

'Help me help my child'

**A qualitative evaluation of views on support for
parents of children with mental health problems**

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*Too often we underestimate the power
of touch, a smile, a kind word, a listening
ear, an honest compliment, or the
smallest act of caring, all of which have
the potential to turn a life around...*

Leo Buscaglia

*Great opportunities to help others seldom come, but small ones
surround us daily...*

Sally Koch

Introduction

This study explored the support needs of parents who are caring for children with mental health problems in Fife. At any one time, 10% of children and young people under 19 years have mental health problems which are so significant that they have difficulties with their thoughts, their feelings, their behaviour, their learning and their relationships on a daily basis (Meltzer et al, 2000). This equates to approximately 8500 children and young people in Fife. This study considered, in particular, four of the more prevalent problems, i.e. Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), emotional and behavioural disorders.

It is well documented that good parenting is fundamental for the development of a child's mental health and wellbeing. All parents need to be supported and helped, but especially when they are parenting in difficult circumstances (Scottish Executive, 2005). The time of diagnosis or identification of a child's mental health problem is a crisis for a parent. They will need to adapt to different patterns of living and they may suffer feelings of pain, stress and sometimes a sense of bereavement. They may need support in the form of someone to talk to about their feelings, to build up their self-esteem and their ability to cope with looking after their child. This form of support is counselling in its broadest sense which has been defined as:

'any situation where there is mutual agreement that one person should interact by listening and communicating with another in an attempt to help. It encompasses the work of all health, council or voluntary workers who have contact with parents and carers as well as the work of specialist counselors, psychotherapists or family therapists who are highly skilled and have extensive training in counselling.' (Davis, 1993).

A previous study looked at the effects of health visitors counselling parents of pre-school children with behavioural and emotional problems. Parents valued the service highly and there were a number of significant improvements including: increased parental self-esteem, reduced parental stress and decreased child behaviour problems (Davis and Spurr, 1998).

As part of the recent Needs Assessment Report on Child and Adolescent Mental Health, (Public Health Institute of Scotland, 2003) a consultation was carried out with children, young people and parents. However, only a

small number of parents were involved (n=10) and the report focused on the needs of the child rather than the parents' own needs.

A policy Framework was developed by the Scottish Executive following this Needs Assessment to support local practice in line with the report's main recommendations (Scottish Executive, 2005). The Framework highlights the need for support for parents, but more information is needed from the parents to know exactly what kind of support they need and from whom they would like this support.

In a recent survey of views of health and local authority professionals working in child and adolescent health and wellbeing services in Fife, one of the gaps identified by service providers was the lack of a counselling service for parents of children with mental health problems. This led to the recommendation that a needs assessment of support for parents should be carried out. The current survey of parents' views is an essential component of this needs assessment.

Aim

To identify the specific support/counselling needs of parents whose children have additional needs as a result of mental health problems.

Objectives

- To assess parents' personal feelings about having a child with mental health problems.
- To assess parents' experiences of service provision (formal and informal services) and type of support/counselling received.
- To assess the parents' views of an ideal support service.
- To use these assessments to inform service development.

Methods

Design

The study involved qualitative survey methods: focus groups and in-depth, semi-structured interviews.

Procedure and Recruitment

Four different groups of parents were included in the study in an attempt to focus on four of the more highly prevalent mental health problems in

children; Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), emotional disorders and behavioural disorders.

An Attention Deficit Hyperactivity Disorder (ADHD) parent support group took part in an initial focus group (n=9) to generate areas of interest and concern which were used to develop the topic guide for the subsequent one-to-one interviews and focus group.

Participants for the interviews were accessed via patient lists from clinical psychology, and via the Patient Information Management System (PIMS) for the generic CAMHS service and the child and adolescent psychiatrists. A target number of 5 parents or couples in each of the four groupings was set. The researcher then identified those on the list eligible for inclusion in the study with assistance from clinicians who had access to patient records. Inclusion criteria were that the child was of primary school age and time since diagnosis or first contact with support services was approximately one year.

Fifty-three eligible families were selected for possible interview (25 from CAMHS and 28 from Clinical Psychology). They were sent a letter from the researcher via the clinical service manager asking if they were willing to participate in the survey. A patient information sheet was enclosed. A reply slip was enclosed to send to the researcher with contact details if they wished to take part in the survey.

Response rate was low, even after a second mailing (3 from CAMHS and 4 from Clinical Psychology) giving a total of 7 interviews. The interviews took place in the participants' own homes and lasted on average 35 minutes.

It was agreed that a second focus group should be carried out to increase the study participant numbers. This was arranged with an Autism Spectrum Disorder (ASD) support group during their normal meeting time. Six parents took part in this group all of whom had a child with ASD.

All interviews and focus groups were carried out by the same researcher. They were audio-taped with participants' consent and transcribed by an administrative assistant. Data were coded and analysed independently by two researchers to reduce the likelihood of researcher bias.

All participants were fully informed about the aims of the study and confidentiality and anonymity were assured. Written consent was obtained and witnessed by the researcher.

