

The citizen-worker: Ambivalent meanings of ‘real jobs’, ‘full citizenship’ and adulthood in the case of autistic people

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Abstract

In this paper we discuss the experiences of autistic people in engaging with the workplace, and hence becoming an active citizen within dominant constructions of adulthood. We focus on transition into work as a key way in which children become adults in many societies. Such a transition to adulthood is seen to be less straightforward for children with ‘disabilities’, including those with a diagnosis of autism (or self defining as autistic). In this paper we draw on data from our previous and ongoing research examining neurodiverse spaces for children and adults with autism, and the importance of such spaces. Issues for neurodiverse spaces are also key in the workplace and the implications for refocusing an examination on transitions into work by autistic people through a lens of neurodiversity are far reaching in terms of how autistic people fashion their own positive citizenship identities; how service providers negotiate opportunities for some; and how workplaces shift in terms of accommodating difference. We argue that there is a need for inclusive and diverse workspaces, where the strengths of some adults with autism can be part of a shared neurodiverse and non-autistic (neurotypical) space. We therefore argue that by attending to the workplace from a neurodiverse perspective community psychologists can work to support a diverse range of young people into working activities, if they choose to participate.

Keywords: Autism; citizenship; work

Introduction

In this paper we seek to critically explore notions of autism and autistic people in relation to dominating neo-liberal notions of citizenship; namely through engagement in work. We will do so by discussing non-autistic (neurotypical) meanings of 'real work' and 'full citizenship' and how autistic people are expected to engage with these arrangements. Our position within this paper is informed by three key perspectives: Community Psychology, Critical Developmental Psychology and Critical Autism Studies. Community Psychology is a discipline with potentially far-reaching influences through its focus on challenging and reframing notions of the family and disadvantage (Kagan et al, 2011; Fox & Prilleltensky, 1997). The focus of community psychology is upon strengths, with a positive focus on education and skills training, an important position from which to begin this paper. Thus intervention is not to change 'faulty' or 'deficient' individuals but to change systems and communities to allow individuals who are seen to be 'different' to have a place within them. Complimentary to this are theoretical insights in the construction of 'normative' and 'non-normative' childhoods evident within critical approaches to developmental psychology, where boundaries between what is considered 'normal' are strongly regulated and prescribed (Burman, 2007; Phoenix et al, 2009). Such dominant understandings of (ab)normality are frequently drawn upon when constructing the autistic adult, who is typically presented as impaired in typical social and emotional communicative skills, positioned therefore as *deficient* rather than *different*.

Finally, we draw on a perspective of theorising autism that emphasises issues of *neurodiversity*, which positions autistic people as *different* rather than *deficient*. Our work is therefore informed by the growing movement in critical autism studies (see for example Davison & Orsini, 2013), which seeks to question the representation of individuals and the interests best served by such representations and consequent positionings. The terminology that we draw upon in this paper will therefore include neurodiverse, reflecting the positioning and respect of difference, and neurotypical or *NT*, a term that was coined by autistic self-advocacy movements to refer to non-autistic individuals. In order to reflect the strong debates surrounding autism within identity politics, we also use the term 'autistic' rather than people first-language in order to reflect the inclusion of autism within individual identities rather than as a separate 'add-on' to an individual, which can consequently be modified and 'cured' through treatment by professionals. Adopting such a position has important implications for our

understanding of citizenship and what this means for an individual to be a citizen of a particular community.

The following discussions will focus on what (neuro)typical understandings of citizenship may look like, and what normative representations of full (adult) citizens are produced within these dominant discourses. We then go on to discuss what this might mean for autistic individuals as they transition from 'childhood' to 'adulthood', sometimes 'lacking' the key markers of what is assumed to be necessary to be a full adult citizen. We illustrate the discussion with excerpts from previous projects, one of which analysed articles in a Swedish magazine, *Empowerment*, produced by and aimed at adults with autism. The second consists of English-speaking discussion forums that take place in online communities focused on autism. More detailed analyses of issues of work for individual autistic identity construction in both datasets have been discussed elsewhere (see Bertilsdotter Rosqvist & Keisu, 2012; Brownlow, 2010). We therefore seek to use excerpts from our datasets to illustrate our arguments about the engagement of young adults with autism in working activities, rather than present a full discourse analysis of texts. Through drawing on the neurodiversity discourse informed by critical autism studies and the neurodiversity movement more broadly, we present illustrative examples from our previous research detailing the narratives of autistic people within NT-dominated workplace and the implications of this for (autistic) citizenship.

