The Tizard Centre is one of the leading academic groups in the UK working in learning disability, mental health and services for older people.

Our primary aims through our research, teaching and consultancy are:

1. to find out more about how to support and work with people effectively
2. to help carers, managers and professionals develop the values, knowledge and skills that enable better services
3. to help policy-makers, planners, managers and practitioners organise and provide better services

We seek to provide teaching through short courses, certificate, diploma and degree programmes at the University of Kent and elsewhere. We seek to maintain an extensive programme of research and consultancy, nationally and internationally. In all our work we are committed to acknowledging diversity and addressing issues arising from social inequality. We seek to align ourselves with service users and to reduce the disadvantage and discrimination they experience. We support user empowerment and the development of services that are responsive to user need. We seek to achieve our mission without further disadvantaging carers and service staff whom, we recognise, are often, themselves, relatively powerless and disadvantages.

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Evaluation of Mindfulness training

Overview of qualitative interviews: ‘The more I understand him the less I lose my patience with him.’

Introduction
Tizard Centre were asked to evaluate the implementation of a programme of ‘Mindfulness / Positive Behaviour Support/ Active Support’ aimed at ‘increasing mental-wellbeing and resilience for a group of parents/carers of Children/Young People with severe challenging behaviour at risk of being removed from their home/local communities’. The programme took place over five sessions with five parents completing the programme.

Three participants agreed to be interviewed following the training. They were asked a number of questions about their hopes for the group, their experiences during the group, their emotional wellbeing pre and post the group and to talk about anything that they had found useful or that they thought might be improved upon. Each interview was conducted by phone, recorded and then transcribed and analysed for key themes. The three people interviewed were all people who had attended most, if not all of the sessions. It is likely that these people were those who had found the group of benefit, not least because they had completed the training. Of the eight participants who started, three were reported to have dropped out after the first session.

Due to such a small number of participants, no information has been provided regarding participant characteristics. Quotes will not be attributed to an individual participant as this would mean it was rather too easy for other group members to identify who had said what.

All participants were women. They all had at least one child or young person who had special educational needs, including challenging behaviour.

Before the group

Expectations
Participants reported that they knew very little about what the group was going to be about and commented that this was a result of the group having to run at fairly short notice because of the way it was funded.

‘…just what was in the flier, just what the aim of the project was that it was positive behaviour support and the active behaviour support but on the mindfulness side nothing really.’

‘…so I think you know for the mindfulness part I didn’t really know’
Given that they knew little about the group, it was difficult for some to describe what they wanted from the group or thought that they might get from attending. However, one participant reported scepticism:

‘I was kind of sceptical of the mindfulness as I say probably based on ignorance because I didn’t know anything about it and probably still sceptical on the first session as well when I found out’

Another participant had heard very positive things about mindfulness and was really looking forward to the group:

‘I know that all the staff in my son’s school rave about mindfulness and keep going on about it and so I was quite hopeful...’

When asked, this participant hoped that the group would help to keep her calm and reduce her anxiety:

‘...help keep me calm and help my anxiety as opposed to you know I mean I knew it wasn’t going to be a course on how to change (name of son)’s behaviour but the way I looked at it and the way I dealt with it’

with a clear understanding that this training was going to support her to change rather than aim to change her son’s behaviour.

Another participant had thought that being mindful was beneficial but had not thought about the ways in which being mindful might apply to her and her son.

‘I went in with an open mind and I was quite away of the benefits of being mindful but just never really related it to my situation.’

**Reported emotional wellbeing before the group**

Emotional wellbeing prior to the group was reported as mixed, with two participants reporting feeling anxious, fearful and having panic attacks.

‘... had depression actually for years, panic attacks were actually something coming and going depends how much pressure I am going through’

Whilst the other reported generally good emotional wellbeing in the months leading up to the group

‘...pretty good but a specific reason to it I don’t know I am just quite happy a person anyway’
Particular issues impacting on emotional wellbeing

All participants talked about stressful times in the preceding months, for example around transitions such as moving house or thinking about post-education and managing on little sleep.

All parents talked about the impact of challenging behaviour on their emotional wellbeing:

‘It was the behaviours more than anything but the way that (name of child) was acting you know he was being quite volatile and it was emotionally draining’

Participants mentioned anxiety as a possible contributory factor to difficult behaviours in their child/young person:

‘...he suffers from anxiety quite a lot as well which impacts on him lashing out at everyone’

Another mentioned being afraid and being worried about doing something to trigger difficult behaviour:

‘...fearing him all the time and thinking I don’t want to you know walking on eggshells.’

Fear was something that could also lead participants to be rather isolated in terms of being worried about what other people might say:

‘I was always very anxious myself and like I see I think it was fear driven because when you are going through long term behavioural problems it is as if you lock yourself away from the outside world because you know it is fear you feel you are going to get judged’

Sometimes the isolation led people to feel like they were trapped and unable to escape.

