Storying transition-to-work-to-work for/and youth on the autism spectrum in the United States: A critical construct synthesis of academic literature

Jennifer R. Wolgemuth, University of South Florida
Vonzell Agosto
Gary Yu Hin Lam
Michael W. Riley
Roderick Jones, University of South Florida, et al.
Storying transition-to-work for/and youth on the autism spectrum in the United States: a critical construct synthesis of academic literature

Jennifer R. Wolgemuth, Vonzell Agosto, Gary Yu Hin Lam, Michael W. Riley, Roderick Jones & Tyler Hicks

To cite this article: Jennifer R. Wolgemuth, Vonzell Agosto, Gary Yu Hin Lam, Michael W. Riley, Roderick Jones & Tyler Hicks (2016) Storying transition-to-work for/and youth on the autism spectrum in the United States: a critical construct synthesis of academic literature, Disability & Society, 31:6, 777-797, DOI: 10.1080/09687599.2016.1205474

To link to this article: http://dx.doi.org/10.1080/09687599.2016.1205474

Published online: 25 Jul 2016.
Storying transition-to-work for/and youth on the autism spectrum in the United States: a critical construct synthesis of academic literature

Jennifer R. Wolgemuth, Vonzell Agosto, Gary Yu Hin Lam, Michael W. Riley, Roderick Jones and Tyler Hicks

ABSTRACT
We explored how academic literature constructs the ‘worker with autism.’ Drawing on a systematic review of transition to work for youth with disabilities, we analyzed how 17 articles constructed ‘autism,’ ‘work,’ and the ‘worker with autism.’ We identified two argumentative approaches: the intervention story and the complex story. Intervention stories centered autism as a problem in need of treatment and work as a simple, positive endeavor. Complex stories offered various and more positive accounts of autism alongside broader notions of work. We recommend that academics experiment with writing which expands work (and career) possibilities for youth situated on the autism spectrum.

Points of interest

- A critical review of academic literature revealed how 17 peer-reviewed articles talked about the ‘worker with autism’ in two kinds of stories.
- Simple stories talked about autism as a problem in need of treatment and work as making the ‘worker with autism’ useful.
- Simple stories were found in systematic reviews that attempted to answer ‘what works’ questions.
- Simple stories were unlikely to conclude that ‘what works’ is supported or unpaid work as a human right.
- Complex stories had more various and strengths-based accounts of autism and broader notions of work. They talked about the ‘worker with autism’ in more complicated ways.
- Academic authors should experiment with alternative ways of talking about autism that expand, rather than limit, the work and career possibilities for those situated on the autism spectrum.

CONTACT Jennifer R. Wolgemuth

© 2016 Informa UK Limited, trading as Taylor & Francis Group
Introduction

Tracing the history of rising autism diagnoses over the last few decades, Eyal and colleagues (2010) noted that the discourse of neurodiversity arose alongside the disability rights movement and neoliberalism. They claimed that while disability activists were seeking to have neurological diversity recognized as another type of social difference, neoliberalism was threatening to shift responsibility for ‘vulnerable populations’ from state-supported institutions back to the family. Discourses about disability and impairment related to participating in a major life activity (i.e. work) interact with other discourses (e.g. neoliberalism) to shape meanings (in academic literature) about particular (types of) people, their prevalence, and their possibilities.

The rise of neoliberal discourse, with its focus on individuals and their contribution to the global market, shapes discussions of preparation for work in the United States. Neoliberalism takes freedom to be the independent ability to make and manage personal economic choices, and assumes that individuals who participate in the labor market are ‘freer’ than their social welfare dependent counterparts (McDowell 2004; Rose 1999; Wilton and Schuer 2006). Meanwhile, policies enacted in the United States to affect employment for ‘individuals with disabilities’ (a term emphasizing individuals) are criticized for assuming sufficient jobs and livable wages exist for them, positioning ‘paid work unproblematically as the principal mechanism to secure social inclusion,’ and focusing on the individual rather than the context of employment (Wilton and Schuer 2006, 186).

Despite the plethora of educational and clinical interventions available to school-age students (situated) on the autism spectrum, educationalists in the United States note an absence of structured services in the community to support transitions to adulthood (Shattuck et al. 2011). For students (situated) on the autism spectrum transitioning from education to employment sites, neoliberalism presents them with expectations that include being flexible, reasonable, sociable, and available while multi-tasking; expanding the autism label to include being unable to perform as such (McGee 2012). Concerns about their (lack of) participation in the US labor market (for example, National Collaborative on Workforce and Disability for Youth 2009; US Department of Labor 2013) circulate amidst questions as to whether tomorrow’s workforce will satisfy neoliberal demands for and of employees – in quantity and quality.

