# Disability as a Social GRACE

## Making the Invisible Visible

Written by Stephanie Bews-Pugh

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## Introduction

In this practitioner article, I reflect on my experience of having a hidden disability and how this informs my practice as an Assistant Psychologist (AP). Throughout I will use some illustrative examples, both from my personal life and from a clinical case study. The case study I describe is of a young woman named Emily who received a diagnosis of Autism in adulthood. Like many women on the Autism spectrum, Emily's difficulties were often not noticed by others. Nonetheless, she experienced some very real challenges from living in a world not set up for her needs, and often felt misunderstood by people around her. In this article, I explore some of the similarities between this experience of late diagnosis and my experience of hidden disability.

To gain a fuller understanding of my personal identity and of how this relates to my professional identity, I employed John Burnham's (2012) personal and social 'GRRRAAACCEEESSS' to write a reflexivity statement. The letters in this mnemonic stand for Gender, Race, Religion, Age, Ability, Appearance, Class, Ethnicity, Education, Sexuality, and Sexual orientation. Burnham and Nolte (2020) write that this serves to remind us of the multiple experiences that contribute to identity; the final S also stands for 'Something else,' to give space to other aspects not explicitly stated. My personal and social GRACES include identifying as a woman and as an 'aspiring Clinical Psychologist.'

Burnham and Nolte (2020) point out that aspects of identity are often viewed by ourselves and by others as being either a resource or a restraint, in both our personal and professional lives. I am aware that some of my GRACES do confer power and privilege in society, and therefore could place me in a position of advantage over others; for example, being white and educated. However, this is not the whole picture.

Burnham (2012) notes that GRACES may be seen or unseen, voiced or unvoiced. In my professional life, aspects of my identify that are less visible include that I have encountered many barriers to my chosen career path. To qualify as a Clinical Psychologist is a competitive process, requiring high levels of achievement in work, education and research before there is even a remote chance of gaining a place on a doctoral training programme. I completed my Undergraduate degree when my children were at nursery and primary school. Due to parental and financial commitments, it took many more years to return to university again to gain a Masters degree.

Another less visible aspect is that I have a disability. I have a congenital eye condition and am partially sighted. However, as I have developed many compensatory coping strategies, my difficulties often go unnoticed by others. As such, this is a 'hidden' disability. While some of my less visible GRACES could be construed as 'restraints,' I personally view them as resources that can be drawn on to enrich my practice.

## My Personal Experiences

Just prior to the 1981 Education Act, my parents succeeded in their fight to get me into the local mainstream primary school. Unaware of my parents' efforts or of the wider political context, I quickly learned to hide any difficulties so that I could 'fit in' and be 'normal.' In those days, teachers wrote on a board at the front of the classroom, from which I was unable to decipher letters and numbers. When I was around 6 years old, I was given a large desk with an easel-like contraption to bring paper nearer to my eyes, a lamp, a monocular, and some support from a teaching assistant. My new desk was placed at the front of the classroom in the hope this would enable me to read from the board. None of this helped with what I wanted, which was to be like the other children. Unsurprisingly, I learned to read relatively late, eventually teaching myself over the summer holidays when I was 10 years old. To this day I am an avid reader of stories, and am also fiercely independent.

As an adult I have gained skills and experience to voice my needs, for example by asking for adaptations at work. The Equality Act (2010) requires employers to make reasonable adjustments that prevent employees with disabilities being disadvantaged in the workplace. It is good practice for employers to assess the needs of disabled employees, to propose adjustments based on this assessment, to check proposed adjustments with the employee, and to implement agreed adjustments in a timely fashion (Equality and Human Rights Commission, 2011). Despite this, my experience of disclosing disability and of employers' responses has been mixed; ranging from waiting a long time to be assessed, to waiting an even longer time for adjustments, to provisions that do not account for my actual needs. One manager expected me to work from a laptop with a 15" screen despite having been informed of my visual impairment, and persisted in ignoring requests for reasonable adjustments which I made in person and via email. Eventually, after escalating my request to my manager's manager, the company bought me the largest monitor imaginable. This must have cost them a great deal, but as they had still not taken the time to talk to me to find out about my vision or what would help, it was not fit for purpose. This caused me to wonder if the barriers I was coming up against were due to the hidden nature of my disability; is it because my partial sight is not immediately apparent that others failed to see it as 'real,' or to appreciate the multiple ways it affects me? Such experiences of not being heard are isolating and disempowering, and have an eroding effect on personal resilience.

