

Editorial

This book, which complements the *GAP Journal*, focuses on promoting wellbeing and happiness. The main aim of the *GAP Journal*, since its inception in 2000, has been to provide a positive view of autism and practical ideas on how to develop good practice, with a view to enhancing people's lives. Previous papers in the journal have reported on work which has led to increased levels of happiness and wellbeing for autistic children and adults, and their families. However, happiness and positive wellbeing have often not been the primary aims, rather a hoped-for, secondary outcome. Traditionally, research in autism has often focused on the problems experienced – such as stress, depression and anxiety, rather than on strengths, and has aimed at reducing or stopping behaviours which others deem challenging, and, in some cases, on interventions which aim to cure autism. The aim of this book is to prompt discussion on a more positive view of autism. The chapters included encourage us to focus on happiness instead of distress. They challenge us to think about the terminology we use and to consider the impact of stress on ourselves when living with or working with a person with autism and how our own emotional state might contribute to behaviours that concern us.

The first chapter, by Peter Vermeulen, describes the work of Autisme Centraal in Belgium which aims to identify strategies which lead to good feelings and positive wellbeing. He argues that we do not focus enough on promoting happiness within our work and that we should find ways to increase happiness. He suggests that practitioners need to help individuals to identify activities, sensory experiences and people that make them feel good. Staff at Autisme Centraal have devised strategies to help autistic children and adults determine what gives them a 'good feeling' and a 'bad feeling'. The idea is very simple, and it is very telling that despite the simplicity, it is not common practice

within our work to focus on finding activities which make individuals with autism happy and then to ensure they have access to these. We hope that this book will inspire readers to introduce these ideas into their own work.

The second chapter, by Andy McDonnell and Charlotte Gayson, introduces the PERMA model, which focuses on developing resilience. PERMA stands for Positive emotions, Engagement, Relationships, Meaning and Achievement/Accomplishment. Within the PERMA model is 'an expectation that positive experiences create a culture of promoting strengths rather than focusing on weaknesses'. The authors encourage us to consider the terminology that we use. They use the term 'behaviours of concern' rather than 'challenging behaviour' to move away from viewing behaviour as within-person and to take an interactionist view. Professionals and parents can contribute unwittingly to behaviours which cause them concern, as discussed by Jakobs and Shapiro in their chapter. It is therefore necessary to analyse all the factors which underpin behaviour and to assess whether, in fact, for the person with autism, the behaviour serves a calming function, as discussed in the chapter by McDonnell and Milton.

Continuing this theme, in the third chapter, Michael McCreadie and John McDermott draw on their experiences of working with staff to understand why individuals act as they do and, in particular, what contributes to increasing and reducing stress. The transactions between staff and people with autism are analysed to emphasise the importance of the 'within-staff' factors in the escalation or reduction of behaviours which cause concern. They argue that staff need to 'tune in' to or become attuned to the person they are working with and to develop knowledge on the situations and events which may pose a difficulty or, conversely, which may help to calm the person. Mindfulness, the assessment

of the understanding of language and communication and the use of social stories are also advocated.

The fourth chapter is written by Linda Woodcock, the mother of a young man with autism. Parents and family members are crucial in promoting and enhancing the wellbeing of children and adults on the autism spectrum. From birth onwards, they have developed detailed knowledge on what their son or daughter finds stressful and have created ways to reduce anxiety and to increase happiness. This chapter charts the journey that Christopher and his family have taken, giving much food for thought to current commissioners and providers of services. The fifth chapter, by Andy McDonnell and Damian Milton, describes flow states, the state where one is so involved in an activity that nothing else seems to matter. They argue that restrictive and ritualistic behaviours could in fact be a means of achieving flow which can be a positive factor in wellbeing. Against this, they point out that some repetitive activities may cause distress and that staff and parents need to ask how the person seems when engaged in the activity. This chapter is likely to lead to a different perspective by parents and staff on repetitive and ritualistic behaviour and so to different responses to these.

