An evaluation of the Insiders' Guide - a peer support course for parent carers of children with ADHD

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Key recommendations

1. The importance and impact of this Insider's Guide for Parents of young people diagnosed with ADHD was overwhelmingly positive and led to a profound positive impact on their day to day lived experience as a parent carer. As such we fully recommend the continued funding of such a crucial service.
2. This was a community-based course that positively impacted the wellbeing and resilience of the parents who took it. Based on the accounts of the parents who took this course we suggest that the ongoing parent peer-support networks that grow from such courses will have a significant reduction on the use of statutory services.
3. We recommend that this Insider's Guide framework for children diagnosed with ADHD be considered by commissioners as a highly effective practical, social and emotional intervention for parent carers of children with mental health difficulties. As such, we also recommend, where possible, its expansion geographically.
4. Current provision for the needs of parents whose children are diagnosed with ADHD is less than sufficient to address the multiple stresses, barriers and challenges that powerfully impact on their wellbeing. Multi-stakeholder collaborations like these provide invaluable assistance in a way that statutory services often fail to achieve on their own. We therefore encourage the continuation of such partnerships that allow for the emergence of carer-driven, peer-supported resources to flourish in Brighton & Hove.

Executive summary

1. There is emerging evidence of a rising mental health need in key groups of young people. However, many young people and their families face difficulties in accessing services.
2. The challenging funding context for mental health services now requires a consideration of alternative approaches in both delivery and content.
3. Since the increasing shift of psychiatric care to the community, the role of families in the care of their loved ones has grown considerably. There is a dearth of empirical material that critically appraises mental health work carried out in informal community settings across the country. This is particularly the case as regards the impact of peer support groups for the parents of children and young people diagnosed with ADHD.
4. This project brought together a new partnership between Amaze, the University of Brighton, and the Community Child and Adolescent Mental Health Service (CCAMHS) to address the critical support needs of parent carers of young people diagnosed with ADHD.
5. Specifically the partnership designed, piloted and evaluated a discreet and specialist course for parent carers that aimed to:

   1. Increase the capacity of parent carers to support their children's mental health and wellbeing
   2. Profile the value of working across community, statutory and university knowledge bases to meet identified local need
   3. Explore the relevance of parent carer support to young persons' mental health and wellbeing
   4. Explore the impacts and potential additional value of group-based support work with parent carers.

6. We carried out semi-structured interviews during January and February of 2016 following completion of the course, so that parents had a chance to reflect back on the experience of being part of this group. We also used an adaption of photo-elicitation. Finally we used a pre

and post course questionnaire to capture parents' perception of key areas of their experience of being the parent of a child or children with special needs.

7. Building a welcoming and safe atmosphere was understood to be essential for people opening up and doing meaningful work and it contrasted directly with the more classroom-based 'feel' of previous statutory and professional encounters which elicited altogether different responses.
8. A sense of comradeship and solidarity was strong and facilitated a change in their collective and individual identities. There was a sense of a space that had opened up where voices, previously silenced through practices of stigma and lack of empathy, were replaced by a sense of shared purpose and belonging in the group.
9. The course focussed not on parental deficits that had to be remedied by professionals but on what peer-suggested social practises they might find useful. This was felt to be refreshing and very beneficial. The parents in this group also focussed on sharing tips on how to cope with the challenges faced when working with professionals
10. The participants on this course reflected on the quite profound impact of the course on their lives, so much so as for it to be called a 'lifeline'.
11. Quantitative findings suggested pre-course vs post-course improvement on all measures, with statistically significant improvements on 'parent self-esteem and wellbeing' and 'overall parent functioning' scores.
12. To conclude, the course was experienced as highly beneficial for all parents who took part. The peer-supported practice orientation of the activities moved away from a passive, deficit model of care to an active and pragmatic model which suited perfectly the disparate care needs of these parents. The importance of the nature of the setting and parent friendly atmosphere of the space had an impact on the way in which the group was able to bond and work together through the course. This allowed for the emergence of solidarity and care that had an impact not only on the confidence and wellbeing of the parent carers but on the children and young people with whom they share their lives.

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Introduction and background

Mental health difficulties affect about 1:10 children and young people and are often a direct response to what is happening in their lives (Mental Health Foundation, 2015). Mental illness accounts for over 1/5th of NHS disease burden but gets only 1/10th of funds and a recent nationwide survey of GPs noted that changes to mental health funding have left many NHS Mental Health services unable to cope (Price, 2015). Indeed the latest Brighton and Hove children and young peoples' transformation plan shows that 3 out of a class of 30 schoolchildren will suffer from a diagnosable mental health disorder (Brighton & Hove CCG, 2016). In this context, the national Children and Young People's Mental Health and Wellbeing Taskforce was established in 2014 to consider ways to make it easier for children, young people, parents and carers to access help and support when needed.