Research Governance

The research was carried out in consultation with the members of a multi-disciplinary steering group which included a clinical psychologist, speech and language therapist, educational psychologist, family therapist/counsellor and public health consultant. Ethics approval was granted by Fife, Forth Valley and Tayside Research Ethics Committee.

Results

Participants

The total number of participants in the study was 22 (15 in focus groups and 7 in one-to-one interviews).

Table 1: Details of children of interviewed parents

Age of child	Gender	Issue	Workers involved
10	Girl	Behavioural problems	HV Police Family worker CAMHS nurse Paediatrician
6	Girl	Anxiety	School nurse CAMHS nurse
10	Boy	Behavioural problems	Psychologist
7	Girl	Behavioural problems	CAMHS Psychology Paediatrician
9	Boy	Aspergers	Paediatrician Psychology
10	Boy	ADHD	Paediatrician CAMHS nurse Family worker Home Start
7	Boy	Aspergers	Paediatrician Psychologist

Differences between groups

Data analyses showed that it was not a homogenous group. There were differences between the views expressed by each focus group and by the group of parents who were interviewed individually in their homes.

Most notably, one of the focus groups had a fairly negative overall view about statutory services and many of them reported feeling depressed. The other focus group was also generally fairly negative about statutory services, but they had lots of positive ideas about how to develop services. The interview group were mixed - some were positive about services and supported well by family / friends, others were unsupported and depressed.

Parents' feelings about having a child with mental health problems

There were several common themes which emerged when parents were asked how they felt about having a child with mental health problems:

- Helplessness

'she was crying out for help and we couldn't do nothing for her, we didn't know what to do'

- Desperation / frustration with long waiting times

'it was 6 months before I received any support, I became close to a nervous breakdown - I was in an awful state - I needed help and I thought I was going to end up hurting him - it was with no one helping'

'From start to actually get things progressing took 3 months. That is a long time, cos' you are at the end of your tether from the first phone call.'

- Depression / Anxiety

'it got to the point where I couldn't cope with him anymore, I ended up on anti-depressants, got to a point too long tip-toeing round him, trying to deal with him but without him getting away with too much - he probably did because I was frightened of how he would react.'

- Lack of knowledge on whom to contact

'there is no-one in the phone books to phone. I wouldn't have known to phone Social Work, I thought they phoned you. I didn't know about Integrated Community Schools [Family workers].'

- Seen as Parents' fault

'[the worker] made out that it was due to us separating. It was always felt as though it was my fault, which I had feelings about anyway because I made the decision for us to move out and there was a lot of upheaval at the time we separated and it made things hard'

- Constant struggle with daily life

'You are left when you are having problems because there is no coping strategies. You don't know if it is normal to be so stressed out, to feel you're not coping. There have been times I have put him in his room and cried, thinking what I am going to do next?'

'I used to drive past in tears just thinking I don't want to go home'

A few less common feelings about having a child with mental health problems also emerged, mentioned by only one or two parents, or specific groups:

- Diagnosis is helpful (ASD, ADHD)

'It's good to have a label...it makes a difference when you tell people he does have a problem - people back off - they don't think he is just a spoilt little boy'

- Fear of child (parents of children with behavioural problems)

'It was getting to the point where I was frightened of my own son'

- Should be able to cope without help

'I think it was a pride thing - I can do this myself, I felt, "well, I am the mum and I should be able to cope"'

- Feel scrutinized by authorities

'I felt constantly scrutinized, I felt everyone was constantly watching me'

- Want child to be normal

'You just want them to fit in. You don't want them to feel different from anyone else - you don't want to draw attention to them'

- Grief when child is diagnosed (ASD group)

- Unable to relax (ADHD group)

Parents' views on support received

Several commonly held views emerged from the data regarding parents' experiences of formal and informal support services and type of support received.

- Often several services involved - health, council, voluntary sector
- Those with strong family network feel well supported
- Support from other parents is very helpful
- Support for the child equals support for the parent

'The more support my child got, the more support I got because he was helped through it'

- Diagnosis is helpful, but follow up not sufficient

'There has been a big lack of information, which would be good to get early on. There is things on the web, but it feels like you're struggling on your own'

- Personality of support worker is important to how the parent feels

'She was approachable, her body language was good, she had humour, she understood, she wasn't just a person in the street with a clipboard so I thought she was wonderful'

- Parenting programmes: Spin VIG, Triple P, Early Bird all mentioned as being helpful

'I feel the Early Bird is great because I get good feedback and I think, oh I'll try that and things do work'

'I went through the Triple P Programme - it taught me to not get involved in an argument, to give eye contact... screaming at her got nowhere, just speaking in a normal voice she took on board better.'

- Behavioural management strategies are helpful

'it has helped her with the phobia... and she feels, well, if I can do that I can do other things as well...'