The first few chapters look at promoting happiness and wellbeing in support services. However, promoting happiness and wellbeing extends to experiences during diagnosis and the period of time after diagnosis when a person is coming to understand their autism or Asperger syndrome and how this affects them. Jen Leavesley writes as a mother of two children with autism. Her two daughters and husband were all diagnosed before she began to explore the idea that she might also be on the autism spectrum. She describes the journey to diagnosis for her entire family, highlighting examples of good practice and bad practice. Her experiences are important as the diagnoses allowed each family member to receive appropriate support and thereby reduced their stress and increased their wellbeing.

The next chapter is a personal perspective from another autistic mother, Cynthia Kim. She was also diagnosed late in life and describes how acceptance of her

diagnosis has improved her wellbeing. She is married, with a teenage daughter, and describes how her diagnosis allowed her to understand that there wasn't something wrong with her and to accept herself. She explains very clearly how the process of acceptance is a gradual, ongoing process and that knowing she has Asperger syndrome has had a big impact on her wellbeing.

In the eighth chapter, Damian Milton explores the construction of autistic selfhood, and what he calls the fragmented sensory appreciation that autistic people often have of social life and its effect on notions of selfhood. He describes the use of photography and other visual media to explore personal constructs and the lived experiences of autistic people of all ages. He emphasises the importance for all autistic people to have their views heard and appreciated, whether they would like to produce a coherent story regarding their sense of self or whether they prefer a more fragmented or 'nomadic' sense of self.

The ninth chapter, written by Peter Jakob and Michelle Shapiro, describes Non Violent Resistance (NVR), an approach which targets violent behaviour in a non violent way and aims to de-escalate the situation and reconcile parents with their children, and vice-versa. Many families of children and adults with autism do not experience violence from their children, but a significant number do and this chapter will be of great interest to family members and staff who live and work with this group. Acts of conciliation without conditions attached are used, and showing and expressing interest in the individual's activities which perhaps have come to worry, annoy or irritate family members are also advised. So understanding and cooperation and not confrontation are key. The strategies used in NVR can also be used just as effectively by professionals working with individuals with autism.

The final chapter, written by Birgit Drasbæk Søgård Isene and Michael Harboe Kvistgaard, describes the implementation of the ATLASS program (Autism Training with Low Arousal Support Services) in two different services in Denmark for children with severe ADHD and autism – one is a school and the other a

residential and respite facility. The ATLASS programme has a particular focus on understanding stress – differentiating between good stress and bad stress. The chapter describes how this increased understanding of stress has had a positive impact on these services.

To conclude, this book encourages us to think about happiness and wellbeing in people with autism. Having this as a focus engenders good feelings in parents and staff as one is focusing on and prioritising the positives in a person's life and not the negatives. Peter Vermeulen makes the important observation that in intervention studies we often assess levels of skill, stress levels, depression and anxiety and the degree of challenge, but we neglect to ascertain whether the individual is now happier as a result of the intervention. Quality of life (QoL) measures are being developed to redress the balance but QoL measures also need to build in happiness and wellbeing.

We hope that this book will encourage people to identify ways they can enhance their practice in this regard and that we see many more papers on strategies to improve happiness and wellbeing in future issues of the *Good Autism Practice Journal*.

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The practice of promoting happiness in autism

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Editorial comment

Emotional wellbeing and happiness have received little attention in the field of autism. When the focus is on wellbeing, it is often from a negative perspective, namely the lack of wellbeing and quality of life in autism. Based on the principles of positive psychology, Peter Vermeulen argues for a change in focus and suggests that instead of concentrating on the lack of emotional wellbeing in people with autism, strategies to facilitate their feeling of happiness should be developed. In this chapter, the main focus is on the first and most important step in promoting happiness in people with autism, namely the assessment of what gives people with autism a good feeling. Based on the educational work with adults with autism that takes place at Autisme Centraal, this chapter describes three ways to assess 'good feeling' in autism. Knowing the sources of happiness for a person with autism is a prerequisite for creating an environment that makes these sources available and for developing strategies that increase the person's emotional wellbeing.