There is emerging evidence of a rising need in key groups of young people. However, many young people and their families face difficulties in accessing services with data from the NHS revealing increases in referrals and waiting times and providers reporting increased complexity and severity of presenting problems (DoH, 2015). The challenging funding context for mental health services now requires a consideration of alternative approaches in both delivery and content.

In Brighton & Hove, recent research has highlighted parent carers' concerns and key themes include: difficulties accessing services and unclear eligibility, particularly when children have mental health issues but no defined mental health condition or learning disability; feeling their parenting was judged and to blame for their child's difficulties; long waiting times for assessment with no guidance about how to manage daily living offered in the meantime; feeling disempowered and difficulties engaging with practitioners (Walker & Stretfield, 2012). Recent research in Brighton & Hove (Amaze, 2013) sought to identify the impact on families of caring for children with additional needs: 47% of respondents are living solely on benefits; 44% are lone parent families managing on their own; 28% have two or more disabled children; 20% feel socially isolated and 18% have at least one parent with mental health difficulties. Overall the picture is one of severe disadvantage.

Since the increasing shift of psychiatric care to the community, the role of families in the care of their loved ones has grown considerably. Many parents of young people with complex needs are involved in advocacy, crisis management, assistance in daily living and do this caring with few resources, little information and no training (Stephens et al 2011). Indeed the potential negative consequences to the carer of providing care to a relative diagnosed with mental illness include persistent worrying, feelings of loss, perceived tension between carer and relative and psychological distress (Stephens et al 2011).

While having a child with a disability does not necessarily lead to difficulties, a substantial body of research documents the stresses and challenges that many parent carers experience (Solomon et al 2001, Walker & Klein, 2013, Walker & Stretfield, 2012). In addition to grief, loss and guilt, many experience isolation, social marginalisation and stigmatization. In such contexts, mutual support groups are thought to have many benefits including a psychological sense of community, emotional support, providing information, ideas on coping, opportunities to help others, companionship and a sense of mastery and control (Solomon et al 2001). However there is a dearth of empirical material that critically appraises mental health work carried out in informal community settings across the country, particularly for people of an age when mental health is typically understood as the preserve of statutory services (Walker, Hanna & Hart, 2016). This is particularly the case as regards the impact of peer support groups for the parents of children and young people diagnosed with mental health issues and specifically ADHD (Dixon et al 2004). In a context where parents are becoming increasingly expert in the practices of, and literatures on, supporting their children (Valentine, 2010), it would appear to be particularly useful to carry out empirical work on a parent peer support group for young people diagnosed with ADHD. Moreover, rigorous studies of family support programmes in childrens' mental health are exceptionally rare (Hoagwood et al 2010). Peer support has been peripheralised in childrens' mental health services (Hoagwood et al 2010), and Kobayashi and colleagues (2011) suggested that a failure to provide such services as support groups can lead to high caregiver distress and family members being directed to inappropriate therapy.

The project

Amaze is a user-led registered charity whose mission is to inform, support and empower parents of children with disabilities and complex needs across Brighton and Hove and beyond. This project brought together a new partnership between Amaze, the University of Brighton, and the Community Child and Adolescent Mental Health Service (CCAMHS) to address the critical support needs of parent carers of young people diagnosed with ADHD. Specifically the partnership designed, piloted and evaluated a discreet and specialist course for parent carers that aimed to:

1. Increase the capacity of parent carers to support their children's mental health and wellbeing

2. Profile the value of working across community, statutory and university knowledge bases to meet identified local need

3. Explore the relevance of parent carer support to young persons' mental health and wellbeing

4. Explore the impacts and potential additional value of group-based support work with parent carers.

Following recruitment through Amaze in November 2015, an initial focus group was held for parents with children or young people who had been diagnosed with ADHD. This was carried out in order to coproduce a new Insider's Guide framework (Hart & Virgo, 2006) for the parents of young people diagnosed with ADHD. The group suggested that the course be developed over six workshops (appendix 1) covering such areas as parental stigma, understanding ADHD, stress and resilience, parenting tips, and negotiating with schools. 13 parents then took part in the final series of codesigned workshops. The workshops were delivered by a former Amaze worker and a Community CAMHS worker who was also a parent of children diagnosed with ADHD. They were delivered in a municipal town hall in Hove, East Sussex on Friday mornings between 9.45am and 12.45pm and during six consecutive weeks.

Method of evaluation

Our aim was to develop a method of evaluation that was both sensitive to and effective for parent carers and the intervention. For this reason we carried out semi-structured interviews during January and February of 2016 following completion of the course, so that parents had a chance to reflect back on the experience of being part of this group. All interviews were audio recorded. The interviews lasted between 30-45 minutes and focussed on a number of key areas relevant to the experiences of the parents and the course.

