# Chapter 3

# Autism Spectrum Disorder: Emotion work in the workplace

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## Introduction

The number of people with invisible disabilities who undertake paid employment is increasing (Vickers, 2017). However, workplaces, particularly small and medium enterprises, are not always structured to manage a diverse workforce with differing needs and often the expectation is that the worker adjust themselves to the norms and expectations of that workplace (Werth, 2013). In reality however, where an employer finds that they have an employee who discloses a disability, employers in Australia have an obligation under the Disability Discrimination Act ([DDA] 1992) to not discriminate against them. The groups of workers who are protected by the provisions of the DDA include those diagnosed with Autism Spectrum Disorder (ASD). There are rising number of workers with ASD in paid employment and there is a need for employers to develop strategies for the support of these workers (Neely & Hunter, 2014). This chapter examines the influences on disclosure decisions and factors that impact on the identity of workers with ASD, include stigma management, peer support, and level of disability and required supports.

## Managing workplace identities

Disclosure has been investigated in relation to a variety of stigmatised social identities (Clair, et al. 2005; DeJordy, 2008), such as sexual orientation (Day & Schoenrade, 2000), disability and chronic illness (Goffman, 1986; Myers, 2004) and ASD (Johnson & Joshi, 2014). We have previously examined the disclosure process from the perspective of individuals with chronic illness, and variables identified which influence the disclosure decision included: the specific attributes of the condition itself, stigma, expected management and peer support and the type of work being undertaken and ability to perform emotion work and/or emotional labour (Werth, 2011).

Disclosure at work is a decision taken by employees with stigmatised identities, and who are mindful that once the decision is made it cannot be taken back. Negative attitudes of colleagues can compound misunderstandings of the individual and of their condition (for those with any form of disability), thus there are risks associated with disclosure. A wide range of factors have been identified as influencing a decision to disclose (Werth, 2013). These broadly cover the types of resources (such as factors which influence internal and external labour market power) and supports (such as management and peer support) that are available to employees with disability, social influences, and the requirements of the workplace. Employees with a stigmatising condition or disability may therefore consider the various risks and benefits of disclosure or non-disclosure, which are specific to their working environment.

The decision to disclose carries with it risks which may result in limited career opportunities, stigmatisation of the individual as professionally incapable or as a “problem” worker, or even as someone who would prefer to feign difficulty due to their disability (Vickers, 1997). Because of these risks some will not reveal their condition until they have no choice (Myers, 2004), while others will choose to reveal their disability in order to gain support and the flexibilities they need to continue working (Vickers, 2010). Disclosure therefore requires a decision process by the individual as the business of ‘keeping up appearances’ is important for the preservation of professional credibility in the face of powerful norms which indicate that those with disability have a “spoiled identity” and are not considered to be a typical worker (Goffman, 1986). These workers may perform *emotional labour* (a complex behavioural coping strategy), to avoid telling others about their condition, or if they have already disclosed their condition, they may employ emotional labour to maintain their credibility. This has been shown to be the case for other types of disability (Werth, 2013). For ASD workers, passing as neurologically typical (non-autistic) may therefore be a preferred position.

**Emotion work and emotional labour**

Emotion work and emotional labour are concepts which are becoming increasingly relevant in the workplace. The two terms are sometimes used interchangeably, but there are some key distinctions. *Emotional labour* is defined as labour that “requires one to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others” (Hochschild, 1983, p. 7), while Bolton and Boyd (2003, p. 291) describe *emotion work* as “presentational emotion management”. Emotional labour is often undertaken by customer service officers in an effort to provide customers with a particular desirable experience within the context of their business environment, emotional labour is undertaken in the context of paid work. Emotion work uses the same type of emotional effort to achieve certain desirable outcomes with colleagues, this type of effort is not remunerated.

