

“There’s nothing mild about autism”: How ‘functioning labels’ create barriers to accessing services for autistic adults

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Overview

- ‘Functioning labels’: what are they, and are they helpful?
- The social model of disability
- Experiences of accessing mental health services: a “services disability”

Functioning Labels

Functioning labels

- When the autism spectrum is imagined as a continuum, ‘functioning labels’ aim to describe where an autistic person falls on this line. The label “high functioning” is often used to communicate that the person has a “milder” form of autism, and the term “low functioning” is often used to describe someone who is unable to achieve so-called ‘normal’ things.
- People can find it difficult to understand the problem with these labels, that seem to be ‘common sense’. For example, it is difficult to see a common disability between *“one person with severe autism and multiple intellectual disabilities who requires full-time care and another diagnosed with Asperger Syndrome who is able to live independently and form a fulfilling relationship with someone else”* (p50).
- Functioning labels are often tied to expectations; “high functioning” means that a person is expected to perform as ‘almost not-autistic’, while “low functioning” means that a person is not expected to achieve much at all.
- The label “high functioning” is often based solely on IQ (or assumed IQ!), but IQ alone is a poor indicator of functional ability (see Alvares et al., 2019)
- People labelled “high functioning” are assumed to be ‘mildly’ impacted by autism, but this assumption does not reflect reality. (For example, see: Howlin, 2003; Fein et al., 2013; Magiati et al., 2014; Howlin et al., 2014)

Functioning labels

“The other labels, ‘mild’, ‘severe’ etc are more about how the autistic affects the people around them”

“separating autistic people into functioning categories most this is related to how easy neurotypicals find particular autistic people to interact with, rather than being a reflection of our real needs”

Rudd, D. 2017. *“There’s nothing mild about autism”: How ‘functioning labels’ create barriers to accessing services for autistic adults*, unpublished Master of Social Work Dissertation, Durham University.



“‘Mild autism’ does my head in, because the mental health side of things are anything but mild”

“what’s mild for you in one area might be severe in another”

“there’s nothing mild about autism”

How 'functioning labels' relate to service provision and accessibility

- ↓ services are designed/constructed on basis of perceived 'need'
- ↓ high functioning; "mild" – presumption of no/low support needs (no service required)
- ↓ people labelled high functioning cannot access autism-specific services because these services have IQ-based eligibility criteria, and/or require presence of learning disability
- ↓ Autistic people labelled high functioning often fall in the gap between learning disability and mental health services (see Department of Health)
- **The label itself (mild) has an impact on ability to access autism-specific services**

“Everything is a constant fight for assessment, diagnosis, and by the time you’ve got that you haven’t got the energy left to fight for support”

“when support is difficult to find for adults with high support needs, when it comes to someone who is apparently more ‘high functioning’ autism, then there is nothing”

- Autistic people labelled “high functioning” are unable to access autism-specific services
- People labelled “high functioning” often require support with mental health. This means attempting to access mainstream mental health services
- The experiences of autistic women labelled “high functioning” suggest that it is difficult to get mental health services to recognise autism and, where it is recognised and diagnosed, this often happens late.
- Where autism is recognised and diagnosed, mental health services often dismiss it; autism is seen as unimportant because it is assumed to have only a mild impact
- Reasonable adjustments are viewed as unnecessary or unimportant; the individual is expected to use perceived intelligence to compensate for difficulties arising from autism
- It is difficult to access mainstream mental health services and receive an appropriate and high-quality service

The Social Model of Disability

The social model

There is a place for medical intervention

- *“the social model of disability does not ignore questions and concerns relating to impairment and/or the importance of medical and therapeutic treatments. It acknowledges that in many cases, the suffering associated with disabled lifestyles is due primarily to the lack of medical and other services.” (Oliver, 2004: 22).*
- *“it may be entirely appropriate for doctors to treat illnesses of all kinds” (Oliver, 1990)*

- **Impairment:** physical (including intellectual/cognitive/sensory) restrictions experienced by an **individual** directly related to a condition they have.
- **Disability:** socially constructed restrictions *imposed upon people labelled with impairments*. For example: negative views of disabled people; discrimination; inaccessibility; lack of control; lack of appropriate support.

Individuals who can't access services... or inaccessible services?

- An autistic individual (or many of these individuals) cannot access appropriate support from mental health services because their autism makes it difficult to navigate services

OR

- Mental health services are not equipped to give appropriate support to autistic people (as a population) in navigating services because these services were designed to provide support to non-autistic people, and/or these services were built upon policy that views the individual as the 'problem' to be targeted through intervention

Autistic people experience a “services disability”