We also used an adaption of photo-elicitation. Photo-elicitation is a method of interview in visual social sciences that uses images to elicit comments (Han & Oliffe, 2015). The types of images used include photographs, video, paintings, cartoons, graffiti, and advertising, among others. The capacity of visual methods to provide powerful nuanced accounts critical to understanding health and illness issues has been under estimated, and people can struggle to convey their emotions using conventional interviews or survey methods that rely on the spoken word and / or responses to specific questions. Indeed it has been suggested that using it to investigate the perspectives of family members and friends of individuals with mental health difficulties may be an important research area (Han & Oliffe, 2015).

The main purpose of photo-elicitation interviewing was to record how people respond to the images, attributing their social and personal meanings and values. We asked parent carers to use cameras to take photographs that represented what they experienced in the group and how it impacted their day to day lives. These photographs were then be used as the basis for in-depth interviews.

A pre and post course questionnaire was also used to capture parents' perception of three areas of their experience of being the parent of a child or children with special needs-

- Parents' self-esteem and well-being
- Parents' experience of parenting
- Parents' perception of their relationships with professionals.

The questionnaire used was devised from a composite of general self-esteem questions taken from the Rosenberg Self-Esteem Scale and some parenting questions from the Parenting Stress Index. It had shown to be effective in previous Amaze research (Hart & Virgo, 2006). The project received ethics approval from the University of Brighton College of Social Sciences ethics committee.

Data Analysis

Descriptive statistics were used to analyse the quantitative date. Thematic analysis was used to analyse the interviews. Thematic analysis is a pragmatically and theoretically flexible analytic paradigm (Braun & Clarke, 2006) that allows researchers to identify, analyse and report patterns within qualitative data. It is ideal for semi-structured interviews where similarities and differences between accounts form key components following which representative themes are developed. All parent names included in this report have been changed to protect anonymity.

Findings/analysis

Reasons for coming to the course

Before thinking through the findings of how parents experienced such a course it is worth reflecting on the reasons that parents decided to be part of it in the first instance and the expectations that they had of the course. Swain et al (1993) spoke of 'disabling barriers' as a useful way of thinking about mechanisms through which people are excluded from full participation in all aspects of civic life, including family, work leisure. These barriers were at the forefront of the expectations that parent had. Parents spoke of a desire for strategies and knowledge, often non-clinical, because of the sense of being thrown in at the deep end with little support. It is clear that the concerns of the parents who came to the course reflected some of the previous research showing how parents benefit from information sharing, skill development, emotional support, and instrumental support with services and advocacy support (Hoagwood et al 2010)

> "…and he can be a danger to himself and others and just can't be left alone so it is hard work so yea I think it was just being able to understand him a bit better." Abby

A number of parents reflected on struggling to cope with very extreme behaviour and having felt that they had failed to do so, had reached a point of desperation or exasperation

> “….but it’s got to the stage that he’s so foul daily every hour that I, we’re getting a little bit beyond empathising and feeling.” Julie

Having had numerous experiences with professionals whose lack of personal experience, both of ADHD generally and their child in particular, meant that most parents were keen to receive support from people who were having experiences similar to theirs. The implication was that meaningful and useful strategies were assumed to be accessible only via those with personal experience rather than professionals who had come to acquire their knowledge of ADHD through static texts or professional contact with families. Parents also had experiences of isolation that had often been compounded by family members and friends who had struggled to empathise with their difficulties, and so they specifically sought support and empathy from other parent carers. Indeed for many that was the single reason that they had turned up at the course

> “…strategies and support from other parents, I thought I would get a lot of support, people that would understand.” Julie

The significance of course ‘atmosphere’

The atmosphere of the group had been carefully thought through by the planning team in response to the initial focus group, and with good reason. If we understand people’s wellbeing not necessarily as an internalised quality but as sets of effects dependent on the situations that they are in and the people that they are with, then we can see that wellbeing is produced by complex assemblages of relations not only between people but also between people and places, material objects and less material elements of places including atmospheres (Walker, Hanna & Hart, 2016). It is important not to assume that such intangibles as the ‘atmosphere’ of a setting immediately confer a lack of complexity or significance. Indeed they can be fundamental to the success of a given intervention. When we look at informal support practices we often find that combinations of social relationships, people, conversations, changes of scene and shared histories of suffering are important and the development of new ways of thinking and new practices are often only made possible by an atmosphere of compassion and warmth (Walker, Hanna and Hart, 2016).