The emotion work that is often required of workers in order to preserve their professional identity and collegial relationships at work, is sometimes very challenging for workers with ASD who may struggle with social situations as part of their dyad of difficulties (American Psychiatric Association [APA], 2013). Emotion work is therefore problematic for those with disabilities who fall outside the neurotypical expectations that are placed on them in their workplaces. Disclosure of an ASD diagnosis forms part of the emotion work which may be undertaken by this group of workers. The disclosed information influences the way in which work colleagues create their own understandings of appropriate behaviour, attitudes, and expectations of what it means for their colleague to work with an ASD diagnosis. An employee may therefore need to deploy emotion work to induce a “proper state of mind” in their supervisor and colleagues (Hochschild, 1983, p. 7). To this end, individuals with ASD perform emotion work in order to “cover” their condition so that they may be considered “typical” in their workplace. It could be this pressure to conform which causes individuals with ASD to manage their condition and working circumstances in ways that allow them to successfully manage the expectations of others in their workplace. Engaging in emotion work may therefore be essential for the preservation of professional credibility in the face of powerful norms, which indicate that those with invisible disabilities have a “discredited identity” (Goffman, 1986; Millen & Walker, 2001).

Stigma is defined as a complex concept that “encompasses individual experience, the interaction between non-marginalised and marginalised groups” (Stuber, et al., 2008, p. 351). The responses of employers to the disclosure of a condition by an employee, shape the meaning of stigma for that worker within the culture of that workplace (Garcia & Crocker, 2008). Social rules that define situations when the application of stigma is acceptable are framed around the expectations of individuals in the workplace (Stuber, et al., 2008). The amount of emotional labour required will depend on the stigma that they experience or fear that they will experience if they disclose. An employee’s revelation of a disability to an employer is therefore a balance between the potential freezing of resources that were available to them while they were regarded as a “useful” worker, and the necessity of disclosure in order to access the resources required to maintain their position in the workforce. Ultimately, whether accommodations are made available will depend on the attitudes of managers and colleagues to the individual’s condition, with stigma playing a significant role in the reactions of others to the disclosure.

## Methodology

Following research ethics approval from a university Human Research Ethics Committee, links to an online in-depth survey were distributed, and adults who identified themselves as being on the autism spectrum and who were currently employed were invited to share their experiences of their workplace. The survey comprised a combination of quantitative rating scales and open-ended qualitative questions in order to explore these experiences, with the primary focus of the survey being the reported experiences. Analysis of the responses was through Thematic Analysis informed by Braun and Clark (2006), guided by the partial disclosure and emotional labour framework (Werth, 2011).

**Participants**

A total of 14 participants took part in the study and shared their employment experiences. These comprised 5 males and 9 females, with the majority falling in the 40-49 years age bracket. The majority of the participants were diagnosed with ASD within the last 5 years. Five participants had a bachelor or honours degree, and four participants held a postgraduate degree such as a masters or doctorate. All names reported are pseudonyms.

## Analysis

 Analysis following Braun and Clarke (2006) focused on emotion work and workers with ASD and identified three main themes, which were interrelated. The main themes were:

stigma; expected management and peer support; and advocating for workplace accommodations. Together these themes enabled a fuller understanding of the emotion work engaged in by the participants contributing to this project.

Workers with ASD undertake emotion work to minimise the appearance of their condition in order to preserve their identity and relationships in the workplace, this can be challenging as individuals with ASD may struggle in social situations as part of their diagnosis. Participants in this study indicated that discomfort in social situations and a lack of understanding of social cues are causes of difficulty in their workplaces, which manifest themselves in different ways that often have negative consequences for the individual. This difficulty will be explored through the three themes identified in the analysis.

### Theme 1: Stigma

The qualitative data from this study shows that disclosure is a significant issue for employees with ASD. Many of their comments reflected concern about a variety of different issues and participants easily identified a mismatch between expectations of worker ability and perceptions of what an ASD diagnosis means for an employee. For example, participants reported negative outcomes following disclosure.

I struggle with disclosure. I have been sacked after disclosing several times.

(Barnaby*)*

Barnaby speculated about the number of people who work in his area of disability support due to the difficulty in accessing and maintaining employment in other sectors, but his comment also highlighted the difficulties that people with ASD routinely faced in their place of employment.

Barnaby felt that his own ASD was a strength in his work, enabling him to more effectively work with his ASD clients, stating that he was able to identify more with the people he supported in his working role than he did with his supervisors who bullied him. Barnaby recognised some of the specific challenges for ASD workers, a position shared by Agatha:

Social awkwardness can lead to a lack of progress in job opportunities. Contracts and permanency are often hard to negotiate or come by.