Reflecting on my GRACES and experiences has made me realise that my disability was not always hidden. From talking to my parents, I know that as a young child I would get up close to things I wanted to see. By the time I was 8 or 9 years old, I can remember pretending to see more than I could. Bringing my psychological knowledge to this, it seems that from early childhood I learned to mask my difficulties, and that most of the time I continue to mask completely unconsciously. Having a ‘hidden disability’ then is in part my own making, in as much as learning to mask was a response to an environment that did not support my needs (despite the best efforts of teachers and my family). That my disability is not immediately apparent to others has its advantages.  Perhaps I avoid some more overt forms of prejudice and discrimination. On the other hand, the hidden nature of my disability makes it more difficult to have my needs met. While the GRACES framework has given me another tool to make this visible and to voice my needs, letting go of my ‘coping’ mask and asking for help involves exposing my most vulnerable aspects - a risk that has not always paid off.

Fortunately, I have also had some positive experiences of support in the workplace. For me, it has made a crucial difference when the person assessing my needs has listened and attempted to gain an understanding of my needs. It is helpful when I am given the opportunity to check the assessment and recommendations, and to give feedback. When these things are in place, they tend to lead to the provision of appropriate adjustments that are helpful.

## How My Personal Experiences Have Impacted My Work

Each person's experience of disability is individual: context, upbringing, nature of condition, age of onset, culture, time and place will all have an influence. However, I do believe that my personal experience of disability in an able world does give me an insight into some broader effects of living with disability, including social and psychological impacts. For example, many of the problems I have encountered have not been about my disability per se, but about systems that are not tailored to my level of ability, or to other people's lack of understanding. Street signs, bus numbers, and boards at train stations are all tantalisingly just out of visual reach: I can see that they are there, but cannot see enough to get the information I need. This experience of being forced to navigate barriers and challenges erected by society is shared by many people with disabilities. For people with a hidden disability, these barriers are just as 'real,' but our struggle is often unseen. Whether hidden or visible, people with disabilities experience being 'different.'

My experience of hidden disability has been particularly pertinent to my recent work with women with Autism Spectrum Condition (ASC). Historically, more boys than girls have been diagnosed with Autism, and it was widely believed that such conditions disproportionally effected males. However, recent research suggests a different reason for this: women and girls with Autism often remain undiagnosed due to a more 'social' presentation and a learned ability to 'mask' their difficulties (Elcheson et al., 2018; Stewart, 2012). Despite (or because of) such learned social skills, Autistic women describe feeling misunderstood by others and being forced to navigate a world that is not designed for them (Dugdale et al., 2021; Scottish Autism, 2021). Whether due to late diagnosis, or to the invisible nature of their difficulties, the needs of Autistic women and girls are often not recognised. This means that their needs often remain unmet in education, employment, social services, and healthcare.

Drawing on my own experiences of support - not only in work, but in education and healthcare settings - I try to support people in ways that I personally have found helpful. This involves being person centred, listening, recognising strengths, and providing interventions in-line with needs and goals.

## A Practical Exploration of How This Influences My Practice

Some of the core skills of Clinical Psychologists are assessment, formulation, intervention, and evaluation. This means working with individuals to assess their needs and strengths, hypothesising or suggesting possible causes for psychological distress, and offering appropriate help to reduce distress and increase wellbeing (British Psychological Society, 2013; Department of Clinical Psychology, 2001). To achieve this, we must pay attention to the personal accounts of the individuals we aim to support (Coles, 2010). In other words, we must listen first. In the remainder of this article, I will focus on how my personal experience of disability influences the way I endeavour to use core psychological skills when supporting clients. To illustrate, I present a clinical case study. This case study does not represent any one person, but is an amalgamation of several individuals I have worked with. All personal characteristics have been changed to protect their identities.

### Case Study

Emily is a young woman who was referred to Studio 3 for help with her mental health. Previously, she had undergone multiple mental health assessments and received various treatments and interventions.

These included anti-depressant medication and Cognitive Behavioural Therapy (CBT) for anxiety and depression. Sadly, none of the help offered had alleviated her distress or enabled her to live a full and satisfying life.

### Assessment

During the initial psychological assessment process, Emily described that she had suffered with debilitating anxiety since her early teenage years. This had initially arisen in relation to an increased demand to participate in novel social activities, such as going to the cinema with friends. At the same time, she began to struggle with schoolwork, despite being academically able. Recently, difficulties had come to the fore in relation to problems she was having at work. She described being confused by interactions with others, and often could not understand where they were 'coming from.' She was often told by her colleagues that she had got things 'wrong' and had misinterpreted an email or verbal exchange. Such misunderstandings had, in some instances, led to conflict at work and in her personal relationships. She described an overwhelming sense of being 'different' and that she was 'lonely.' In addition, she felt that the brightly lit and noisy environment at work was adding to her stress levels. Emily's strengths include attention to detail, being organised, and being creative. She is passionate about art, a painter herself, and regularly attends art exhibitions. Emily wanted to gain some understanding and insight into herself and to improve the situation at work.

