



Transforming Care for Children and Young People: Mindfulness, Positive Behaviour Support and Active Support training for parents.



Summary

In February 2016, Avenues was awarded a Transforming Care grant by NHS England to deliver a project for parents/carers of children or young people with learning disabilities and/or autism and significant behaviour that challenges that were living at home. Five sessions were provided to parents/carers that incorporated training in three approaches:

- mindfulness,
- positive behaviour support,
- active support.

The aim was to develop wellbeing and resilience for families thus reducing the risk of the child/young person being moved into a more secure care setting. An analysis of the project was performed by The Tizard Centre (University of Kent) and suggests that those who attended the group had improved well-being, had developed techniques which allowed them to remain calm and had seen a reduction in the challenging behaviour of the child/young person.

Introduction

Avenues is a not-for-profit social care provider supporting over 600 people who have learning disabilities, dementia, mental health issues or acquired brain injury, alongside behaviour that challenges or complex needs. We work with people aged 9 and up. Our services are community-based and are located in London, the South East, East of England and the West Midlands.

As part of the NHS Transforming Care Agenda, Avenues delivered a focussed training and support programme for families/carers living in the London Boroughs of Greenwich, Bexley, and Bromley who had a child or young person with a learning disability and/or autism and significant behaviour that challenges, potentially putting them at risk of being moved to a more secure setting. The programme therefore aimed to develop resilience for families, to enable them to develop mechanisms that promote more positive outcomes for both them and their family members.

The project was aimed at parents/carers who may find it difficult to access services to help them to sustain their family units. By equipping them with practical tools and techniques, the programme aimed to educate parents and hopefully allow them to reduce their child/young person's challenging behaviour at an early stage. Displaying behaviour that challenges is a means of letting people know your feelings and emotions in the absence of other communication and social skills. It is often a response learned during early or childhood years which, by the time of adulthood has become historical. As such, teaching parents techniques to reduce these behaviours may in turn mean the child/young person will require less support, formal or informal, when they reach adulthood.

The programme focussed on teaching three main techniques which aimed to improve the ability of parents/carers to cope with behaviour that challenges:

Mindfulness: Mindfulness practice involves paying attention, non-judgementally to the present moment (Kabat-Zinn, 2016). Practicing mindfulness has been shown to be an effective way to manage stress and as a protective factor against anxiety and depression (Williams & Penman, 2011). Research also suggests that more mindful individuals have higher levels of resilience and that this in turn increases life satisfaction (Bajaj & Pande, 2016).

Positive Behaviour Support (PBS): PBS is a behavioural management approach often used to support people with learning disabilities and/or autism who also display behaviours that challenge. It focuses on teaching people more effective and acceptable behaviours, which in turn reduces behaviours that challenge (CBFN, 2014). This approach is about looking at the underlying causes of behaviour that challenges in order to reduce it. PBS is the most effective evidence based approach to supporting people with learning disabilities and behaviour that challenges. Research examining the impact of PBS has shown it to reduce the frequency and intensity of behaviour that challenges and to produce positive effects across the life span and improve people's quality of life (CBFN, 2014).

Active support: Active support is a person-centred approach to supporting people which allows them to make choices about things in their lives. It involves adjusting support so that it is provided in the right way at the right time such that the individual is engaged in daily living activities and can live as independently as possible. Evidence suggests that active support is important in contributing to the quality of life of people with a learning disability. It has also been shown to increase participation in daily, social and community activities. Evidence also suggests it is an important part of other person-centred approaches, including PBS (Beadle-Brown, Hutchinson & Whelton, 2012).

As there is a strong evidence base for all of these approaches, Avenues hypothesised that in combination they would have a positive impact on the mental wellbeing and resilience of family members, as a result of the positive consequential effect on parenting provided to the child/young person.

The project

Funding

The project was funded by NHS England through the NHS England Transforming Care for Children and Young People Grants Programme 2015-16.

Participants

Parents/carers who expressed an interest in the programme were screened via phone to assess their suitability according to two criteria:

- (a) A parent/carer of a child or young person with a learning disability and/or autism who presents significant challenging behaviour.
- (b) The child/young person is at risk of being moved from the family home to a more secure setting.

Places were allocated first to those who met both these criteria and then to those that may not fully have met them.