(Barnaby)

He [supervisor] doesn't seem to understand my emotional mutism and, while he gives me a bit of extra leeway, he expects me to manage Aspergers as if it were a disease.

(Agatha)

This is something echoed in the wider literature, with Wehman (2003, p. 137) pointing out that, “job satisfaction and retention is often contingent upon the degree of social involvement that an employee has with supervisors and other co-workers”. However, where stigmatising aspects of the condition are accommodated, workforce outcomes are reported to improve:

If co-workers and supervisors look past my awkward social skills and mannerisms then I often do well.

(Sheila)

However, more commonly participants reported negative situations where they felt their social skills were positioned as inadequate:

[I have] executive functioning problems (particularly in relation to others understanding my difficulties with, for example, last minute meetings or sudden changes in expectations), and, especially, difficulties navigating the "social aspects" of the workplace. This latter point has caused considerable stress and misunderstandings for me and others in the workplace.

(Penelope)

Employees with ASD have been characterised as “often have difficulty ‘reading between the lines’ and uncovering the implicit as well as explicit meanings of a message” (Muller, et al., 2003, p. 168). However, participants reported working hard to understand some of the more implicit messages in the workplace. For example, Mavis reported that she made an effort to get to know people and “work them out” before she would offer her opinion. She clearly understood the need to perform some aspects of the collegial emotion work required in her workplace. However, other workplace experiences were more challenging for her:

At first I am getting to know people and I have a habit of trying to work them out and then telling them what I think. I like routine in my work and get extremely anxious and upset if I'm asked to take on another task I've not been thoroughly trained for. I often find that everyday sarcasm upsets me and I take offence greatly. I tend to make a big deal about small issues. I often get the wrong end of the stick and miss the point. I am not good at articulating events, scenarios or explaining things - I will almost always clam up when asked to explain.

(Mavis)

Despite the fact that Mavis engaged in some emotion work, she had difficulty with sarcasm, unexpected events, and understanding of other social cues. The challenge of understanding social nuances were widely reported with differing strategies for their management, sometimes taking the approach of avoidance, further compounding the perception by others of an individual’s skill base:

It’s hard to fly under the radar and [I] try so hard to fit in. At staff events eg meetings, I HATE it, try to keep my head down and get out ASAP… I avoid things like the staff Christmas party etc.

(Betty)

ASD attributes can mean that, in situations where no understanding or accommodations are available or where the worker has not disclosed, individuals are placed in difficult positions and are left with few mechanisms for preserving their professional identity by avoiding the bias and stigma that may be associated with their condition, (Neely & Hunter, 2014). The importance of the actions of others in the workplace is something that is explored in the next theme.

### Theme 2: Expected management and peer support

The participants reported that understanding and accommodations can create a supportive workplace with positive outcomes, this is supported by the findings of Neely and Hunter (2014). The path to achieving this was however not always straightforward, and a number of participants reported negative workplace experiences with job changes required in order to improve circumstances. Management and peer support was therefore considered important for workers with ASD. Some participants reported that the availability of understanding from colleagues or supervisors in the workplace was a factor that influenced their disclosure decision and their ability to achieve positive workplace outcomes. Betty and Lucy commented on the challenges of finding such support:

No [I haven’t disclosed] because people don't understand it.

(Betty)

My supervisor is one of these social people. She already spreads rumours about me because she doesn't like me. Telling her of my diagnosis might make her back off a little (or not) but she may also start to treat me as though I were mentally deficient, and tell all of her friends at the workplace in order to garner sympathy/compassion for herself.

(Lucy)

Fear of the outcomes of disclosure may therefore cause workers with ASD to choose non-disclosure (Neely & Hunter, 2014). However, despite these fears, the majority of respondents in this research had disclosed in their workplace to some degree. Finding the person to disclose to was sometimes a challenge, with some only disclosing to a supervisor or to a trusted colleague in order to avoid being sacked or ridiculed in the workplace.