When parents spoke of the informal atmosphere they didn’t speak of it as a peripheral bonus but as a central element of the impact of the course. Indeed the informal, friendly, relaxed nature of the setting was understood as essential to the course having any use for them

> “..But, yea, I think it’s a lot more it’s not informal, it’s a friendly relaxed atmosphere so you are far more likely to sort of talk in depth and a little bit more openly and candid about...” Pauline

> “…it was informal, it was relaxed. I think informal to me, to me personally I feel informal is good cos I don’t like feeling like I am back in the classroom but I feel that informal makes people more relaxed, more willing to open up and talk about things than if you’re sitting behind a desk.” Nichola

Building the right atmosphere was understood to be essential for people opening up and doing meaningful work and it contrasted directly with the more classroom-based ‘feel’ of previous statutory and professional encounters which elicited altogether different responses. In such an instance the ambience and atmosphere are not just how the setting is understood or judged but acts as a facilitator of change itself, as something capable of eliciting change in people’s demeanour, outlook and willingness to connect and engage and hence do the work of peer-support

> ”…and there’d be the kettle on and there’d be tea and coffee and you know you’d sit and have a coffee first and a chat and it was it was a bit like going for a coffee morning, the atmosphere was really good it was a really good group of people.” Abby

> “…it was just, just to hear other parents talk and to have support and to be able to speak openly in front of other people that understand the problems that you’ve got.” Donna

The benefits of seeing others struggle

Hochschild (1983) suggests that there are certain ‘should feels’ or ‘emotion rules’ for certain everyday social situations, grief at bereavement, love for family, and so on. She said that guilt or worry functioned to uphold these feeling rules from the inside, almost as an internal acknowledgement of an unpaid psychological debt. Many of the parents had come to experience profound guilt over their incapacity to be ‘a better parent’- an all-powerful ‘feeling rule’ for parents who feel that they fall below the exacting standards of the world around them

> “I’ve got to stop, you know, putting myself down, because the boys, all three boys carry a duplicate chromosome that I carry, two of them carry the seventeen chromosome and the eldest one carries the four one so it all comes from me. When I found out I felt really guilty and I really went into a depression.” Ruth

> “…well just cos I was, I was low, I was stressed cos I was thinking I am doing something wrong, can’t figure out what I am doing wrong. I am doing everything I possibly can. I am doing these things but evidently wrong in some way…you do sort of internalise it and start to feel a bit ‘oh I’m a bit rubbish as a parent’.“ Kerry

However a close reading of their accounts shows that the ‘evidently wrong’ nature of their parental response was judged on the basis of the behaviour of non-ADHD children and the reactions of non-ADHD parents and members of their own family. Their responses were not judged against the lived experiences and parenting practices of other parent carers in similar situations to their own. However when that changes a quite profound shift can happen. This course showed that this shift needs more than a therapist seeking to address faulty thinking patterns but the facilitation of a space with other people in their situation and to watch their responses. To recognise the guilt and sense of failure of others come to light. The effect of this should not be underestimated.

Pols & Kroon (2007) speak of the importance of spaces that provide opportunities to experiment with social roles. It is important to recognise that different and sometimes conflicting notions of what is good care exist. Care practices which made possible a change in self-appraisal based on the struggle and misery of others may at first appear problematic. However in the context of the group seeing others struggle was a positive thing, not through a sense of malice but because it provided a lens through which to rethink their own practices, responses and behaviours. The old ‘typical’ parenting norms were gently pushed aside as new norms started to emerge, norms that they recognised in their own parenting practices

> “…one of the main things is that I, I used to feel very alone as if I was the only one going through this and it has helped a lot to meet with other parents and when I am having a difficult time, it’s not just me going through but I know there’s Nichola, there’s all these other parents that are having just as many difficulties as I am having so now yes it has now helped that I am not a bad parent.” Donna

> “..it was a relief that I was not sort of failing him.” Kerry

Solidarity and care

Having a disabled child doesn’t necessarily lead to difficulties. However a substantial body of research documents the stresses that many parents experience, including grief, loss, guilt, isolation, social marginalisation and stigmatization (Solomon et al 2001). Furedi’s (2014) ‘therapeutic turn of history’ means that people are encouraged to frame their difficulties in the language of psychology and mental health when in fact many of their challenges actually emerge from the world around them. This leads, according to Furedi, to a culture of individuation that erodes social solidarity and community. In line with this Smail (2005) said that we need to recognise the ordinary humanity of the therapeutic relationship and its role as a source of solidarity rather than a technology of change.