Conditional citizenship, conditional adulthood

Traditional concepts of citizenship draw on particular ways of representing individuals, with clear ideas concerning what makes a citizen; such as national and geographical belonging and specific duties and privileges (citizen rights) that are connected to that (see for example Seeleibkaiser, 1995). In contrast, newer forms of citizenship not only draw on geographical and national membership, but also on societal activity (see for example Wagner, 2004). Such alternative framings of citizenship therefore focus on the concept of social, active or 'full citizenship' (see for example Blakeley & Evans, 2009; Scourfield, 2007). This is sometimes also referred to as democratic citizenship, and the active citizen. The most dominant notion of active citizenship can be represented as the adult, independent, able-bodied 'citizen worker' (Lie et al, 2009; Lister, 2003; Lunt et al, 2002), which clearly maps the territory in terms of which individuals are eligible for membership. Such

membership has clear markers, which draw on several normative markers of adulthood such as engaging in full time work and parenthood (see Blatterer, 2007). These understandings draw heavily on dominant developmental psychology discourses surrounding what constitutes 'normal' adult and 'normal' adult activities. Where understandings of citizenship draw on engagement in the world of work as a key marker of adulthood, challenges are presented for young autistic individuals making the transition where they need to craft an identity by engaging in work environments that may be difficult for them or that they may not wish to be a part of.

We argue that notions of 'full citizenship' and age/adulthood intersect. The normative construction of childhood sees children and young people as 'subjects in becoming' citizens from either a passive or an active perspective. From a more passive perspective, children and young people are represented as targets of social policy educational interventions related to the promotion and crafting of 'active citizens' (Hall & Coffey, 2007) conscious of both rights and responsibilities that come with citizenship (Hall & Coffey, 2007; Milbourne, 2009; Montero, 2009; Thornberg, 2008; Timmerman, 2009). Young people are positioned in a more active way in their engagement in activities such as youth volunteering which is produced as "one way in which young people can be effectively re-engaged with their communities, and with the political process more broadly" (Brooks, 2007: 420). Similarly, France and Wiles (1997) connect a modern conception of citizenship with inclusion in production, and young people participating in work therefore as part of the transition process from childhood to adulthood in a modern society (France & Wiles, 1997; see also Room, 1999). From a more active perspective on children and young people, youth transitions to adulthood are explored by researchers in order to understand citizenship as lived and learned by young people (Cross, 2011; Hall & Coffey, 2007).

The most dominant notion of adult full citizenship is sometimes referred to as the citizen worker. This position is produced through an economic discourse of citizenship including 'fully paid work' (i.e. 'real jobs', see Ridley & Hunter, 2006; Wilson, 2003): the fully employed economic independent citizen. Closely connected to this notion of citizenship are notions of 'social exclusion' (see for example Evans & Harris, 2004; France & Wiles, 1997; Pitts & Hope, 1997; Room, 1999) and age/adulthood (Lister, 2003). Within an economic discourse of social exclusion, unemployment, low-income or poverty are produced as a risk of economic marginalization, itself a risk of social exclusion (see for example France & Wiles, 1997; Pitts & Hope, 1997; Room, 1999). Social exclusion,

especially in the context of people from 'minority' or marginalised cultures within society, and young people more generally, is used as an explanation of "social dislocation" - including youth crime, interpersonal violence, and drug misuse (Pitts & Hope, 1997). Seyfang (2004) describes this as a "hegemonic discourse of social exclusion, namely a liberal individualistic model which sees insertion into the labour market as the solution to exclusion" (abstract). Several researchers have criticised the central role of fully paid work in defining the status of citizens from the perspective of the not fully employed citizen (see for example Craig, 2004; McKie et al 2001). Such a view has been criticised for devaluing unpaid work such as caring or volunteering, and therefore for being exclusionary, arguing for the need of alternative more inclusive definitions of citizenship (Craig, 2004; McKie et al 2001). Alternatively, Seyfang, (2004) among others has argued for the need to reconsider what is typically taken to be 'valuable work' or expressed by Toft (2010) as 'valuable citizenship activities'. From the perspective of research focusing on voluntary work in the community (Craig, 2004; Seyfang, 2004; Taylorgooby & Lakeman, 1988) or non- or low paid care work (McKie et al 2001; Toft, 2010), researchers such as Seyfan therefore seek to reconsider dominant ideas of concepts such as 'work' and 'welfare', thereby enhancing possibilities for the social inclusion of a range of citizenship understandings.

