

Responsive Communication

Combining attention
to sensory issues with
using body language
(Intensive Interaction)
to interact with autistic
adults and children

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Hope Lightowler, Kate Richardson
and Jemma Swales



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Foreword

Professor Sheila the Baroness Hollins

Phoebe Caldwell has found some unique paths to achieving deep and meaningful engagement with autistic people and people with profound and multiple learning disabilities. Families and carers are in awe of the deep and intuitive connections she is able to make, adapting her way of being with and responding to each person.

Through her practice of Intensive Interaction over several decades, Phoebe has illuminated the way in which sensory issues can impede communication and emotional engagement of autistic individuals with others. She has shown how both hypo- and hyper-sensitivities can contribute to a scrambled sensory input, and how subsequent anxiety results in either hyperarousal (sometimes seen as 'meltdowns') or hypo-arousal (sometimes seen as 'shutdowns'). These sensory issues are often unrecognised by professionals, families and other observers, as they are not routinely part of the experience of those who do not have autism. When sensory triggers are not anticipated or recognised, distress may manifest as behaviours that challenge.

The authors of this book share their different perspectives, while also all being practitioners of Responsive Communication. One author identifies with autism, and the others bring perspectives from a range of professional backgrounds including biology, service management, speech therapy, occupational therapy and psychiatry. Their own complementary perspectives help to broaden the reader's understanding. Responsive Communication is an approach that combines Intensive Interaction with a necessary attention to the sensory issues described briefly above, both being necessary for effective emotional engagement and reduction of behavioural distress.

From my perspective as a psychodynamic psychotherapist, psychiatrist and parent of an adult autistic man, I see in Phoebe someone who has highly developed listening skills. On World Communication Day in 2016, Pope Francis spoke about listening in a pertinent way, saying: *'Listening means paying attention, wanting to understand, to value, to respect and to ponder...'*. These are the skills a skilled psychotherapist should have and in our own deep listening we should be able to tune in to whatever each person is trying to communicate. My experience living alongside a child with little verbal communication led me to explore the power of pictures as a tool to support my listening and inform my understanding and responding. Later, I began to co-create visual stories with people with intellectual disabilities and autism to explore meaning in relationships and life experiences. In my clinical work I

used them as projective tools to help me understand my patients. In training others to share these stories I have noticed that some people are uncomfortable with the silence which often accompanies an encounter that triggers a memory of trauma. Filling the space, finding someone else to chat to while waiting for a response, shows a lack of respect and negates the careful thinking that is under way. But more importantly it shows a lack of awareness of the nature and quality of silence. Being comfortable with empty and full spaces, with close and distant encounters, is an attribute that I suspect Phoebe shares with me and the Beyond Words approach.

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Chapter 1: Attention to sensory issues: hyper- and hypo-sensitivities

Phoebe Caldwell

Introduction

Responsive Communication is a book about how we can get in touch with children and adults who are struggling to understand and articulate speech. Its authors are Elspeth Bradley (psychotherapist and psychiatrist), Hope Lightowler (expert by experience), Janet Gurney (manager of a service for people with severe and profound learning disabilities) and Kate Richardson (speech and language therapist). Jemma Swales (autism practitioner) is manager of a service for autistic children and adults and the final two authors are Jennifer Heath (occupational therapist) and myself, Phoebe Caldwell (biologist). We have also had valuable assistance on visual sensory problems and Irlen syndrome from Tina Yates, director of Irlen East.

Collectively, we have been using autistic people's personal body language to communicate with them (Intensive Interaction) for well over a hundred years: we know just how helpful this way of working can be to establishing emotional engagement with those who are otherwise cut off from communication.

So if Intensive Interaction is so successful, the obvious question is, why introduce an alternative? What can the approach we are now calling 'Responsive Communication' offer that is not already available?

This book is a cooperative effort. Janet will focus mainly on Intensive Interaction. Hope writes about the problems of being at the receiving end of service provision, when your sensory difficulties go unrecognised. Elspeth considers the neurobiological underpinnings of emotional and mental health issues, including meltdowns and shutdowns. Kate shares insights gained from providing a Responsive Communication service to autistic children and young people and their families. Jemma focuses on her experience of working with people who are able to describe the distressing, traumatic events that arise from the clash between their autistic experience and the demands of society. Jennifer discusses sensory issues and body language at a school and children's home for young people with autism and complex needs. I myself (Phoebe) am writing about engagement with autistic adults and children who have severe sensory process issues. Each of us has a different voice, reflecting the wide variety not

only of our personalities, but also of our experience. What we have in common is a sense that before we can address communication, or alongside the process of doing so, we need to attend to the sensory features of autism that are hindering our ability to get in touch with our autistic partners. In so doing, we are trying to marry cutting edge (and sometimes extremely complicated) research with our clinical experience of what can be very moving personal emotional engagement. In writing this book we have and are learning from each other – and, all of us, from the autistic people with whom we engage.