‘I felt so restricted and I felt like as if I was in prison to be honest’

Ways of managing emotional wellbeing

Participants were asked to describe ways of managing their emotional wellbeing prior to the group. Some participants reported that this was very difficult:

‘I wasn’t very good at managing it, I would just keep having a meltdown all the time, I think I had more meltdowns than (name of child) actually.’

All participants had attended previous groups and had been given many tips and strategies but reported that it was sometimes difficult for them to put what they had learnt into practice:

‘...it is remembering it all in the heat of the moment...’

For another participant, a management strategy prior to the group involved trying to have a break and doing something nice:

‘...coffee and cigarette that sort of has a more positive impact on emotions and stuff.’
But this was difficult to do unless help was on hand as her son was not able to be left unsupervised.

**During the group**

**The people**

All participants were positive about the group. They liked the facilitators and all mentioned how friendly and approachable they were:

‘They were really easy to get on with yes you felt at ease with them straight away’

Facilitators were described as being able to put across information in ways that participants were able to understand:

‘I like her a lot the lady who was delivering the information, she was very good and sometimes it is the way that people are giving the information that can maybe make you understand it more or be able to put in more into practice, she wasn’t condescending or anything like that.’

Being with other participants who had shared experiences was very much valued by all participants:

...all of us had children with quite severe autism but nothing seemed to shock them they had heard it all before or seen it all before it was comforting for us and they were just really really nice.

‘...That [being mindful] is the biggest thing I got from the group apart from the fact that I have met some really lovely ladies’

And had helped people to feel less isolated:

‘I think a lot of people feel isolated when they have children on the spectrum or disabilities and the isolation I think is probably the worst thing because you always think that other people’s lives are better and that other people don’t understand, you are the only person in that situation.’
The strategies

As the group consisted of sessions on both mindfulness and other support strategies, the participants were asked to comment on both.

The support strategies

Participants were asked to describe what happened during the groups in terms of the support strategies. There were a number of strategies mentioned including engaging their child in activities:

...I didn’t realise until they were giving us examples that there are also times when I have not engaged (name of child) at all because I don’t want to rock the boat and if he is calm I just want to leave him...

Although not always new information, some of the strategies were particularly helpful:

‘I have sort of located the triggers and straight away I will kind of react in a different way’

The mindfulness strategies

Participants generally enjoyed the mindfulness-based elements of the group. One participant noticed an immediate benefit after the first mindfulness exercise, reporting that she felt much more relaxed:

‘I thought after the first practice I am actually feeling more relaxed than I probably have done in a long time.’

Another participant reported feeling a little unsure at first but that this was something she had quickly overcome:

‘oh I am shutting, has everyone else got their eyes open are they keeping them open and you are kind of feeling a little bit silly maybe’

All saw the benefits of being in the moment and paying attention to things they may not ordinarily have been aware of:

‘I was very quite pleasantly surprised really because the teachings that we were given you know it is about putting yourself in the moment and realising your reaction and things like this and it was quite astounding to realise just how quick you can react but when you put yourself in the moment and being aware of you know everything that is going on you kind of actually realise the extent of what is going on.’

Some people had expressed a preference for the shorter practices:

‘I had a preference for the shorter ones at home, the shorter ones were much better more for time at home I think for fitting in the shorter one’
Both elements together

Participants reported that the combination of the support strategies with the mindfulness teaching was particularly helpful:

‘I think that is what made the difference really I think the two together worked really well’

In what ways have the groups helped?

There were a number of ways in which participants described the groups as having helped. A focus on the ‘now’ meant that they didn’t worry about what had happened in the past or about what might happen in the future:

‘I think to be in the now without worrying about the future so much or the past to focus on now that is really helped.’

They now had a number of strategies that they could call on to help them to be calmer. For example, some key words such as ‘feet’ enable them to feel grounded:

‘...say “feet” in our head and it is way of just keeping us grounded and to not you let the situation escalate and it has also helped me in looking at what causes the meltdown and triggers and what happened before that, during and after’

‘...key words in my head now that I can say that will bring me back and calm me back down’

They felt much more in control:

‘...just actually in that moment being able to be more in control of what was happening or myself or thought processes...’

‘...just being able to step back and reflect in the instance...’

As a result of being more in control they felt much more able to take note of the events going on around them:

‘...pay attention to all the little things that are going on with my son.’

They felt able to react in a more thoughtful and less emotional manner:

‘...made me a little bit more detached and so I have got less emotional...’