 [I have disclosed to the] current company director [who is a] highly intelligent and open minded individual who understands, and with whom I can much more easily communicate.

(Donald)

Donald may therefore have found a supportive supervisor in his current workplace, but his previous experiences were less positive:

Previously in the public sector- [I was] bullied, ideas stolen, marginalisation, isolated. Now, in small firm (engineering) - none of above behaviours (suspect working with others also with mild Aspergers).

(Donald)

The risks of disclosure are by no means unique to workers with ASD, but the challenges experienced by this group with social situations can make the decision riskier (Davidson & Henderson, 2010), and experiences in previous workplaces following disclosure will impact on disclosure in subsequent settings.

 The importance of social judgement is common throughout workplaces, with an increasing focus on the importance of social relationships evident within a workplace. Due to the difficulties that some workers with ASD may have in social relationships, this extra layer of working requirements can present additional challenges. For example:

[ASD] Mostly causes problems with co-workers who are more social. I work great with the people who want to actually work, but when it comes to those who'd prefer to slack off or socialise, they tend to dislike me.

(Lucy)

The focus on social relationships for many may be a source of support amongst fellow workers, but for individuals like Lucy these place an additional strain on an individual, requiring additional emotional labour work to manage not just themselves but others. The action of advocating for workplace accommodations is explored in the final theme.

### Theme 3: Advocating for workplace accommodations

The data show that these employees might experience one or more unhappy jobs or positions before ultimately finding work or another position where they were valued. Penelope reported a lack of accommodations after disclosure, but subsequently had a more supportive supervisor.

[My] first supervisor was dismissive, incredulous, and unsupportive. Nine of twelve requested accommodations were routinely violated; three were completely ignored. My most recent supervisor(s) were accommodating, but the stresses of full-time work and related depression led me to resign my employment after a year. This has been a pattern in my entire adult working life.

(Penelope)

The stigma associated with ASD can mean that supervisors might be reluctant to provide accommodations or understanding, and therefore advocating for accommodations is crucial:

No. There is a notable lack of understanding in ASD. Often, I am told things like ‘but you look so normal.’ This invalidation of the very real issues and challenges I face on a daily basis compounds the problem further.

(Penelope*)*

The lack of understanding of ASD, and a lack of accommodation and support can have profound consequences as shared by the participants. Mavis was verbally abused in her workplace and both she and Sheila reported that they experienced a variety of negative outcomes as a result:

Anxiety, depression, withdrawal from workplace social gatherings, despondency and fear of building friendships, cutting off all contact with the outside world when I go home except for my dogs.

(Mavis)

My anxiety and depression are a result of how I have been treated in the work place.

 (Sheila)

 Fitting in within the work environment therefore involves more than just being able to do the job from a technical perspective (Muller, et al., 2003). Supervisors are often looking for employees who fit in and who are not considered to be too difficult. Often this means that people with disability, in this case ASD, are not considered for positions in which they could perform well with some accommodations. Individuals who are not able to adequately perform the required emotion work in their place of employment will find that they will suffer a penalty. The experiences of the participants above demonstrate how severe these outcomes can be.

For some, disclosure outcomes can be mixed. Terry’s disclosure experience was initially positive, but as staff changed he needed to consider whether or not to disclose again.

Initially my supervisors understood my condition and gave support. However as personnel changed and there was no support. The company has no policies in relation to people with my condition.

(Terry)

This has put him in a difficult situation: in order to continue in his position he will need some form accommodation, and frequently this will be left for the individual to advocate and negotiate.Unfortunately, where there are no formal policies in place to assist employees in Terry’s situation, there is no guarantee that the next time he discloses that the experience will be positive and the accommodations or understanding he needs will be made available to him. Employees with ASD are highly dependent on their ‘ways of managing’ in the social sphere, that is, they are advantaged where they are able to perform the emotion work that enables them to fit in with the dominant culture. Alternately, they may be dreadfully disadvantaged if they cannot perform the required emotion work. Penelope commented:

I feel cheated because there were no services or support for those like me growing up. We have been left to fend for ourselves as best we can, and the residual effects of this are damaging and denigrating, especially for those who (like me) are diagnosed late in life. It is as though we are an invisible blight.