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Introduction

It is remarkable that emotional wellbeing and the pursuit of it, although being highly valued for every human being, have received so little attention in research on the autism spectrum. Studies of the effects of certain treatments, for instance, rarely take emotional wellbeing as a desired outcome. The effects of treatments are instead evaluated by measurements and assessment of aspects such as number and degree of autism symptoms, levels of cognitive functioning and measurements of all kind of skills and behaviours, in particular social skills. It is good to see that certain treatments of autism are evidence based, showing evidence of a significant increase in the children's IQs and adaptive behaviour scores, a decrease in challenging behaviours, less need for support and more inclusion. But does being smarter, more skilled, less challenging, more independent and more included, necessarily mean a child is also happier?

What is seen in research of treatment effects is also true for follow-up or outcome studies which explore the outcomes of autism in adulthood. In these cases, more 'objective' criteria tend to be used. We look at whether adults with autism have a job or not, where they live, what their levels of cognitive and adaptive functioning are, if they have friends and how many, and how much support they (still) need. In evaluating the outcome of autism, most studies use labels (very good outcome, good, fair, poor and very poor) based on the original criteria defined by Rutter et al (1967). According to these criteria, a *very good outcome*, for example, means living independently (alone or with a partner), being employed or in higher education and having a (near) normal life, including having friends. A very poor outcome means having no friends, no autonomy, needing intensive and high-level care in all aspects of functioning and is often used for adults with autism who live in institutions or hospitals. So, criteria for success

in life exclusively focus on levels of independence and adaptive functioning, not on quality of life and certainly not on the personal experience of emotional wellbeing. Behind this lies the assumption that success in life and happiness are based on high levels of independence and adaptive functioning. This assumption should be challenged.

Consider the following two cases:

Andrew is an adult diagnosed with Asperger syndrome. He finished his studies as a computer engineer successfully but did not succeed in finding a job in the IT business. He works as a packer in an expedition firm, a job he finds very boring. He is ashamed of this. He lives independently in a small flat. He spends all of his free time playing computer games. The other players on those games are his friends. He had some short relationships with women, but they all finished the relationship after their first visit to his flat: he rarely cleans up (the only chair available to sit on is the one at his computer desk), he only eats junk food, the flat does not smell very nice, and except for the specific soft drink he prefers, he has nothing to offer. He wants to have a romantic relationship and is desperately seeking one through dating sites. He is also worried about what will happen to him after his mother dies: she's the one who reminds him of all kinds of chores and things to do, such as paying the rent. He knows how to do many of those activities, so he's quite independent, but never thinks about initiating them.

Michael is an adult with severe learning difficulties and autism. He needs support in almost everything he does: domestic activities, free time, self care etc. He lives in a group home with five other adults with a disability. During the day he goes to a day care centre where he helps in the kitchen. He loves food, so he is always very eager to do whatever they ask him to do in the kitchen. Because he has a short attention span, he gets regular breaks during which he can 'play' with his favorite toys and have a cup of coffee, which is his favourite drink. At the group home he joins the free time activities that are being organised by the staff, but only when he likes the activity. He especially likes the trips they organise to the shops, the swimming pool and the animal farm nearby. Michael's social network is very limited (his parents and sister, who visit him regularly) but he calls the staff members 'his friends'.

According to the commonly used outcome criteria, Andrew has a very good outcome and Michael a very poor one. But who would be the happiest one?

Assessing quality of life

In their study on quality of life in adults on the autism spectrum, Renty and Roeyers (2006) found no evidence that IQ and autism-specific traits (severity of autism) contributed to the prediction of quality of life. On top of that, the amount of support received *did not* correlate significantly with quality of life. However, the amount of perceived support received did, as well as the discrepancy between needed and received support. In other words, personal wellbeing does not seem to be related to the degree of disability but to the perception of support, in particular the perceived discrepancy between needed and received support. This finding was recently replicated in the Khanna et al (2014) study, where greater perceived adequacy of support from family and friends was associated with better (health-related) quality of life.

