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Autism, employment and disclosure: a personal reflection

Dr. Damian E M Milton
damianmilton.sociology@yahoo.com
Hourly paid Lecturer – London South Bank University
Project Consultant – University of Birmingham
Head of Autism Knowledge and Expertise (Adults and Community) – National Autistic Society
Introduction

- Reflection of my own personal journey and experiences of the workplace.
- Reactions pre and post diagnosis and how this can affect how one experiences the workplace.
- Exploring wider issues affecting autistic people in the workplace, with a specific focus on disclosure.
An enduring issue

- It is often claimed that only 15% of diagnosed autistic adults are in paid full-time employment (NAS, 2014), less than any other category of disability status.
- It is also claimed that 79% of autistic adults would like such employment (NAS, 2014).
- So – one has to wonder to what extent traditional job coaching has made regarding significant differences to the job prospects of autistic people.
My employment history pre-diagnosis

- 1991 – Became a student.
- 1992 – Withdrew from course and became unemployed.
- 1995 – Became a student again.
- 1996 – First job in a wool-packing factory (£2.12 an hour).
- 1999 – Gained a Masters Degree.
- 2000 – Started PhD and Teaching assistant at a University (part-time).
- 2001 – Withdrew from course, reliant on money from DJ’ing music.
- 2002 – Cashier in a bookies.
- 2004 – FE Lecturer in Sociology and Academic Skills.
- 2008 – Made redundant. Distance learning courses.
Post-diagnosis

- 2009 – Start of PhD course.
- 2010 – Volunteer role for Ambitious about Autism.
- 2012 – First consultancy work and work for the NAS and Autism Education Trust.
- 2014 – Appointed at London South Bank University.
- 2015 – Appointed Head of Autism Knowledge and Expertise (Adults and Community) at the NAS.
- 2016 – Appointed at the University of Birmingham.
Some key issues and opportunities for autistic people

- The sensory environment.
- Autism and the ‘spiky profile’.
- Passionate interests and flow states.
- An exacting gaze / systematic logic.
- The ‘double empathy problem’.
- Stress, anxiety and comfort.
- The need for predictability and transparency.
Advice often given regarding the job interview

- Dressing for success
- Grooming tips
- How and when to give a handshake
- Sitting up on one’s chair
- Facing the interviewer
- Using an ‘upbeat tone of voice’
- Smile and make eye contact
Passing and masking – the dangers

- May have some limited uses – but not good as a general tactic to employment.
- Stress – shutdowns, panic attacks and long-term wellbeing.
- Reputation management and exposure anxiety.
- Exhaustion and burnout.
- Needs continue not to be met.
- Nothing changes regarding the structures and attitudes one works within.
- Does it work?
- When to disclose? Disclosure is not without its own issues.
Ways to find work

- Job advertisements – ‘scatter-gun’ approach or targeted applications?
- Showing your worth – work placements and the ‘portfolio’ approach.
- Being persistent and following passions.
- Not being afraid of being open – if you are rejected for it, it is likely you will be rejected at some point later on and at greater personal cost.
- Working with others that can advocate for you.
- Reasonable adjustments and the issue of ‘compromise’. 
Barriers in the way

- Social attitudes, prejudice and stigma.
- The design and wording of job descriptions.
- Opportunities to gain experience and being given a chance to prove one’s worth.
- Systemic issues.
- Your own efforts? Your ‘autism’...???
- ‘Selling oneself’.
- Paid employment not an aim for all and yet someone’s disposition should not be seen as a barrier to being meaningfully occupied.
Meaningful occupation

- There is a proportion of autistic people who will be unable to work under current work conditions, or for whom it would be exploitative and not a ‘meaningful occupation’.
- How one may utilise one’s interests, motivations, and strengths to attain meaningful occupation, and when wanted paid employment.
- A case in point – the photography group.
- Often a keen interest will be within the field of autism in some way.
Sustaining employment

- The first 100 days.
- Finding out who your friends are...and those who one might struggle to work with.
- A culture of openness.
- ‘Compromise’ – how much is reasonable?
- Access to work and mentoring.
A two year pilot project designed by people on the autism spectrum to evaluate a mentoring intervention.

After mentor training, selection, matching and completion of the Melbourne Personal Wellbeing Index (PWI), 12 pairs met for one hour per week over 6 months. Supervision was built in throughout.

3 Goals were set initially and reviewed throughout project.

Meeting record sheets jointly completed and a reflective journal were individually completed after each session.

After the final mentoring session, research assistants completed another evaluation and PWI with participants.

Data has been collected and analysed by the research team with input from The Advisory Group.
### Personal wellbeing index results

<table>
<thead>
<tr>
<th>PWI</th>
<th>All – pre-intervention</th>
<th>Pre (who finished)</th>
<th>Post</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?</td>
<td>5.08</td>
<td>6</td>
<td>7.8</td>
<td>1.8</td>
</tr>
<tr>
<td>How satisfied are you with what you are achieving in life?</td>
<td>5.08</td>
<td>5.4</td>
<td>7</td>
<td>1.6</td>
</tr>
<tr>
<td>How satisfied are you with how safe you feel?</td>
<td>6.42</td>
<td>7.4</td>
<td>8.8</td>
<td>1.4</td>
</tr>
</tbody>
</table>
## Average progress toward goals

<table>
<thead>
<tr>
<th>All – pre-intervention</th>
<th>Pre (who finished)</th>
<th>Post</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.75</td>
<td>4</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>
“...this helped me dig my way out of a life threatening hole that I could not see any way out of. It reminded me to make progress towards goals. [The mentor] Listened when I needed it, was a regular weekly marker in my chaotic life, provided an opportunity to reflect and plan and self manage. I wouldn't have done this otherwise.”
What is under your control/influence and what is not?
Targeting efforts and following interests.
Disclosure is a personal choice and can be problematic, but not disclosing can also lead to significant issues.
What is meaningful occupation for one is not for all.
For advisors and mentors – being person-centred is vital.
References