Five people completed the programme all of whom had at least one child with a learning disability and/or autism who also displayed behaviour that challenges. All participants were women. Originally Avenues aimed to deliver the programme to 12 parents/carers however due to time constraints for delivering the programme, only five were able to attend every session. The programme also ran through school holidays and as such, some parents/carers who had shown an interest in the programme were not able to find alternative care for their child during the sessions, meaning they were unable to attend.

The Programme

The project was delivered in five consecutive weekly sessions beginning 8th March 2016 and finishing 5th April. Sessions lasted 3 hours and were split into two sections, which each lasted 90 minutes:

Section one: Mindfulness

The mindfulness element of the programme was based on an established 6 week mindfulness programme delivered to Avenues employees. The sessions were delivered by Chris Gregory and Damien Wells from Avenues, who are experienced mindfulness trainers.

During week one participants were introduced to the principles of mindfulness including being aware of the present moment without judgement, automatic pilot and bringing curiosity to mindfulness practice. They were also introduced to and took part in three mindfulness practices: a five minute mindfulness of the breath practice, a ten minute body scan and a sounds and breath practice. Participants were invited to practice these at home and were provided with a CD which would guide them through these.

In week two participants took part in another body scan practice and were introduced to the three minute breathing space, another mindfulness practice. There was then an open discussion about how practicing at home had progressed and overcoming barriers to practicing mindfulness regularly. Finally the trainer talked about how to incorporate mindfulness in daily activities and guided participants through a mindful eating practice.

Week three involved another formal mindfulness practice led by the trainer. Participants then discussed whether they had been able to bring mindfulness to their daily activities. The group also explored what being 'unmindful' as a parent would look like and how mindfulness could be incorporated into parenting. This was followed by the three step breathing space practice. The session ended with a discussion about how we are not our thoughts, and how our thoughts do not define us, with particular reference to parenting.

During the fourth session, participants completed another formal practice led by the trainer and discussed their progress around bringing mindfulness into parenting. The

trainer then explored with the group how the body reacts to stress and introduced participants to another mindfulness practice – 'soles of the feet' - and looked at uses of the three step breathing space practice to manage stress.

In the final session participants again reviewed their progress using mindfulness at home focussing particularly on using mindfulness to respond wisely during times of stress. The trainer then led a discussion on how to continue to use mindfulness once the course finished and sign posted participants to possible next steps.

Section two: Positive behaviour support and active support

The PBS and active support elements of the sessions were delivered by Sarah Kean and Pippa Woodford from Avenues, who both provide extensive training and support around PBS and active support to Avenues employees.

During the first two sessions participants learned about active support, and ways in which they could engage their child/young person in everyday activities. They were provided with a general overview of active support by the trainer and then discussed their own experiences.

The following three sessions, focussed on PBS and ways to manage behaviour that challenges. They focussed on figuring out why behaviour that challenges might occur, through trying to identify the root causes of behaviour. Parents/carers were given worksheets that they could use to record episodes of challenging behaviour, i.e. what happened before, during and after the behaviour occurred. This helped them to reflect on the behaviours and think about what some of the triggers or causes of these might be. The trainer shared example of challenging behaviour and the way PBS had been used to address it. Participants then discussed their own experiences and ways they might begin to use PBS to reduce behaviour that challenges.

The sessions were relatively informal and provided participants with a basic knowledge of active support and PBS, such that they would be able to call on these techniques when they needed them in the future.

Outcomes

Evaluation

Researchers at the Tizard Centre, University of Kent, completed an evaluation of the project and the following extracts are taken from Bradshaw & Triantafyllopoulou (2016). The full evaluation is available on request from Avenues. The Tizard Centre is one of the leading academic groups in the UK working in learning disability, mental health and services for older people.

Three participants were interviewed following the training, and their responses form the following results and analysis. They were asked a range of questions about their hopes for the group, their experience of the group and their wellbeing pre and post the group. Participants were also invited to talk openly about which elements of the

training they found useful and improvements they thought could be implemented. Each interview was conducted by phone, transcribed and then analysed for key themes.

Results

Emotional Wellbeing

Emotional wellbeing before attending the training was mixed, with two participants stating that they felt anxious, fearful and had experienced panic attacks. While the other participant reported generally good emotional well-being. All the participants cited their child's challenging behaviour as having an impact on their emotional wellbeing. They also talked about stressful events which preceded the training for example around transitions such as moving house or thinking about post education and managing on little sleep.