Questions and concerns about the ability of tomorrow’s workforce to meet labor demands take on a sense of urgency with a global rise in the prevalence of individuals diagnosed as (situated) on the autism spectrum (Elasbbagh et al. 2012). The current prevalence rate in the United States is estimated at one in 68 (Centers for Disease Control and Prevention 2015). Mallett and Runswick-Cole (2012), noting the increased popularity of autism and the neoliberal context in which research about autism is carried out, warn about the commodification of autism in the academy. The mass production and consumption of knowledge and clinical practices involved in the study of autism are lucrative for universities and researchers, whose scholarly articles and policy reports often eschew advocacy and critique to produce efficient and easily consumed results (Mallett and Runswick-Cole 2012).

Academics play an important role in producing knowledge as authoritative social actors whose work shapes social attitudes, contributes to policy, influences practice, and suggests ways in which lives studied can be experienced (Breheny and Stephens 2007). While the power of language to create knowledge, label and locate individuals, and regulate behavior...
is well theorized (for example, Fairclough 1989; Foucault 1991; Gee 2000), it is not often foregrounded as occurring in academic writing about disability (Lester and Paulus 2012; Mazher 2012). Research and scholarship often echo dominant discourses about disability and impairment, eclipsing other ways they can be understood and experienced (Lester and Paulus 2012; Osteen 2008). For instance, although autism is a complex and contested label, dominant discourses about disability often convey it with a false sense of fixity and unity (Lester and Paulus 2012; Molloy and Vasil 2002).

Given the influence of academic research on policy and practice (Slavin 2008), we were interested in how the literature on work for youth (situated) on the autism spectrum variously constructs ‘autism,’ ‘work,’ and the ‘worker with autism.’ Taking a discursive approach (Gee 2000), we used a new form of literature synthesis that we call a critical construct synthesis (CCS) (Wolgemuth, Hicks, and Agosto 2016) to review literature associated with autism and work in order to show the ways in which academic writing creates labels and people, rather than objectively studies and reflects them. More specifically, our aim was to critically and systematically explore the ways in which notions of the ‘worker with autism’ are produced in published, educational literature.

**Background on neoliberal discourses of disability and autism, work and school**

The social construction of disability is explored in scholarship on the politics of disability identity (Davis 2013) and ableism – the marginalization and oppression of persons with disabilities (Hehir 2007). A more recent trend we follow is toward conducting intersectional analyses of disability and another socially constructed difference, such as race (Anamma, Connor, and Ferri 2013; Erevelles and Andrea Minear 2010). Our study focuses on the intersection of disability (neurodiversity, autism) and classism (neoliberalism, capitalism, employment, welfare services). We first introduce literature providing background on the development of prominent models of conceptualizing disability before turning to an emerging model. We discuss each as embedded in broader discourses (neoliberal, neurodiversity) and reforms (education, welfare).

**The social construction of models of disability and autism**

During the mid-twentieth century, Hans Asperger and Leo Kanner each began constructing understandings of a distinct, complex psychopathology of autism (Feinstein 2010). Since then, many researchers have addressed autism through a psycho-medical model based on a pathology-oriented approach that seeks to understand autism through/as either intrapersonal conditions or social environmental variables. The former basis of understanding disability uses medical procedures to fix individual deficits, while the latter attempts to change environments to better accommodate individual deficits. Both models, rooted in prevailing ideologies of normalization, inform social policies and clinical interventions to support people with disabilities to live a life that is as good as one valued by the normative population (Wolfensberger 1980). While the psycho-medical and social models of disability advanced psychopathological understandings of autism and contributed to the development of myriad clinical practices directed at treatment and inclusive policies and practices,
critical social constructionists critiqued both models for constructing and privileging the social status of ‘normal’ professionals (Chappel 1992).