What became clear from the parent’s experiences on the course was that the solidarity that Smail and Furedi spoke of was an emergent product and central to the successful experience of the course. Indeed one of the key benefits of the course were the nature of the social relationships formed within (Manning 2010). And here we define a clear difference between social support and solidarity. Social support is the perception and actuality that one is cared for and has assistance available from other people. Solidarity is a sense of unity and agreement of feeling or action, especially among individuals with a common interest. Our parents spoke of comradeship and implicitly evoked the growth of solidarity enabled by this setting and course

> “…and I think the biggest thing it does is it’s the support aspect: of the parents you know, comradeship, whatever you want to call it: it’s, that’s the thing, knowing and we keep in touch.” Sarah

Recent research by the Joseph Rowntree Foundation (2014) focuses on the importance of a shared sense of understanding and experience often not found in relationships with professionals and where closeknit relationships and a sense of shared identity can provide a strong basis for mutual support and can act as a form of capital (Haslam et al 2012)

> “… obviously cos of the age he is now there are different challenges etc. and stuff, a lot of it more emotional and I felt in a way that I just really felt like I needed a little bit of support and understanding from like, you know, people who are going through the same thing.” Pauline

This comradeship and solidarity allowed for an emergent change in their collective and individual identities and status (Harper & Speed, 2012). There was a sense of a space that had opened up where voices previously silenced through practices of stigma and lack of empathy, were replaced by a sense of shared purpose and belonging in the group

> “It was a bit like an offloading, you could think ‘oh I can go there I can just talk about it’ or ‘I can just tell them how things went’, whether there was positives or negatives so I really got excited about the next weeks’ course.” Julie

> “I really enjoyed the people, the people were, were fabulous, there was a real sense of, of belonging, of, people not, not being afraid to be there and to share their emotions and then their knowledge and talk about experiences, that was good. The two ladies that were running it was great.” Nichola

The idea of relational citizenship makes sense of citizenship in terms of being able to live successfully with others. A key idea in the modern world is to think of people as needing to become autonomous, self-regulating individuals (Pols, 2015b). However mutual support groups have many benefits that are rooted in a social and relational mode of citizenship- a psychological sense of community, emotional support, role models, providing information, ideas on coping, opportunity to help others, companionship and a sense of mastery and control (Solomon et al 2001). They can encourage benefits at the level of socio-political, interpersonal and intraindividual and hence groups like this one move beyond the narrow strictures of the more conventional statutory helping relationships and services and are characterised by a more active and social citizenship. There is a move from feeling alone to being recognised as being part of a valued group who support and stand with you. In Western industrialised society, discourses of disability include victimhood, powerlessness, isolation and dependency but through this course, which has since its completion transitioned into a monthly support group and a facebook community, people were enabled to experience solidarity, empathy, and to see others struggle. Through this, a form of peer-care emerged that was active, social and empowering

> "…and now I am in contact with a few of the parents, one in particular, and it's nice because we actually support each other now. I know Julie has got a very difficult meeting coming up tomorrow and we text each other." Abby

"and there was one little bit of growth, that was the leaf. There was one little bit of new growth that was a bit of sort of yea that leaf all on its own, it was a little bit of positivity um just probably the new friends that I'd found on the course and I just thought oh it's a little bit of a support a little bit of newness so it was just a little new path that was leading in my life." Julie

Changing practices rather than people

Many of the challenges that cause strain in families with children with mental health problems are consequences of the macro environment, for instance, lack of appropriate childcare, failure of an under-funded health care system and widespread stigma (Mendenhall & Mount, 2011). Interventions like peer-support groups are arguably better able to recognise and respond to this.

Moreover, when trying to make sense of whether peer support groups differ substantively from professional encounters, it is important to think through the culture of helping interventions in which they are embedded. Many of these parents had experiences of situations where they and their children became an object of intense observation and documentation, a process reserved for children who perform outside of a range. And they happened in professional settings where their knowledge often had less value than that of professionals because they did not carry the authorization of 'scientificity' (Reid & Valle, 2004). Indeed many family members report dissatisfaction regarding their interactions with the mental health system (Dixon et al 2004).

Central to wellbeing is connectedness, the rebuilding of positive identities, often within contexts of stigma and discrimination, and Tew (2011) suggests that there is a need for social rather than clinical interventions to enable people to develop new personal relationships, particularly if they are socially isolated, which a number of these parents were. Indeed previous work suggested that peer-run family to family groups showed immediate benefits for attendees, including increased empowerment and decreased subjective burden, increased problem solving skills, coping, empowerment and knowledge (Luckstead te al 2012). It is important to note that these are not clinical or therapeutic but practical and social benefits. A perspective on social practices rather than cognitive change is important for parents with experience of being blamed for personal parenting deficits.