As a consequence, participants reported being able to reduce the number of episodes of challenging behaviour by being able to intervene at an early stage:

‘So realising the things that the child is going through and your reaction to that and so I think the two worked perfectly together, the techniques of being able to reach your child before they get to the meltdown stage is fantastic and that is something that I am looking for, trigger points for my son’
They were also able to be more reflective following an episode where an individual had presented with challenging behaviour:

‘Little tricks and tips we had a sheet where you logged what happened before a certain behaviour, what led up to that, that was really useful and I have been writing things down which has helped me sort of see things that I wouldn’t have wouldn’t have the patience to notice.’

Anything to change?

There were very few suggestions regarding changes though one participant mentioned a less noisy room and another felt that she would have preferred ending on the mindfulness practice:

‘I got very tired after doing the mindfulness first and so it kind of affected a bit of my concentration when it was the second session.’

It clearly could have been problematic that some sessions fell in the school holidays for some:

‘…it was just a shame that some sessions fell in the Easter holidays.’

The smaller than intended group size was also noted:

‘…that people dropped out and weren’t committed as they were taking up space from people who could have really benefited from it.’

Although there had been some follow-up sessions, some participants were perhaps unaware of these:

‘I think may be not so much a longer course but maybe like I say follow ups would be great or maybe a support group from it being set up if you know what I mean because then it keeps people it gives people I chance I guess it is like you go to a slimming club isn’t it you need the support of other people.’

‘More ongoing support would be useful even if one was set up for parents who had attended these courses is one of things that would really helpful, you know so even if we didn’t attend the course at the same time but at some point you had done that course we could all you know get to know some new people and support each other and they might have picked up on something that we hadn’t picked up on and we could all share and that would be useful.’

Following the group

All reported very positive changes in wellbeing following the group:

‘I think I am calmer, I think I am a lot calmer.’
‘...because I am not doing everything on autopilot now I am more aware of it approaching and actually able to calm a situation before it even gets to that too far. I am more aware I am more in tune with him and what he is feeling and I can pick up on it better now.’

‘I am happier, my partner’s happier and the children are happier’

They felt that their mindfulness had led to an increased understanding of their children and young people:

‘The more I understand him the less I lose my patience with him.’

Participants reported having more patience with their children and young people:

‘snow rather than getting impatient and telling him to hurry up and stuff like that I will try to make sure that there are not other things I have to attend to and I will sit and try and just be a bit more you know that it will take him a bit longer than it would anyone else you know that is the biggest thing that I apply back to’

These changes were also seen as having an impact both on participants’ behaviour and on the behaviour of their children and young people:

‘I must say it is has kind of changed because my behaviour has changed because my reaction has changed it has had an impact and has changed the behaviours from him because he is not feeding off my negativity’

This was seen as having contributed to more enjoyment of spending time with their children and young people:

‘I have really changed as a parent and the result is (name of child) is so much calmer or it has coincided with the fact that he has come through the worst of puberty anyway and things would be calming down but there is a lot more harmony in the house anyway the last couple of times [name of child] has come home I have actually really really enjoyed him being here, we have enjoyed each other’s company.’

Participants also reported feeling pleasure from the fact that they had acquired skills and were able to be more mindful:

‘it does make you feel pretty good that you are being mindful’

Looking towards the future

All participants were continuing to use mindfulness techniques and practising where they were able to:

‘Well I am still practising not as much as I was when the group you know because we had homework and we had to practice but I am still doing it as and when I can.’
This included using the CDs containing mindfulness exercises that they had been given on the course.

Participants thought that mindfulness might have some longer-term benefits such as being a protective factor against future depression:

‘I have had a couple of bouts of depression before and so may be it just might you may be if I was prone to going that way again maybe just being more mindful in everything that you do I think could maybe kind of prevent that.’

They reported feeling much more positive about their futures and the options available to them:

‘I feel more positive about the future about anything really I am not living in fear all the time to the point where I am actually looking at studying’

Some people had plans to attend more mindfulness groups either at the same or a more advanced level:

‘Actually I would quite like to attend another mindfulness course to be honest with you just to keep it in your mind and keep it refreshed ‘

‘...do an advanced course....’

They thought that it was important to continue to seek out people who were parents of children who had similar needs as a means of support:

‘...and so after attending the mindfulness I thought just to be able to get together with other people and have a rant or a nag can really help with someone who may be feeling pretty isolated or you know not in a very good place.’

All participants would advise other people in their situation to attend the group:

‘I would tell anybody to give it a go really and to not go in with a kind of any preconceived ideas.’

**Concluding thoughts**

Despite these interviews having probably included those participants who were likely to have found the mindfulness groups useful, their very positive views show just how much value the participants placed on the sessions, their clear enjoyment and the benefits they had found, not just for themselves but also for their families. Future groups, including follow up support, are likely to be of benefit as part of a package to support parents and carers of children and young people who may be at risk of placement breakdown.

I am very grateful to the three participants who agreed to take part and who shared their experiences with me.

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