- Respite is helpful in short term, but doesn't improve coping skills

'There has been a big lack of information, which would be good to get early on. There is things on the web, but it feels like you're struggling on your own'

A few less common views on support received emerged, mentioned by only one or two parents:

- Referral for parental depression (ADHD) viewed positively
- School system is supportive to parents

'The school are brilliant, they have personal learning plans...they (children) know what is expected of them and that is what they need.....It is what we need as well - it is a huge help for us because it helps us learn...not just getting letters back from the school'

- Parents respond well to workers who listen to them

'[Child] had a turn, a setback. I was in tears. I phoned [worker] but we talked through it and it was good because I could phone her anytime. Good that we had someone to turn to'

- Some workers have not provided the support that parents expected

'I thought the purpose of getting him [worker] in was to support myself as well...all he did was observe [the child].'

Parents' views of an ideal support service

The main themes emerging from the data regarding parents' views of what services should provide were:

- Support for child is important as that helps the parent

'if that is the problem then he can get help and support to make his life easier and in turn help me and get the support I need as well instead of feeling I am a bad parent'

- Knowledge on whom to contact when a problem arises

'I think initially, if there was support quickly, some number you could have....I know there is no magic cure....but something like a parent link...I am saying this with an understanding of knowing there are a number of children out there and things do take time, but when you are in the middle of that, you feel it is like years.'

- More information at an early stage following diagnosis

'A precise information pack detailing what services are available, whether that be schools, respite, services in the house, extra support in the house, after school care. Someone who could spend 1-1½ hours to talk to you. One point of contact who could give you all the information you need. Some people don't even know that there are groups for special need children. We weren't even told that he was entitled to disability living allowance until 2 years after'

diagnosis. Someone who is centralised to even to listen to your worries, so you can ask what is there to help you.

- Reassurance that they are not 'bad parents'

'Someone to say it will be alright - it isn't your fault'

- Someone to talk to with experience, time and a friendly supportive attitude

'Having someone neutral, someone with previous experience of the problems or somebody with kids that could give emotional support and advice if there are steps I could take'

- Practical training on how to manage behaviour - relevant and followed up

'It would be helpful to have some sort of training for parents to equip them with the tools that will assist them in their every day life - dealing with different situations, identifying trigger factors, trying to capture things before they go too far, gaining an understanding'

- Direct contact with 'expert' support for advice (ASD group)

'We want people who are expert in the field of autism from a psycho-social perspective who can help with strategies, who can help you understand'

- More communication between parents and education staff
- Support offered automatically without having to ask for help
- More emphasis on their needs as a parent

Discussion

This study was set up because a group of health and local authority professionals had identified the need for a counselling service for parents of children with mental health problems. It was decided that parents should be asked for their views. Although the parents expressed many views about their experiences and needs for support, the majority did not specifically use the word 'counselling' to define what they needed. However the type of support they were requesting is similar to that defined by Davis (1993) as counselling in its broadest sense: they want someone to take the time to listen to them, to understand what they are

going through and to help them cope with daily life. This is the kind of support that can be given by all health, council or voluntary workers without the need for specialist training in counselling skills. It was clear from the results that most parents find an informal, friendly approach more helpful than a formal, 'professional' manner.

Many parents found it difficult to talk about what they needed personally because they felt their needs were met if their child was being supported adequately.

Other parents described feeling overwhelmed and not being able to manage on a daily basis: giving them the skills to manage their child's behaviour wasn't enough because they didn't feel personally capable of putting the knowledge into practice.

Conclusions and recommendations

Having analysed the main findings of this qualitative study, I have made some conclusions and would propose the following recommendations for consideration for service development:

- Parents are expressing a need for more support, but not specifically from a trained counsellor. A friendly, informal attitude towards support is likely to be more effective than a formal, 'professional' attitude. Frontline workers from all backgrounds can provide this support with some awareness of what constitutes basic counselling skills.
- The majority of parents want to be recognised by workers as the main service providers for their child's care and should be supported by workers to be able to provide that support: workers need to show parents the practical skills and nurture their belief in their own ability to manage their child's troubling behaviour.
- Some parents may be unable to put helpful information on what to do into practice because they are suffering from emotional problems themselves, such as anxiety or depression. Workers need to consider the mental health of the parents as a priority.
- Parents have requested that they are given information about how they can respond helpfully to their child's troubling behaviour as early as possible and verbally as well as in written form.

- It is important that all parents should have a break from caring for their child, but some parents with low self-esteem report that respite can make things worse because they see someone else coping better than they do. A carer working alongside the parent may be an effective alternative solution.
- Parents report that support from other parents in a similar situation is helpful. However, support groups will not suit everyone. It is important to consider alternative means of linking parents with other parents. Also it is important to maintain a positive, solution-focused approach to support groups.
- Parents of children with mental health problems are not a homogenous group. They all have different needs. Professionals should be aware of this and take time to ascertain the parents' own specific needs for support.

Overall the main message coming across from parents was that they want *help to help their child*: they want the knowledge on whom to contact for help; they want training on skills to manage their child's behaviour themselves, as well as their child receiving direct input from specialists; they want to feel better about themselves so that they can put these skills into practice and they want a friendly ear to listen and understand what they were going through.

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