Sensory sensitivities and difficulties with social communication can sometimes be indicative of ASC. I discussed this with my clinical supervisor, who agreed this should be explored. I talked this over with Emily, and with her agreement my supervisor and I conducted a full assessment for ASC. We concluded that Emily did meet the diagnostic criteria for Autism.

### Formulation

A formulation attempts to make sense of information gathered during the assessment in the light of psychological theory and clinical knowledge. Harper and Moss (2003, p.8) describe formulation as 'a process of ongoing collaborative sense making' between client and practitioner. When formulating the difficulties Emily had been experiencing, we noted that she had a very 'literal' thinking style. This presented her with challenges within social interactions that are often inherently ambiguous. As detailed above, she would sometimes misinterpret the communication of others, which impacted on her ability to form and maintain relationships. Sensory sensitivities meant that bright and noisy environments, such as the open plan office at work, triggered increased stress, and decreased ability to focus on the task in hand. Like many women on the Autism spectrum, she had developed a range of coping strategies and was accomplished at 'masking' her difficulties, including her anxiety and stress. As her difficulties were not immediately apparent to others, this further contributed to misunderstandings in social situations and at work being 'blamed' on her.

**Recommendations for Interventions**

In addition to making sense of data gathered, a formulation makes predictions about interventions that will make a positive difference to an individual's life. Recommendations for Emily included Autism-informed mentoring and support to develop a strengths-based individual Autism profile. We also made some recommendations to Emily's employers regarding reasonable adjustments. These included support in the workplace, communication strategies, and the development of an individualised stress management plan.

**Evaluation**

At the end of this process Emily gave feedback that she had developed a deeper understanding of herself and of her difficulties. She felt that insight gained would enable her to 'play to her strengths,' adapt her environment to her needs where possible, and enable her to communicate her needs to her employers.

Throughout the assessment process, my aim was to demonstrate my concern for Emily's concerns, and to show that I was listening to her words and to the emotion conveyed within them. By demonstrating compassion, I built her trust in me, enabling her to tell her story, and to provide her with evidence that I was willing and able to work collaboratively with her to find solutions. By sharing the psychological formulation and gaining her input into this, I was able to ensure it ‘made sense’ and held some explanatory power from her perspective. I have learned through my own experience of support that being listened to and feeling ‘empathically understood’ are the most important factors. I am acutely aware that help has to be adapted to the individual’s needs, but also that it should be perceived by the individual as helpful. For this reason, I sought feedback from Emily throughout. When Emily was asked to evaluate this process, she described that she felt heard and understood. I was pleased that Emily felt that she had gained insight into her needs and strengths, and that through our recommendations she felt empowered to ask for the help needed in her workplace.

Burnham and Nolte (2020) write that the GRACES mnemonic can be used to consider multiple aspects of another person’s situation. Working with Emily, this framework enabled me to pay attention to aspects of her identity that were salient to her, including that she is creative and an artist. Reflecting on my experience of hidden disability gave me a language to enquire about aspects of her identity that are less visible, including her experiences of feeling ‘different,’ and of her needs not being met in the workplace. During the assessment process, while helping Emily to ‘tease out’ and articulate such challenges, I chose to share some of my own experiences in school and at work. I did this because I believed it would benefit my client in terms of normalising what is often an isolating experience of being ‘different,’ and to facilitate her feeling safe enough to ‘unmask’. I believe that by self-disclosing I did achieve these aims, enabling her to talk more freely as well as enhancing my own empathic understanding of her. I hope that by helping Emily to reflect on her identity that she is now able to view some aspects previously viewed as ‘restraints’ as resources or strengths instead.

Writing a reflexivity statement using the GRACES framework has had a huge impact on how I work with people. Reflecting on aspects of my identity has increased my awareness of my position in relation to others, and of the way in which my worldview is shaped by who I am, my background, and my experiences. Sharing previously hidden aspects of my identity has benefitted me in both my personal and work life, enabling me to build bridges with others experiencing disability or marginalisation. I now view aspects of my identity, such as disability and lone parenthood, as resources that enhance my ability to form therapeutic relationships with others experiencing adversity. Reflecting on my experiences of hidden disability has given me insight into the impact of this on my choice of work and on how I choose to work with people. The example of Emily has hopefully highlighted the way that I try to apply a person-centred approach which recognises that people are experts of their own experiences. Disability rights is a subject that I have a great passion for, and I always work towards ‘evening out the playing field’ for individuals who are disadvantaged by society. In the future, I hope to advocate and campaign for individuals like myself who have hidden disabilities which are often overlooked.

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