The importance of work in framing understandings of what constitutes an active and engaged citizen is centrally important in discussions in the Swedish magazine Empowerment, for example the following extract draws on what such meaningful work might look like:

"Contrary to what some other speakers said, Thomas thinks that a profession is not important to having a sense of community. However, it is important to be involved in club activities if you don't have a job. Thomas thinks that the voluntary work he does now feels more meaningful than the work he did as a paid employee."

(contribution to the Swedish magazine Empowerment)

We can see that meaningful work forms a central role in the construction of sense of community, and therefore citizenship. However, this example shows a focus on community engagement rather than economic benefits for individuals or organisations as constituting meaningful work.

Transitions into an autistic citizenship through employment

'Real jobs' and 'full citizenship' are powerful examples of markers of adulthood. Such understandings position adulthood as a time of economic independence and engagement in work. In contrast, those individuals who do not engage with activities that would qualify them for membership as a full citizen, may either be seen as excluded or isolated or possibly be accorded 'conditional citizenship' status if they are active members of a community (c.f. Mackay, 2011; McKeever, 2012), for example by active participation in the community. However, we critique the underlying principles of normalization that are inherent in these kinds of actions as well as the consequences of exclusion for people with disabilities who choose to not conform (or may not be able to) with the mainstream expectations of them.

As previously discussed, work is seen as a central process in the transition to adulthood (Holmqvist, 2008). This is particularly complex when considering young people with disabilities who are likely to be more dependent on social interventions, less involved or integrated into society and to therefore find the move into adulthood more challenging (Holmqvist, 2008; Murray, 2007). The transition of young disabled people from statutory schooling has been seen by many as a difficult time in their, and their families', lives (see for example, Adreon & Durocher, 2007; Knapp et al, 2008). Overall there is a significant difference in employment rates and average earnings for disabled adults in comparison to their non-disabled counterparts (Knapp et al, 2008). Knapp among others (see for example Caton & Kagan, 2006) suggests that the findings are partially explicable by differential education attainment and lack of support services. Whilst there is a growing research literature documenting the process of transition for young disabled people in the UK (Caton & Kagan, 2006), the USA (Smith, 2005) and Australia (Murray, 2007), very little of this has focused on young autistic people (Adreon & Durocher, 2007). Where research has been conducted the findings are similar to those for young people with other forms of intellectual disabilities (see for example Barnard et al, 2001).

Research evidence suggests that transition to adulthood is the beginning of lifelong inequalities and difficulties faced by autistic adults, who are largely operating within NT dominated social and employment domains. Transition for some young autistic people is further complicated because of the often hidden nature of autism (Adreon & Durocher, 2007), both in terms of NT others being able to recognise and respect the difference, and also in terms of the discursive practices which serve to construct the challenges faced by autistic people.

The transition from school occurs during adolescence when these differences are experienced with increasing awareness by both autistic and NT young people. With respect to autistic individuals, many research studies and first person accounts point to a commonly experienced lack in social awareness for autistic people, and Folstein (1999) suggests that a lack of such social abilities can become particularly problematic around adolescence, when autistic people become increasingly aware that they are different to others and do not 'fit in' to the dominant NT ideal constructed within both social and employment settings. Several studies within the growing field of autism and work life have shown that autistic people, despite great potential, have found it difficult to find and keep a job that is commensurate with their abilities due to the additional requirements in terms of managing social relationships in the typically NT dominated workplace (Hendricks, 2010; Smith-Myles & Smith, 2007).