In the 1980s Geraint Ephraim, clinical psychologist, introduced the idea of using body language to interact with people who were struggling to understand speech (Intensive Interaction). Gary, as he was known, was my supervisor for four years while I held a Joseph Rowntree Foundation Fellowship. Drawing on the work of Daniel Stern,¹ he called his approach ‘augmented mothering’, a title that proved to be unfortunate since it coincided – and got lost in – the then emphasis on normalisation and age appropriateness.² Services felt (mistakenly) that the title was inappropriate for interventions with adults and in danger of infantilising them. Relunched as ‘Intensive Interaction’ by Nind and Hewett,³ Intensive Interaction is now widely, and successfully, used to tune into the affective world of our conversation partners, both adults and children. The practical experience of the writers of this book is that immersion in the body language of one’s partner is accompanied by a decrease in their level of anxiety and helps to encourage them to use such communication as they have. The general quality of their lives is improved.

Practical experience of working with people with autism led the authors to ask themselves whether there are there additional ways that we can help to reduce stress and improve the conditions that facilitate communication. Can we use these to improve the quality of autistic people’s lives?

Spurred on by advances in the neurological understanding of the nature of autism, and the new inclusion of sensory issues in DSM-5,⁴ it is increasingly clear that addressing these difficulties opens up further ways of reducing the information processing distress so characteristic of autism, and providing an environment that has meaning for the autistic individual. (While Responsive Communication particularly refers to autistic people, the approach described also has relevance to those with severe and profound learning disabilities, who may equally have sensory issues.)

1 Stern DN (1985) *The Interpersonal World of the Infant*. New York: Basic Books Inc.

2 Wolfensberger W (2000) A brief overview of social role valorization. *Mental Retardation* **38** 105–123.

3 Nind and Hewett (2001) *A Practical Guide to Intensive Interaction*. London: British Institute of Learning Disabilities.

4 Described as hyper- or hypo-reactivity to sensory input, or unusual interests in sensory aspects of the environment, in the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders, most recently released as the DSM-5.

So for example, it may be counterproductive to try to engage the attention of an autistic person simply by using their body language, if at the same time we are wearing a jazzy coloured T-shirt that triggers visual processing difficulties. They may try and tear off the offending garment, a response that is misinterpreted as aggressive or even sexual behaviour (instead of self-defence against the real pain engendered by visual sensory overload). We need to look for the underlying triggers to the behaviour: the simple remedy in this case is to wear a plain, dull coloured T-shirt, which does not cause visual sensory processing overload.

While independent of cognitive performance, sensory processing issues show up differently in each autistic adult or child. And importantly, the sensory experience of each will be different from that of the people supporting them who are not on the spectrum. Non-autistic people do not see, hear or feel things in the same way as the autistic people with whom we share the world. This 'difference' is spelled out by the Autistic Self Advocacy Group, ASAN:

*'While all Autistics are as unique as any other human beings, they share some characteristics typical of autism in common, such as, different sensory experiences. For example, heightened sensitivity to light, difficulty interpreting physical internal sensations, hearing loud sounds as soft and soft sounds as loud, or synesthesia.'*⁵

This is how Ben, a clever young man who lacks speech, actually feels. He focuses on phrases he has extracted from a tape and spliced into relevant video, which he plays repetitively with total attention and evident pleasure. One of his favourites is, *'I'm different from all you guys, I'm different from all you guys'*. Ben feels himself to be different, and has found a way of affirming this. Our experience is that it is helpful to engage not only with positive feelings, but even more so with negative affect. As we shall discuss later, validation of feelings helps the individual confirm their feeling of self, the loss of which emerges as a problem for many autistic people.

Unless we in the non-autistic world recognise these differences (and adapt our interventions and the environment to meet the sensory needs of the autistic individual), the sensory overload and consequent meltdown they trigger in the autistic brain can have behavioural consequences. While these may be difficult for their care providers to manage, they can be catastrophic for those who experience them. As the autistic child or adult struggles to keep up with the flood of incoming stimuli, most retreat into their own world of repetitive behaviour in order to isolate themselves from the sources of overload. Or they try and get away from the source of intolerable pain and confusion by aggressive acts. Rather than excluding such children, we need to rethink the design of their environment.