Fear was also mentioned as something that had led participants to feel isolated and worried about what other people might think. In some cases this left participants feeling trapped and unable to escape; 'I felt so restricted and I felt like I was in prison to be honest.'

Some participants were asked about how they looked after their emotional wellbeing prior to the group. Some found this 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.'

The training

Participants were asked about the training received, this included mindfulness, active support and PBS. Although not all of the strategies were new to parents they found some particularly useful; 'I have sort of located triggers and straight away I will kind of react in a different way.'

All the participants stated that they had really enjoyed the mindfulness element of the group. One participant said that they felt immediately more relaxed after the first mindfulness exercise. Participants also stated that it was the combination of strategies that were taught that was particularly beneficial; 'I think that is what made the difference.'

How did the training help?

Participants described how the training provided had helped them. A focus on the present moment meant that they worried less about what had happened in the past and what might happen in the future. They felt they had gained a number of strategies that would enable them to remain calm. Participants also said they felt more in control and as a result of this they felt much more able to take note of the events going on around them, and react in a more thoughtful and less emotional manner.

As a consequence, participants reported being able to reduce the number of episodes of behaviour that challenges by having the strategies to intervene at an

early stage. They also reported that they were now able to be more reflective following an episode of challenging behaviour.

All participants reported positive changes to their wellbeing following the training. They felt they were better able to understand their child/young person and had much more patience with them; 'The more I understand him the less I lose my patience with him.' This consequently was seen as having an impact on both their behaviour and that of the child/young person and this was seen as contributing to more enjoyment spending time with their children and young people. Participants also reported that they were pleased they had learned new techniques and that they were able to be more mindful.

Moving forward

When asked, all participants said that they were continuing to use mindfulness techniques and were doing formal practices when possible, and this included using the guided practice CDs they had been given. They also felt that mindfulness may have a long term impact on their life, for example as a protective factor against depression.

Furthermore, participants stated that they felt more positive about the future following the training and some had plans to attend more mindfulness training. They also felt it was beneficial to have connected with people who had children/young people with similar needs, as a means of support. They reported that they felt it was important to continue to seek these connections.

All participants stated that they would advise other people in their situation to attend the group. In terms of changes participants would make to the course there were very few. They did state, however, that it would have been helpful had the sessions not fallen in school holidays. Additionally, there were some follow up sessions, but some participants were unaware of these and felt that more ongoing support in addition to the course would be useful.

Conclusions

The evaluation of the programme suggests that it was a positive experience for those who attended the sessions. Avenues aimed to increase the emotional wellbeing and resilience of parents and provide them with techniques that they could use to better cope with challenging behaviour. The results show that the wellbeing of all participants was improved, challenging behaviour in their child/young person had reduced and they felt more positive about the future. In turn this will hopefully mean that the participants will be better able to cope with and continue to reduce their child/young person's challenging behaviour and as such reduce their risk of being moved to a more secure setting.

It is important to note that those participants who agreed to take part in the evaluation stage of the programme were probably those who felt they had benefited from it most (Bradshaw & Triantafyllopoulou, 2016). Their overwhelmingly positive response to the programme, however, alongside the trainers' reporting they

were highly enthusiastic and engaged in the sessions, highlights the value the participants placed on the training and the benefits they found from it.

In future Avenues would like to work with larger groups of up to 12 parents/carers as originally planned and feel this could be achieved given more time to recruit participants. It would also be beneficial to run the groups in term time so that parents/carers would not need to find alternate care for their child/young person. This would not only give more parents/carers an opportunity to participate in the group but also connect with others with similar experiences, which those involved highlighted as an additional benefit. Having a larger group may also allow for a more in depth analysis of the programme, for example using the Depression, Anxiety and Stress Scale (DASS) to measure these constructs in participants before and after the group.

In conclusion the results of the evaluation of the project suggest it was highly beneficial for those parents/carers involved. The aim of the project was to develop resilience for families, to enable them to develop strategies and techniques that promote more positive outcomes for both them and their family members. The increase in wellbeing of those who took part in the groups, the reduction in challenging behaviour and the fact people felt they were better equipped to deal with challenging behaviour and remain calmer, suggest the project contributed towards that aim.

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