A practice perspective implies an imminent relationship between knowledge and practice, whereby knowledge is constituted in practice, not a tangible asset that can be moved between professionals and individuals. Here, knowledge belongs to specific groups of people and their situated practices (Marabelli et al 2014) and this is perfectly shown by this peer support group which exhibited a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement on what was helpful (Dixon et al 2016). Here the course focussed not on parental deficits that have to be remedied by professionals but on what peer-suggested social practises they might find useful

> "…you kind of think, well actually I've probably been doing that wrong, I could try doing it that way cos that makes you think yea probably that's the wrong approach, maybe I have been doing that wrong and I need to do it this way." Abby

“Kim and Karen gave us all a little key ring. And I think it was the elephant was meant to represent you know trying to remember what you have learned at the course, to remember that you are not alone and there’s other people that are in the same situation and I just thought that’s actually really good and had to take a photo of it.” Abby

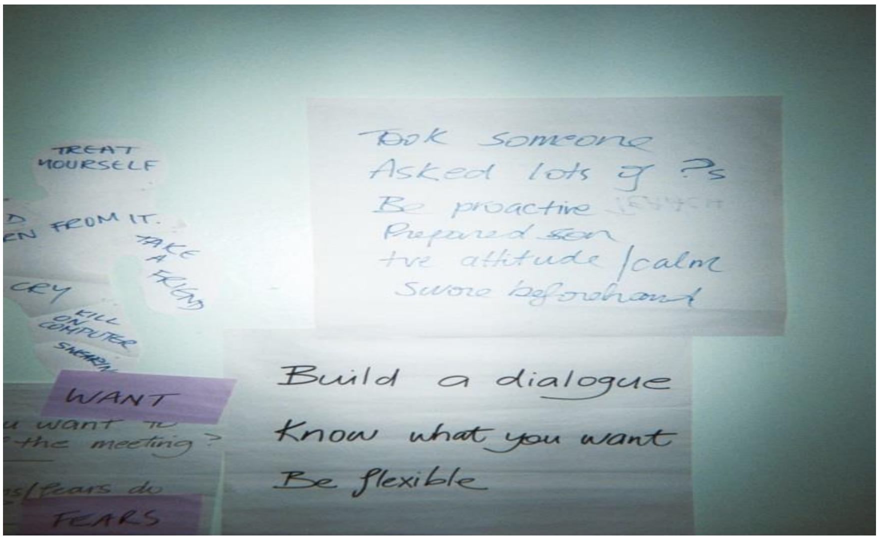
For parents used to taking responsibility for personal failures this represented a difference and a welcome and refreshing one. The actual changes made could be quite small, for instance the use of reward charts, or thinking through the dynamics of disciplining their child in different ways

> “and also I do reward charts as well, I find that that really helps, he’s really getting it you know getting a lot out of it so yea reward charts I find really, really good and I mentioned that to everybody and you know, I think hopefully some of them have taken that on board.” Ruth
>
> “.. yea, she was saying because she has children with ADHD and autism and she gave me quite a few strategies. She was saying that ‘don’t ever take all his money away from him’ so that he’s got something at the end of the week you know so he gets five pound pocket money, try and leave him a little bit so he’s always got something to keep going for.” Julie

One of the significant areas that parents discussed as beneficial was supporting each other to think through different strategies to help to communicate with the professionals with whom their child would come into contact. Reid & Valle (2004) speak of parents of children with complex needs often experiencing ‘walk-on roles’ when they enter into professional arenas of medicine and education where their children’s welfare is discussed. Here, frequently their knowledge can be disqualified or marginalised in favour of professional forms of knowledge and as such, the sense of shared awareness and understanding so often shared by peers is often not to be found in relationships with professionals (JRF, 2014). Moen et al (2011) speak of parents feeling entirely at the mercy of professionals and their decisions with virtual tug-of-wars between parents and professionals on who was ‘right’ or ‘wrong’.

The parents in this group focussed on sharing tips on how to cope with the challenges faced when working with professionals

> “..yes when we were discussing about actually making a clear inventory of what you wanted to get out of the meetings cos I’ve never done that, I sort of go in without knowing what the meeting is about”. Nichola



“Yes this is me taking a picture of the things to do when you are going to have a, a meeting with someone because it was it was like yea this these other things that really have to tick the boxes so if you have got the information beforehand then you can.” Nicola

> “… but she said oh well you know isn’t he not entitled to this or have you tried this and it was just somebody to be on my side whereas before I sat there on one side of the table and they all sit there and I felt like I was being interrogated. It felt really supportive to have somebody else.” Julie

Breaking down complexity

For those parents who had come to the course to learn more about how and why their child behaved the way that they do, a combination of metaphors and a capacity to break down the complexity of the lived experience of children diagnosed with ADHD was important. In so doing these practices helped to introduce new coordinates that parents could use to make sense of their children’s actions and reactions

> “Like they said, imagine your brain as an office building and you’ve obviously got the, like, reasoning department and the memory department and this department and that department and like the people that deals with the child’s reasoning, they are all on holiday, no one’s in that office and it’s like oh my god, yeah. And the people in the memory department, there’s only one person in there and they are sitting feeding the paper shredder and it was just the way it was explained to you and how the brain works and kind of why it’s not really their fault, and a lot of it they can’t help. It was just the ins and outs of it and the way it was explained it was really good. I’ve never had that.” Abby