From a critical social constructionist perspective, the psycho-medical and social discourses produce an ontology of personhood conducive to marginalizing and excluding people (situated) on the autism spectrum (Nadesan 2005) because it constitutes a ‘marker of identity for non-disabled people’ (Murray 2008, 163). Understandings of autism as a social construction and the ways in which it is constructed have been explored in studies of professional communities (Molloy and Vasil 2002), advocacy campaigns (McGuire 2013), fiction literature (Grandin 2013; Hacking 2009, 2010; Murray 2008), and film (Murray 2008). In recognizing the limitations of the psycho-medical and social models of autism to explain discourses about intellectual impairment in South Africa, McKenzie (2013) theorized (poss)ability, which acknowledges discourses as interactive (see also Goodley and Runswick-Cole 2013). Through a survey study, she found that an interactive discourse circulated in which competence was taken as something created in a social context, dependent on the application of the person identified/identifying as intellectually disabled to the task at hand, and dependent on the support of the community. McKenzie posits that (poss)ability supports the continuous search for enabling contexts that are multidimensional and involve other actors in a collaborative effort to build competence through social interaction. She further suggests that (poss)ability would encourage contributions not narrowly defined by productivity.

Whether operating in a psycho-medical, social, or critical social constructionist model, discourses about disability promote particular ways of thinking and engaging. Understandings of autism affect social responses to persons (situated) on the autism spectrum (Bagatell 2007, 2010), and therefore the extent to which they can pursue ‘meaningful’ lives. Because work is generally considered a major life activity and is variously understood (Prideaux et al. 2009; Roulstone 2002), what counts as work and what constitutes work are implicated in discussions of the ability and preparation of youth (situated) on the autism spectrum for work.

The social construction of disability in neoliberal education(al) research and work

In the mid-1970s came the rise of neoliberalism, neoconservatism, and global capitalism. Neoliberalism arose as a form of governmentality in response to more radical and progressive positions that were being forwarded in education (Davies and Bansel 2007). The new forms of governmentality were first installed in schools and public service as part of reform efforts to make subjects more governable (Davies 1996). Douglas (2010) noted, for example, that shifts in educational policies around ‘inclusion’ of students with autism into gifted programs in Canada were no more than attempts to reconstitute these students in neoliberal terms – not only could they be ‘included,’ but also, more importantly, they could be improved, be normal, and be governable.

Over time, themes of fear and morality combined with neoliberal tactics of power, such as persuading people their worth would increase once they chose to be less dependent on the state, or else the state would suffer (Ben-Moshe et al. 2009). Such tactics produce an ‘enabling state’ whereby individuals and institutions are enabled to support their own and society’s well-being by taking on responsibility for services previously provided by the state. The enabling state discourse encourages schools to produce the new student/subject who is appropriate for (and appropriated by) the neoliberal economy (Davies and Bansel 2007).
Under these socio-political and economic influences also came a redefinition of education as a financial investment in a service to be provided to the citizen consumer by the government, and managed through a technical and managerial accountability regime (Biesta 2004).

Given the rise of neoliberal discourse in education, whether emphasizing a culture of evidence or reliance on scientifically-based research, we found Donmoyer’s (2012) statements concerning research complementary to our CCS, a social constructionist approach to reviewing and synthesizing literature. He pondered how research guided by a social constructionist paradigm, which is epistemologically and ontologically subjective, might respond to policy-makers who ask about what works in education. We revised Donmoyer’s (2012) general statement by replacing references to (social) reality with our focus – ‘work/autism/worker with autism:’

We cannot ask which view of ‘work/autism/worker with autism’ is more correct, because we cannot make judgments about the nature of ‘work/autism/worker with autism’ independent of our constructions of it. We can only ask: What do different conceptions of ‘work/autism/worker with autism’ allow us to do; which conception is most helpful – that is, most functional – in accomplishing the particular task (e.g., driving a car, making social policy) in which we are engaged? (Donmoyer 2012, 665; emphases added)

Donmoyer’s question is central to our CCS into the constructions of ‘work/autism/worker with autism’ in academic literature about transition to work for students (situated) on the autism spectrum. Responses to this question circulate within current education reform and its neoliberal emphasis on the capacity of schools to prepare students to be career ready and responsible global citizens. These interactive discourses speak to issues of competence in work and beg the question of how the nexus between disability, work, and education in academic research operates in the construction of the student and transition toward work while (situated) on the autism spectrum.

**Methods and data sources**

Our research was guided by the following question: how do varying types of academic literature on school-to-work transition for youth with disabilities construct the ‘worker with autism’? To address this question we developed a CCS (Wolgemuth, Hicks, and Agosto 2016), which combines discourse analysis (for example, Gee 2010a) and a qualitative systematic review method called critical interpretive synthesis (Dixon-Woods et al. 2006). A CCS reviews extant literature on a topic to reveal the ways in which the topic’s constructs – people, contexts, interventions, and outcomes – are constructed via the language and style of academic research and writing. The CCS seeks to illuminate both varying understandings of the topic’s constructs (e.g. different ways of viewing autism and work) and the ways in which the research methods and the research write-up contribute to those understandings. Before describing the process we used, we provide a reflexive account depicting our initial engagement with academic language, constructs, and social constructionism.