Given the fact that most studies used the traditional more objective outcome criteria, it is not surprising that these studies found a rather poor outcome for the majority of people with autism (for recent reviews, see Levy and Perry, 2011; Henninger and Taylor, 2013; and Magiati et al, 2014). But is this conclusion valid? Does it really reflect how people with autism themselves would evaluate their own lives? Assessing person–environment fit and subjective factors such as life satisfaction and emotional wellbeing could possibly give a more complete and accurate picture of adult outcomes in autism (Henninger and Taylor, 2013).

A Swedish study by Christopher Gillberg's research team (Billstedt et al, 2011) offers support for this. In 2005 they did a large longitudinal outcome study with 120 individuals on the autism spectrum (Billstedt et al, 2005). They used the traditional outcome categories based on Rutter et al's (1967) and Lotter's (1978) criteria and found that none of the adults had a *good* outcome. Instead, 21 per cent had a *poor* outcome and 57 per cent a *very poor* outcome. In 2011, they reevaluated the same sample, but this time the researchers included measurements of objective and subjective indicators of quality of life and wellbeing, including an assessment of how autism friendly their environment was.

That new approach gave a different picture of the overall outcome, one that was, contrary to the first study, 'encouragingly positive' (Billstedt et al, 2011, p 17). Despite the fact that almost all of the adults were (still) very dependent on parents or other caregivers for support in education, residential and occupational situations, wellbeing and quality of life was estimated by parents and/or carers to be high to very high in 91 per cent of the cases and poor to very poor in only 4 per cent of the adults. Quality of life was found to correlate with having regular and meaningful recreational activities, but not to the level of intelligence, nor to occupational situation and accommodation type. The studies by Billstedt et al, (2011), Khanna et al, (2014) and Renty and Roeyers (2006) support the idea that wellbeing is not necessarily associated with higher IQ, lesser severity of autism and higher levels of independence, shedding a completely different light on the indicators

commonly used to evaluate the usefulness and support the evidence base of certain autism treatments. They also illustrate the importance of targeting wellbeing and quality of life in treatment and education.

From a negative definition of wellbeing (lack of distress) towards a positive one (happiness)

Some researchers do focus on emotional wellbeing in autism, but usually from the perspective of a *lack of it*. For example, a number of studies assess the (hypothesised negative) impact of autism on quality of life (for a recent meta-analysis of these studies, see van Heijst and Geurts, 2014), show lower quality of life in people with autism compared to people without autism and/or focus on mental health issues in autism. There is increasing evidence for a higher risk for mental health problems in autism with worrying prevalence numbers for depression and anxiety (Ghaziuddin, 2005; Stewart et al, 2006; White et al, 2009; van Steensel et al, 2011; Strang et al, 2012). These studies have drawn a lot of attention, resulting in a focus on assessing, preventing and treating mental health problems in autism. Although this is undoubtedly a step forward in the development of strategies to improve quality of life, it still reflects a focus on negative feelings. According to Joseph and Wood (2010) clinical psychology and psychiatry have been using a restricted and negative view of wellbeing, defining it as 'an absence of distress and dysfunction' (p 831). Joseph and Wood argue in favour of a more positive approach, calling for the adoption of measures of positive functioning and that we should strive towards what is called 'flourishing' in positive psychology (Gable and Haidt, 2005; Keyes, 2002; Seligman, 2011). That means that we should not focus on preventing or treating stress and mental health problems in people with autism, but instead strive for wellbeing and ask ourselves: what makes them happy? Or, in the words of Martin Seligman, it isn't 'enough for us to nullify disabling conditions and get to zero'. Instead, we need to think 'How do we get from zero to five?' (Seligman, 1998, cited in Wallis, 2005, p A1). In other words, instead of trying to prevent people with autism from having negative feelings we should develop strategies that foster and increase positive feelings.