Hout et al (2015) suggest that if we want to understand care, we need to focus on the vital detail of material practices that people engage in and the way that these shape relationships and ways of being present with one another. This course was able to do exactly that by focussing on some of the everyday material tasks that shape social relations in the parent’s homes and helped them to work through different possibilities for how those tasks might be enacted and what the implications might be

> “When we would explain to our children if they want to cook beans on toast, how we would prepare them to do it? How many stages it would take: because they said you wouldn’t be

> able to with an ADHD child, you wouldn't just say 'well go and do some beans on toast' you have to break it down." Donna

A focus on developing and sharing different practices around dealing with professionals disciplining children, rethinking their children's responses, rewarding their children and coping with the reactions of other adults was described by one parent as the 'mum repertoire' (Pauline). This parent nicely summed up the impact of the course in this context where she felt she had previously 'run out of mum repertoire' and hearing the accounts of what other parents had tried, including one of the trainers, allowed for a 'rebooting' of their own capacities to work through some of the everyday challenges that they faced. And the expanded nature of this 'mum repertoire' had become obvious to the children themselves in some cases

> "..and he went up into his bedroom and I thought right I am going to leave it, rather than go 'oh you've got to come down', I left it and he did come down, he put his arms around me and said I am sorry mummy he said let's do the homework and I thought wow!" Donna

Impact on wellbeing and confidence to

It could be argued that the experiences of the parents on this course are analogous to a form of recovery- not a recovery from mental ill-health but rather a form of recovery from the guilt and impositions projected on to them by a world defined by the trajectories of typical parenting. This could be understood as a recovery from feeling helpless to feeling able to practically address some of the key challenges that presented in the world around them. Not least from isolation and a sense of being unable to unpack the often overpowering impacts of their child's behaviour.

Previous to the course they believed that they must be responsible for the things that go wrong and for not finding the right solutions; that they parented poorly and that they needed to supine themselves to professional experts in order to learn how to improve. However on this course, social solidarity, practice learning and community integration were crucial in terms of their health and wellbeing. Hope is a central part of any form of recovery and it is invariably linked to a capacity for change (Duff, 2012)

> "The single biggest thing (about the course)? Hope. Real hope of the, the sort of kind of like you know despite all the things that, that you kind of go through. You worry about your children's future and even though we know that they have got challenges ahead of them but there is hope because you know that there are people out there that do understand this condition, who will give you support. Hopefully there will be funding at some stage to still carry on these courses and, and just have that level of support." Pauline

Very often evaluation reports on CVS sector organisations use 'confidence' as a general metric of improvement. However it too often takes the form of a disembodied and generic personal attribute. When these parents talked about what confidence meant for them it becomes clear that rather than thinking of it as a general property, it tended to be related to the capacity to *do* specific things or *think* specific things. The parents that went through this course spoke of confidence as having an expanded arsenal of ideas regarding dealing with professionals and creating strategies

> "I'd say it has (impacted my confidence). I'd say, it just gives you a bit more on your arsenal of ideas and on thoughts and on how he is okay so he's special but so is everybody else, he is just different and you just have to put things in place to make sure that you help him achieve cos what we want in the end is, is to get a child that when they become an adult will be able to cope with life." Sarah

> "..it's probably given me more confidence although I have always been confident in dealing with professionals but it probably has given me more confidence especially with schools. It is always schools that I have never been quite so confident." Nichola

> "through the support I feel a bit more confident to put into, you know, like the strategies and things and then I feel a little bit more confident that yeah, if it doesn't go right or it does go right, I've got a bit more support I think." Julie

"..it was about, I can't remember which week it was but it was about opening the windows the first time and, understanding like letting understanding come in cos there had been that you know total and lack of understanding that what was going on and I just felt that those kind of represented my world getting a bit bigger". Sarah

McGrath & Reavey (2015) speak of how some spaces offer a zone of possibility, where distress can be dispersed or stretched beyond the self and people can have experiences of sanctuary. The participants on this course reflected likewise about the quite profound impact of the course on their lives, so much so as for it to be called a 'lifeline'

> "…it would be good to keep this going, it needs to be kept going. It can't be allowed to fizzle out because they are a bit of a lifeline." Pauline

The focus on practice, solidarity and strategy allowed parents to reboot the everyday norms of living that they had developed but that had been based on understanding themselves, their child and the world around them in a quite different way. Here their children's problems had been largely their responsibility and guilt abounded on why they as a parent couldn't do better to address them. But these norms had shifted with the growing experience of solidarity, the development of their canon of practices and their clear sense that others were struggling just as much as they were. It allowed them to address the challenges they faced and access a range of practical, material, and social resources that were previously absent. As a result of this the benefits were felt not only by the parents but by their children also. Parents spoke of developing the capacity to be more patient following their participation on the course and of how their capacity to cope had impacted their childrens' wellbeing and behaviour