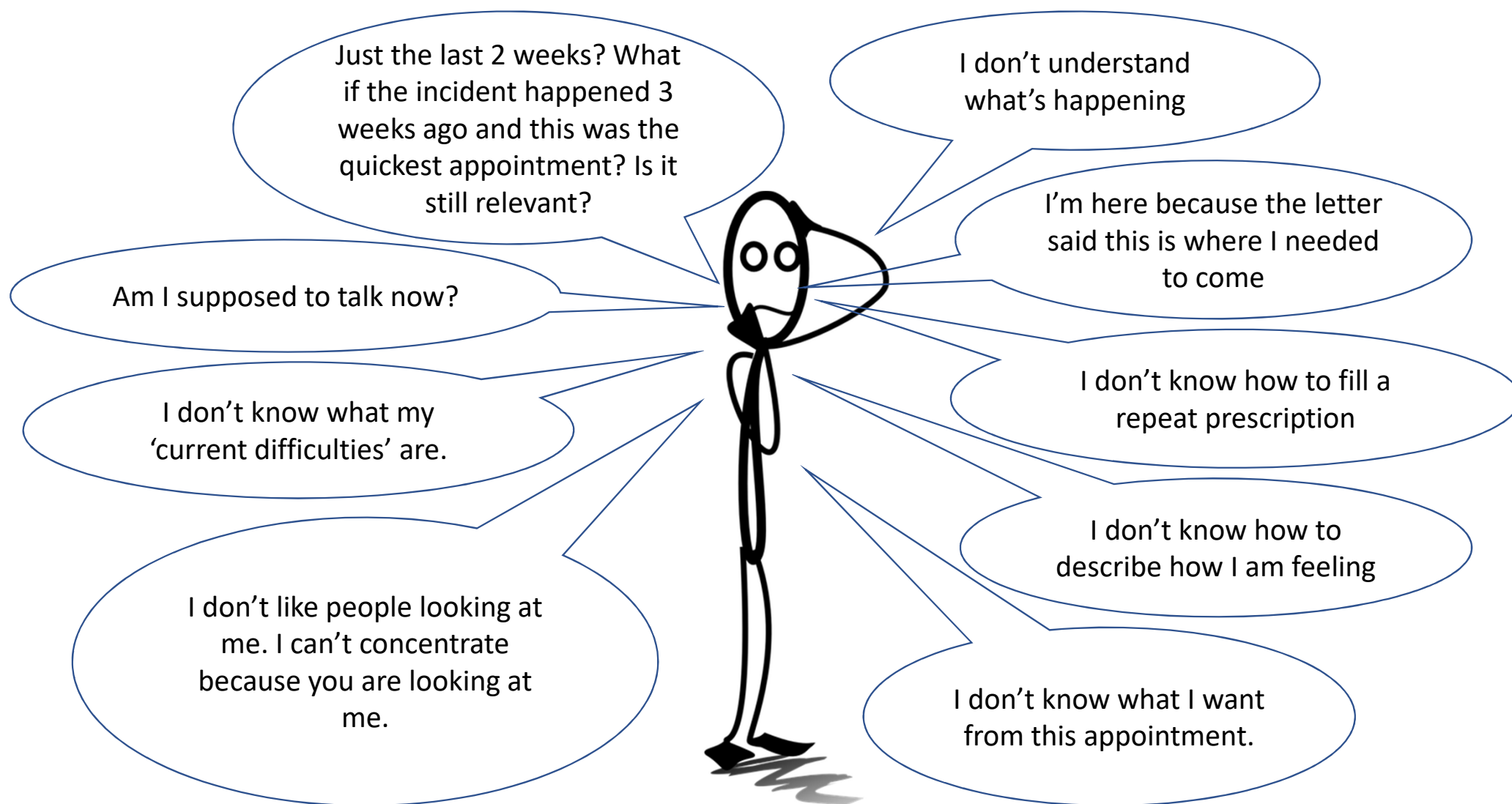
Presumption of (no/low) support needs

“I told my GP and social worker and it was all just well autism is a spectrum I assume you’re very high-functioning”

“it’s very frustrating when people assume I’m capable”

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Personal experience:
my “services disability”



I really don't
know how to be
any more clear.

But you're obviously
very intelligent

I'm sure you're more
than capable of doing
that

Why don't you understand?

You attended a
mainstream school
didn't you?

But what exactly do you
not understand?

When did you start
feeling paranoid about
people watching you?

It's really not a
difficult question.

Do you actually want
another
appointment? You're
clearly not engaging in
this.

“A psych was actually consulted about me on the phone and they even suggested that it might ASD, but the CBT therapist asked if I understood jokes... So I said yes and she said ‘then it’s unlikely to be ASD because ASD people don’t understand jokes’.”

“I had an assessment with a psych nurse. By this point I was sure (and so is my husband) that I was autistic. The psych nurse had other ideas and tried to manipulate my answers to her questions to make it sound like I had borderline personality. She said I was pissed off at being discharged so I had abandonment issues. She immediately dismissed the idea of autism (she said it was her special area). She said autism always gets better in adulthood”

“every professional I saw knew [nothing] about autism and so I was dragged through hell for no...reason” (*referring to CBT therapist, staff at A&E, and a psychiatric nurse*)

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“Providing a barrier free environment is likely to benefit not just those with [an impairment] but other groups as well”

(Oliver, 2004, p21)

Summary/Key messages

- Professionals often presume that a person's autism has a 'mild' impact; this is sometimes based on assumptions about intelligence or stereotypes about autism in general, rather than clinical judgements about a particular individual or their circumstances
- These assumptions do not accurately reflect/predict abilities or outcomes, but do limit access to appropriate services. Individuals are expected to 'overcome' their autism-related difficulties, and little consideration is given to the context/environment.
- Instead of focusing on the individual (and their 'deficits'!) to understand why an autistic person has difficulty accessing services, it might be better to consider the ways that a service designed to meet the needs of non-autistic people might create barriers for autistic people.