(Penelope*)*

Penelope is highly qualified, with a PhD, but despite this she struggled with maintaining ideal forms of employment. She reported that she had recently resigned her position and she was not sure what she would do next. A workplace that is supportive of people with ASD will be understanding and accommodating for individual difficulties. Sometimes finding this will require job changes in order to find the workplace that suits individual needs if the advocating for change within the current workplace is not met positively. One example of this is Donald, who had previously had negative workplace experiences but has since found a positive working environment where the fit was to the extent that he no longer required any form of accommodation:

[I work] now in small private company, I feel much more accepted and appreciated. As such, no special support needed.

(Donald)

Similarly, Mavis worked as a cook in a mining camp and has found a niche where there is understanding despite working long and difficult hours.

Well what I found is that a lot of the guys I look after are ADHD or Autism Spectrum so I feel that I fit. They have enhanced my life beyond measure because I feel at home in their company. Only recently have I talked to some of them about my Autism and they don't find it peculiar though a couple thought I might have tourettes too as I sometimes let loose with the colourful language however there's a lot of us that display "strange and unusual" behaviour out at camp.

(Mavis)

The navigation of different work places and work colleagues remains however an ongoing challenge for all of the participants as they balance “fitting in” with the advocating for workplace needs and accommodations.

## Discussion and conclusions

The presence or absence of positive or negative factors relating to the performance of emotion work, stigma, and support will influence the workforce outcomes of these employees, and the issues associated with stigma, the reaction of peers, and advocating for accommodations are linked and nuanced. Outcomes for workers with ASD appear to be different from those we have seen previously in research, which focuses on individuals with chronic illness and other forms of disability, due to the stigma and attributes that are specific to a diagnosis of ASD. Neely and Hunter (2014, p. 276) point out that the stigma associated with ASD can be greater than that associated with other disabilities “due to the stereotypes and perceptions [which] can range from doubts about their diagnoses to unfair expectations of savant-like capabilities”. A ‘good’ employee who is regarded as high performing might need to make a number of mistakes before they are considered to be poor performing, while an employee with a disability, regardless of their performance in the workplace, is given fewer chances for mistakes and may be more harshly judged, before they are told that “things aren’t working out” and they are asked to resign.

One of the biggest problems is that a label such as ASD might cause colleagues in a workplace to bring a level of misunderstanding of the implications of the diagnosis. Much research in the area of disability focuses on disclosure as an important step towards receiving accommodations, which in turn assists these workers by helping to preserve their professional identity in the workplace. The success of disclosure depends on whether others are willing to provide understanding and support and ultimately some form of accommodation. The data in this study shows that accessing understanding and support may be problematic for this group.

Where employers may be willing to provide accommodations for workers with ASD who are qualified and motivated they will have gained an excellent employee. Unfortunately, stigma and a lack of workplace support mean that employees with ASD may work in many different workplaces before they find one which suits them. The subtleties of the impacts of shifting workplaces are neatly captured by Penelope:

I think there is a circular aspect to the problem. The negativity in the workplace fuels depression and feelings of inadequacy and low self-worth, which in itself channels into behaviour and attitude that creates greater misunderstanding and unease. It is a depressing cycle.

(Penelope)

ASD differs when compared to other forms of disability because it brings with it not just differing ways of doing and being, but it also has different attributes in terms of ways of thinking. Employees with chronic illness or physical disability are, perhaps, better able to conform to social expectations and can develop coping mechanisms, which are acceptable in their workplace (although we should note here that they may not always be successful [Werth, 2013]). Employees with ASD, because of their social difficulties, may not be able to see a solution, and if they can, they may not be able to perform the emotion work required to maintain the professional identity associated with a typical worker in their workplace.

Workplaces that have characteristics of clear structures, few distractions and reduced noise to promote concentration have been demonstrated to be the most inclusive for ASD workers (Krieger, et al., 2012). Further, Wehman (2003, p. 137) suggests that “making job site modifications, providing social skills instructions, advocating on behalf of the employee, and teaching the “social culture” of the job site” have been shown to be useful for workers with ASD. Our data show that one important characteristic of an inclusive workplace for people with ASD is full integration and acceptance of the unique characteristics of each individual worker.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.), Washington, DC: Author.