> "I've probably got a lot, actually I've got a lot more patience, a lot more patience where I didn't have, you know, I was 'come on you've got to do your homework' and I was getting frustrated." Donna
>
> "…and also it's made, it's made the boys a lot more happier, and a lot more calmer because I'm not stressed." Ruth

Indeed this had been noticed in some cases by the children themselves

"…he does actually say 'oh, you are very calm, you are very calm, what's the matter with you' and I have noticed actually he tends to now, it's very strange but he, he's more readily to apologise now." Kerry

Quantitative findings

The findings below highlight the impact of the course in some of the key areas of parent's lives. The combined questionnaire focussed on parents' self-esteem and well-being, parents' lived experience of parenting and parents' perception of their relationships with professionals. To make sense of the table below, low scores connote better functioning, higher scores suggest poorer functioning. Table 1 suggests an improvement on all measures, with statistically significant improvements on parent self-esteem and wellbeing and overall parent functioning score.

Table 1- summary of pre- and post-course quantitative measures

Measure	Mean score pre-course	Mean score post-course
Parents perceptions of relationships with professionals	21.23	16.22
Parent self-esteem and wellbeing	36.08	29.89*
Parent's experience of parenting	18.69	17.00
Overall parental functioning score	75.62	63.00*

*statistically significant at the level p<.05

Conclusions and recommendations

This course was experienced as highly beneficial for all parents who took part. The peer-supported practice orientation of the activities moved away from a passive, deficit model of care to an active and pragmatic model which suited perfectly the disparate care needs of these parents. The importance of the nature of the setting and atmosphere of the space had an impact on the way in which the group were able to bond and work together through the course. This allowed for the emergence of solidarity and care that had an impact not only on the confidence and wellbeing of the parent carers but on the children and young people with whom they share their lives.

Recommendations are as follows-

- The importance and impact of this Insider's Guide for Parents of young people diagnosed with ADHD was overwhelmingly positive and for most parents led to a profound positive impact on their day to day lived experience as a parent carer. As such we fully recommend the continued funding of such a crucial service. We also recommend, where possible, its expansion geographically.

- We recommend that this Insider's Guide framework for children diagnosed with ADHD be considered by commissioners as a highly effective practical, social and emotional intervention for parent carers of children with mental health difficulties.
- Current provision for the needs of parents whose children are diagnosed with ADHD is less than sufficient to address the multiple stresses, barriers and challenges that so powerfully impact on their wellbeing. Multistakeholder collaborations like these provide invaluable assistance in a way that statutory services often fail to achieve on their own. We therefore encourage the continuation of such partnerships that allow for the emergence of carer-driven, peer-supported resources to flourish in Brighton & Hove.

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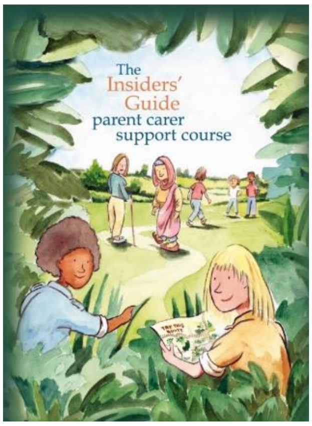
Appendix 1- summary of course content



The Insiders' Guide … support course for parent carers of children with ADHD

This course is for parents and carers of children with additional needs with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD). It aims to help parents to review the journey so far, gain new skills and build their resilience and confidence to tackle challenges in the future. Parents and course facilitators share experiences and solutions, learn more about ADHD, and together practice how to successfully negotiate with school and practitioners and apply strategies to support their children at home. The materials are delivered over six 3-hour sessions.

Course Outline

Module One: The journey so far

Getting to know each other and finding out what you might have in common
Reflecting on me the past and me now; noticing the adaptation you have made
Learning more about what other parents have said helps
Thinking about me in the future and practicing what can help

Module Two: Understanding ADHD

Identifying your child's ADHD features and reflecting on their difficulties and strengths
Learning more about the ADHD brain and executive functioning skills
Practicing ways to teach children tasks by breaking them down
Noticing what you already do well

Module Three: Travelling on

Thinking about stress symptoms and stress busting ideas
Reflecting on the ordinary magic needed to be resilient parents
Creating your relationship web
Taking care of yourself by enlisting the help of others

Module Four: What works with ADHD?

Thinking about your parenting style and what works well for children with ADHD
Learning more about parenting strategies worth trying
Practicing how to use these strategies at home

Module Five: Getting the best out of others

Thinking about the meetings you have been to and why they can be tricky
Learning more about preparation and good communication skills
Practicing ways to keep meetings positive
Putting yourself back together if you are feeling in pieces

Module Six: Looking ahead

Recalling what the course has covered so far
Reflecting on your journey and noticing what you felt and learnt along the way
Relating the learning to resilience ideas and practicing what you might do differently
Taking care of yourself and each other; group ending.