Very little is known about how young autistic people move from school and this transition may be more complex because it may not actually mean moving on in the same way it does for young NT people (Murray, 2007). Young autistic people often have their service needs met through schooling, therefore transition from school involves a change in service provision (Knapp et al, 2008). They often lose contact with specialist services at this stage (Caton & Kagan, 2006) and move into adult services, which are often less resourced (Murray, 2007). In addition for some young autistic people the transition means moving to adults services, whereas for others with different capabilities the transition is into a different educational environment. There are an increasing number of young autistic people leaving school to go to university (Adreon & Durocher, 2007; Martin, 2007). Madriaga, Goodley, Hodge, and Martin (2007) traced the experiences of young autistic people into Higher Education. A key finding of the study was that young autistic people experienced a lack of support during the transition to Higher Education, which was linked with feelings of isolation on the part of the young people and a lack of autism awareness on the part of staff.

A common discussion which was shared by both online and face-to-face communities was the need to 'fit in' with environments that are dominated by NTs. The ability, and pressure to, 'pass' as an NT is an area of debate for contributors in both datasets. For example:

If you want to tell people about your disability when looking for work, think carefully about how. Talk about your strengths. "Be prepared to be disqualified immediately", Hans warns. Many employers believe that autism/AS means that one cannot handle a job. Opinions differ on whether or not it is best to tell. If you know you need special adaptations to cope with the work, then of course you have to say that you have autism/AS. Otherwise, the employer will not receive a wage subsidy, for example. But if you do not need support, you can gain by not revealing that you have the disability – or at least by waiting until you have started working and showed that you can do the job.

(contribution to the Swedish magazine Empowerment)

Such issues of disclosure and 'passing' are not exclusive to autistic people in the workforce, and similar decisions concerning the decision to disclose or pass are also evident in literature examining other 'hidden disabilities' and their negotiation of the workplace (see for example Werth 2011). However, the decision to 'pass' as an NT raises some pertinent questions that draw on key debates within autistic identity politics (see for example Bagatell 2007; Bertilsdotter Rosqvist, 2012ab). The need to adopt an NT style reflects the powerful position accorded to an NT identity both within a workplace specifically and society more broadly. Through adopting a position of *different* not *deficient* an autistic position should be afforded equal rights and privileges as that of an NT position. However, it would seem from the discussions of autistic individuals that the two positions are far from equal, and therefore passing, if it is an option, may be a strategy employed in a bid to negotiate and navigate through NT dominated workplaces in pursuit of active citizenship status.

Caton and Kagan (2006) argue that transition can therefore mean many things such as: transition to employment; to become integrated in the community and a transition to adult services. Caton and Kagan use the concept of transition to adulthood to allow a full consideration of the transition process. In this paper we take a similar view of transition to enable a broad and inclusive consideration of transition in its many versions experienced by young autistic people. This paper seeks to explore the experiences of autistic people in engaging with the workplace, and hence

becoming an active citizen within dominant, normative constructions of adulthood. In doing so we draw on illustrative examples from two data sets that highlight the complexities involved in autistic people working in NT dominated workplaces.

The notion of 'difficult workplaces' was evident in our previous project that explored online communities for autistic people. For example, one contributor to an online forum highlights the importance of social skills in navigating and negotiating a position within a workforce, and the different, and in some cases, inferior abilities of NT colleagues to facilitate this:

With the "New Economy" now sweeping us, the NTs had made a come-back with the "New Age" employment tactics, including making a work place extremely sociable. [...]
Some companies have an autocratic boss with a rigid hierarchical structure. While the simplicity and the direct orders may sound nice, but if you had experienced higher mental development the inconsistencies will drive you crazy.

(contribution to an online discussion list)

Here autistic people are discussing a type of workplace that are difficult for them. The issues raised in this exchange are in relation to the social environment in some workplaces and also the physical environment. We can further see the implication of a firm focus placed on the importance of social networking abilities in navigating entry to and management within the workplace in the following quote:

Always look for a company environment that supports (or at least tolerates) your [autism]. You don't just go for an interview but you have to survey your future work place. You just can't believe that some computers still use primitive computing technology from the 1980s. The furiously blinking monitor, the glare from flickering fluorescent lights and the uncomfortably loud workplace will prove to resemble an endurance test when you join the company. If you can find a company with an AC¹ boss, count your lucky stars.

