at the end of each session for children, young people and parents alike went some way to addressing this issue by allowing attendees to give qualitative and quantitative feedback of their experiences.

The evaluation team have sought to represent the views and opinions of young service users, their parents and professionals as accurately as possible. However, some degree of bias will always be inevitable within our findings because we have only been able to gather the views of those individuals that chose to share their perspectives with us.

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Conclusion

Service users expressed strongly positive appreciation of the experience of attending Kidstime workshops. In particular five themes emerged as to how the workshops were experienced and impacted on attendee's lives. In terms of initial engagement, the workshops marked a step on a journey of families recognising an issue and wanting to focus on the needs of the children in respect of mental health issues. The opportunity to meet other families and share experiences was endorsed as a positive experience by interviewees and experienced by many as a way of helping reduce any sense of isolation and to support access to more open discussions beyond the group, though the limitations of this were also noted. Learning about mental health emerged as a third theme and was identified as helping reduce stigma and dispel myths. Having fun was a key aspect commented on by both parents and young people, though a number noted the need for more age specific activities especially for older teenagers. The final theme noted was that the impact on family, though not necessarily transformative, was helpful. All the above suggest that Kidstime is highly valued by those who attend it and would warrant a more rigorous assessment with a control group.

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Appendix 1: A typical workshop structure

Sessions begin with a 5-10 minute warm up and introduction session during which light refreshments such as tea, coffee and biscuits are available.

The warm session is followed by 15-20 minutes of whole group learning in the form of an informal seminar on a mental health related topic. Topics are covered in accessible terminology and attendees are able to ask questions for further clarification should they wish to do so. Games and interactive exercises may also be used as a way of introducing non-verbal aspects of learning.

At the end of the seminar session the parents and children split into two groups for approximately an hour.

- Parents spend the time discussing experience and concerns of being a parent or partner of parent with mental health issues. Topics usually revolve around the sharing of experiences, concerns and solutions with each other. The lead clinician or family therapists usually facilitate and guide these discussions and are also there to answer questions about support services if they arise.

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- Children spend the hour in another group; the specific format of how this group is run can vary depending on how many children are there and what topics have been raised. However the session for children usually starts with a warm up game and then moves on to an exercise in which they develop a theme or story around mental health as a group. The children's group usually culminates in the production and filming of one or more dramatizations based on issues and topics covered. There is a degree of flexibility built into the drama sessions as occasionally children may not want to act out the theme they have been discussing. In these cases children may choose to speak directly to the camera, there may be one or two children who are happy to represent the group as a whole whilst some may choose to operate the camera.

Following the separate sessions the parents and children reunite for the last half hour to eat pizza and watch the children's film together. After the film has been shown, there is a discussion period about issues raised in the film during which there is also input from the parent's group about issues that arose during their earlier group discussion. The degree and level of participation can vary and can depend on the topics covered in the children's video and topics covered during the parent's session.

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1.338 Topics that may arise in a typical session

Once the warm up and icebreaker sessions are over the clinical lead usually introduces a topic that will act as the theme for the session. However sessions are dynamic and interactive, topics covered often lead on from earlier sessions and are frequently based on topics attendees have expressed interest in or feel are most relevant to them. Some examples of themes which have been covered during the workshops are:

- Worried about each other
- How do we talk about it?
- Recognizing other's feelings
- Disturbed and disturbing communication and behaviour
- Spoken and unspoken anxieties
- Thinking and talking about our feelings and those of others
- How any expression of feelings could be misinterpreted as coming from a 'crazy person' rather than just an opportunity to blow off steam, as with every normal person.
- Dealing with helplessness and mental disorder
- How kids sometimes feel responsible for looking after parents and making them better, in a role reversal that was not always appropriate for their age or status as a child

- Worries that families could not help their children with their education because of their language difficulties
- Experiences of loss and how this affects relationships within the family
- Parents need to own anxiety as their own, letting kids know that it did not belong to them, and that they were not responsible for what parents were feeling or to make them better
- Experiences of being bullied at school
- Fear of ‘catching’ the illness

1.339 Costs

The average annual cost of running a monthly workshop in each site is around £14,000 per year. This cost includes facilitator drama therapist and family worker hours, venue hire, transportation costs for families who require taxis and refreshments including pizza for all those who attend.

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Appendix 2

ii.i Topic guide for interviews with parents

1. How long have you been in Kidstime for?
2. How did you hear about Kidstime?
3. How often do you go to Kidstime?
4. What led you to participate in Kidstime?
5. Do you think it helps? And why? *What things you like about Kidstime?*
6. What things you don't like about Kidstime? And why?
7. What helps you attend Kidstime? *What things make it easier for you to go to Kidstime?*
8. What gets in your way of attending the workshops?
9. How would you describe Kidstime to a friend or relative?
10. What do you think would be helpful for parents in similar situations to you? *Do you think you could help them? And why?*

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ii.ii Topic guide for interviews with children and young people

1. Tell me about Kidstime, what is it? *How you would describe Kidstime to a friend of yours?*

2. What sort of things do you do in Kidstime?

3. What things do you like about Kidstime? *What is your favourite thing about Kidstime?*

4. What things you don't like about Kidstime? *What is your worst thing about Kidstime?*

5. Is it easy/ difficult for you to go to Kidstime?

6. Would you like to continue going to Kidstime?

7. Who do you think should go to Kidstime? *Who would you recommend it for?*