Bolton, S. C. & Boyd, C. (2003). Trolley dolly or skilled emotion manager? Moving on from Hochschild's managed heart, *Work, Employment and Society*,17(2), 289-308.

Braun, V. & Clark, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Clair, J. A., Beatty, J. E., & MacLean, T. L. (2005). ‘Out of sight but not out of mind: managing invisible social identities in the workplace’, *Academy of Management Review*, 30(1), 78-95.

Davidson, J. & Henderson, V. L. (2010). ‘Coming out on the spectrum: autism, identity and disclosure’, *Social and Cultural Geography,* 11(2), 155-170.

Day, N. E. & Schoenrade, P. (2000). ‘The relationship among reported disclosure of sexual orientation, anti-discrimination policies, top management support and work attitudes of gay and lesbian employees’, *Personnel Review,* 29(3), 346-363.

DeJordy, R. (2008). ‘Just passing through: stigma, passing and identity decoupling in the workplace’, *Group & Organization Management,* 33(5), 504-531.

*Disability Discrimination Act* *1992* (Cth) p. 1, s. 4 (Austl.).

Garcia, J. A. & Crocker, J. (2008). Reasons for disclosing depression matter: the consequences of having egosystem and ecosystem goals, *Social Science and Medicine,* 67, 453-462.

Goffman, E. (1986). *Stigma: notes on the management of spoiled identity,* New York: Simon & Schuster Inc.

Hochschild, A. (1983). *The managed heart: commercialisation of human feeling,* Berkeley: University of California.

Johnson, T. D. & Joshi, A. (2014). ‘Disclosure on the spectrum: understanding disclosure among employees on the Autism Spectrum’, *Industrial and Organisational Psychology,* 7(2), 278-281.

Krieger, B., Kinebanian, A., Prodinger, B., & Heigl, F. (2012). ‘Becoming a member of the workforce: perceptions of adults with Asperger Syndrome’, *Work,* 43, 141-157.

Millen, N. & Walker, C. (2001). ‘Overcoming the stigma of chronic illness: strategies for normalisation of a spoiled identity’, *Health Sociology Review,* 10, 89-97.

Muller, E., Schuler, A., Burton, B. A., & Yates, G. B. (2003). ‘Meeting the vocational support needs of individuals with Asperger syndrome and other autism spectrum disabilities’, *Journal of Vocational Rehabilitation,* 18(3), 163-175.

Myers, K. R. (2004). ‘Coming out: considering the closet of illness’, *Journal of Medical Humanities,* 25(4), 255-270.

Neely, B. H. & Hunter, S. T. (2014). In a discussion on invisible disabilities, let us not lose sight of employees on the Autism Spectrum, *Industrial and Organisational Psychology,* 7(2), 274-277.

Stuber, J., Meyer, I., & Link, B. (2008). ‘Stigma, prejudice, discrimination and health’, *Social Science and Medicine,* 67,351-357.

Vickers, M. (1997). ‘Life at work with ‘invisible’ chronic illness (ICI): the ‘unseen’, unspoken, unrecognised dilemma of disclosure’, *Journal of Workplace Learning,* 9(7), 240-252.

Vickers, M. (2010). ‘Exploring illness disclosure for workers with Multiple Sclerosis’, *24th Conference of the Association of Industrial Relations Academics in Australia and New Zealand,* Sydney, 3-5 February.

Vickers, M. (2017). ‘Dark secrets of impression management: workplace masks of people with multiple sclerosis’, *Employee Responsibilities and Rights Journal*, In press, pp. 1-21.

Wehman, P. (2003). ‘Workplace inclusion: persons with disabilities and coworkers working together’, *Journal of Vocational Rehabilitation,*18(2), 131-141.

Werth, S. (2011). ‘Stigma, stress and emotional labour: experiences of women with chronic illness at work’ *25th Conference of the Association of Industrial Relations Academics in Australia and New Zealand.* Auckland, 4-6 February.

Werth, S. (2013). ‘An investigation of the interaction of chronically ill women and their working environments’, PhD thesis, Griffith University.