¹ AC is a term used on this particular discussion list a lot to refer to NTs who have experience of autism and are therefore 'promoted' to a level of AC – so here it is referring to a boss who would understand and be sympathetic to the challenges faced in the workplace by an autistic individual

(contribution to an online discussion list)

In this example also from an individual contributing to an online discussion list, we can see the importance placed on careful selection of the working environment. What is also evident from the two example quotes above are the dominant NT discourses that serve to shape the social nature of the workplace and the requirements for the worker to navigate through these often implicit social rules. Such workplaces therefore favour dominant NT ideals concerning sociality at the expense of alternative *autistic socialities* (c.f. Ochs & Solomon, 2010; Brownlow et al, 2013) failing to invoke the discourse of neurodiversity, which may be more flexible in affording suitable working spaces and practices for autistic people and NTs alike.

Concluding remarks

In this paper we have discussed how some autistic people feel that NT dominated workplaces can be a difficult environment to navigate. However, there are some key examples as to how the world of work can be adapted for autistic friendly working practices such as 'Specialsterne' (translated from Danish to English as 'The Specialists') and 'Left is Right'. 'Specialsterne' and 'Left is Right' demonstrate a move towards neurodiverse workspaces, which may serve as an inclusive workplace, which is reflected in the mission statement of Left is Right being to "transform the Swedish employers' views on the concept of "competence"".

Specialisterne for example is a software testing company that draws on the skills of autistic people in the successful development of a company model that draws on a principle of neurodiversity. It is a showcase of what could be possible by adapting to the needs of autistic people. It recognises the talents of autistic people and also the barriers to drawing on these talents where there is a heavy emphasis on social networking within the workplace or within the recruitment process. For example it uses complex forms of Lego to assess the abilities of potential employees, rather than the more conventional social interaction of a formal interview which potentially talented employees may find difficult. A similar approach has been taken more recently in the USA, with Freddie Mac (the large finance company) advertising for paid internships aimed specifically at autistic students or new graduates; "Only by employing people who think differently and spark innovation will SAP be prepared

to handle the challenges of the 21st Century," (SAP's board member for human resources, Luisa Delgado).

Individuals such as Ari Ne'eman, president of the Washington DC-based Autistic Self Advocacy Network (ASAN) and a member of the U.S. National Council on Disability, are encouraged by the shifts that we are observing within the workforce. Ne'eman argues that such a shift indicates that neurodiversity may be considered in a similar way in the workforce ultimately to diversity standards applied to race, gender and sexual orientation. Such innovative philosophies leading to successful company developments indicate a shift in the thinking in the organisation of some workplaces. However, there may still be reservations from various stakeholders in terms of whether such an inclusive neurodiverse approach is either possible or desired.

If community psychologists are supporting young autistic people in the transition to work there needs to be consideration of the young person having a variety of differing views about engaging in NT dominated work and to recognise that they may feel a pressure to 'fit in' and on occasion feel under pressure to 'pass' as an NT. More work therefore needs to be done to examine the disabling practices of dominant NT discourses within the workplace specifically and society more broadly in shaping constructions of autistic individuals. This echoes calls from within the autistic advocacy movement to reposition autism within such discourse.

Such repositioning may however present a key challenge for the discipline of community psychology in terms of how does community psychology account for separatism? From the perspective of our data and the voices of autistic people in other arenas some people may not want to have NT workplaces 'adapted' to their needs and may wish to remain outside of the dominant NT world, preferring instead to engage with an autistic focused environment. We can see drawing on examples cited above in Specialisterne and Left is Right that there are possibilities for immersion into the meaningful world of employment for some autistic people, particularly those with specific abilities attractive on the regular employment market. However, the challenges and resistance in some workplaces for this to effectively take place are also evident in some of the example situations described in the quotes from our previous research. We therefore call for more emancipatory research paradigms to be invoked that foreground the positions of a range of autistic individuals in seeking to understand the nature of the workforce and the meanings attached to this for shared

senses of community, work and citizenship. The question therefore remains concerning what role work plays in the according of such citizenship to individuals, both those who identify as NTs and those who identify as autistic. Previous research indicates the key role that paid employment plays in constructing the citizen, and in the absence of this due to barriers faced by individuals, the question remains concerning the construction of such individual citizenship for autistic individuals'. If autistic individuals do not transition into work in the same way that other NTs may, what does this mean for their (and others) sense of their own citizenship?

We argue that the concepts of adulthood, work and citizenship are complexly intertwined, and therefore in order to be considered a productive and active full member of a particular community, more work is required in order to actively engage some autistic people into neurodiverse workplaces in order to enable the construction of an active citizen worker identity.

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