⁵ ASAN (2019) *About Autism* [online]. Available at: www.autisticadvocacy.org/about-asan/about-autism (accessed March 2019).

In writing this book, the authors have thought carefully about the language we are using. This is partly out of regard for the preferences of the autistic people with whom we are trying to engage and partly because the words we use to describe a condition reflect the nature of personal sensibility, but also because our descriptions can influence how others will interact. What we are looking for is definitions that balance accuracy with respect. So we have rejected 'sensory impairment', 'sensory deficit' and 'sensory deviations' as being seen to have negative overtones, looking instead at 'sensory problems' and 'sensory concerns' before settling for 'sensory issues'. At the same time we recognise that when we ask autistic people about their preferences, those who can tell us are highly articulate, but there are many on the spectrum for whom 'issues' does not truly reflect the gravity of their distress and how this impacts on their quality of life.

We use the term 'people' rather than 'case studies' or 'histories', since they are more than this: if one has been using body language to set up emotional engagement, getting the therapeutic distance between oneself and partner right has become important. As they struggle to make sense of a world that is behaving like a kaleidoscope where the pattern never settles, we have become close to each other; they are people with whom we have opened up a relationship, not examples.

Finally, there is lack of uniformity as to a collective description for those on the autistic spectrum, between those dedicated to 'people first language', who use the term 'people with autism', and those who prefer 'autistic people'. The latter is favoured by articulate self-advocates since they feel that 'people with autism' overlooks the reality which they experience (as if it were somehow separate), and also presents autism as a negative condition. This is a deeply felt emotional quagmire with entrenched arguments on both sides. Lydia Brown, of ASAN offers a fair summary of the different points of view.⁶

In this context it seems important to remind ourselves of the wide variation in presentation of autism. Donna Williams, who was among the first autistic people to write about her life and experiences, emphasises that she cannot be a spokesperson for all people with autism, since everyone is different.⁷ Some professionals feel it is disrespectful and dismissive to use 'autistic people' for those who are non-verbal and have severe learning disabilities. While acknowledging that our choice may be regarded as sitting on the fence, the authors of this book have decided to use the terms interchangeably, as appears most respectful to them in any given context.

And as regards personal attitude (while not all professionals would agree and we need to guard against the danger of projecting our own feelings onto

6 Brown L (2011) *The Significance of Semantics: Person-first language: why it matters* [online]. Autistic Hoya. Available at: <https://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html> (accessed March 2019).

7 Williams D (1995) *Jam-Jar*. Channel 4. Glasgow: Fresh Film and Television.

our partner – and also taking on board their feelings as our own), when we are practicing, we do have to find ways to become as vulnerable as the person we are working with. Otherwise we cannot fully enter the space of intimate mutual attention, where we are open with each other, testing out each other's emotional boundaries and starting to build engagement and trust. This is what we mean when we talk about 'valuing' another person (valuing them not just as we think they should behave to be socially acceptable but as they actually are), so that we take the trouble to learn not only their emotional language, but the nuances of their affective status. Fortunately, this is not as difficult as it sounds, since human body language is a direct route to how we feel. As we shall see, navigating its skill is not new to us, since we have all been through the process of learning to read each other's body language in infancy.

To summarise, 'Responsive Communication' is the name adopted by a combined holistic way of getting in touch with autistic children and adults with whom we struggle to communicate, they with us and we with them. It is an add-on to Intensive Interaction that not only pays attention to and responds to body language but at the same time addresses sensory processing issues. As well as increasing incoming signals that do carry meaning, by using signals the brain recognises easily, it aims to reduce incoming messages that are overloading the processing system. And while seeking to avoid trespassing over professional boundaries, this approach draws together a number of different angles on the most effective ways of tuning in to the lives of those we are trying to engage with. It offers a truly person-centred way of engaging with them, especially with autistic people, one that facilitates the interventions of all parents, therapists and all who support them. We need to pool all our skills.

Some of the people we shall meet will be familiar to readers of my earlier books. I have gathered them together, because collectively they represent the sensory difficulties with which so many autistic people are struggling (even if they personally do not recognise these as out of the ordinary since the sensory overload they experience represents 'normality'). I am revisiting them in order to emphasise the possibility of taking remedial action by paying attention to the individual's sensory issues.

I also need to make a personal apology. My practice spans forty-five years and while my memory of relationships with individuals as people is clear, references to some have been mislaid, although I did have permission to write about them at the time.

I am reintroducing some of the people with whom I have engaged because, rather than dwelling on behavioural outcomes, their stories illustrate the courageous way autistic individuals continue to tackle a world that is not making sense. Most of what I know I have learned from the people with whom it has been my privilege to engage.