**Reflexivity**

Although we began our conversations using ‘people first’ language (i.e. ‘students with autism’) to place the person ahead of the disability, we became concerned that this language failed to reflect our social constructionist understanding of autism as involving power and
action. We wanted our language to reflect that autism may not be best presented as a condition someone has, but a condition constructed to shape presumptions and identities about who one is/can become. Therefore, we settled on the phrase ‘(situated) on the autism spectrum’ (rather than autism spectrum disorder [ASD]) to emphasize the constructive power of language, relationships, and labels such as autism. By encasing the passive construction (situated), we allow variation and flexibility in identifying with the autism spectrum and the influences shaping that relationship. We use ‘autism,’ ‘work,’ and ‘worker with autism’ as socially constructed categories.

A CCS iteratively and reflexively involves the following phases: selecting the review topic and extant systematic review, (re)searching the literature, screening the literature, extracting data, examining the data from a discursive lens, and producing a CCS of the data. Throughout the phases of screening, extraction, analysis, and writing we reflected on our individual and collective assumptions about work and autism to attend to the ways in which our conversations and writings were also discursively constructing the ‘worker with autism.’ We reflected on the constructions we wanted to privilege – critical, discursive ones that might serve to challenge essential, humanist, and neoliberal accounts of disability and work.

**Selecting the review topic and extant systematic review**

A CCS is critical of other systematic reviews and illustrates how a synthesis done differently could yield other accounts of people, problems, and solutions. It therefore begins with a topic previously explored in a systematic review in order to reveal how the inclusion and exclusion of academic literature enables particular understandings and prevents others. We began our CCS with the topic and search strategy used in a US Department of Education commissioned systematic review of the impact of high school interventions on post-school transition outcomes for youth with disabilities (Cobb et al. 2013). This commissioned review used modified What Works Clearninghouse (WWC) review procedures and therefore sought to synthesize only quantitative research that met ‘rigorous’ validity and reliability standards. It included all disability categories and three kinds of transition outcomes: work, postsecondary education, and independent living. We chose that systematic review as a starting point for the following reasons.

First, we sought to produce a relevant and current critique. At the time, Cobb and colleagues’ review was the most recently published systematic review on employment outcomes for youth with disabilities in the United States and it relied on the WWC standards. The US Department of Education’s WWC was established in 2002 and its primary function is to identify and synthesize ‘studies that provide credible and reliable evidence’ to ‘inform researchers, educators, and policymakers as they work toward improving education for students’ (Institute of Education Sciences 2016, para 1). According to their website, the WWC has produced more than 700 reports about what works in education and has reviewed over 10,500 studies. WWC guidelines for including and excluding studies are considered by some to successfully identify studies that provide the best evidence in education (for example, Whitehurst 2012) and by others, including some of WWC’s early supporters, to be overly methodologically restrictive (Lykin 2012; Van Cleave 2012).

Second, the first author (who was ‘Deputy Principal Investigator’ on the subcontract that funded Cobb and colleagues’ systematic review) worried that of the 738 studies which passed the abstract screen, only 17 met WWC standards after the review guidelines were applied.
(with some minor modifications) to include and exclude studies. She wondered what understandings about disability and employment – and what recommendations for policy and practice – might have been enabled in a more inclusive review? These questions were the initial impetus for our current work.

Third, we chose Cobb and colleagues’ review because the detailed reporting of its search terms and inclusion criteria meant we could easily replicate its search strategy and maintain its original scope. Thus our CCS of Cobb and colleagues’ systematic review points to the limitations of methodologically ‘rigorous’ systematic reviews, such as those produced using WWC guidelines. The analysis uncovers how the processes and products of academic writing rely on constructs and underlying assumptions, which determine how arguments are framed and supported to produce what can be known – in this case, about autism and work. Critically analyzing methodologically included and excluded literature reveals how the ‘worker with autism’ story is variously told and how it can be retold to open up rather than constrain possibilities for youth to inform policy and practice.

**Literature included in the critical construct synthesis**

Since the aim of our CCS was to illuminate understandings enabled and prevented by the inclusion and exclusion of literature in a previous review by Cobb and colleagues, we augmented their search strategy by adding qualitative key terms. Our focus on autism meant we also modified the original search strategy to include only key terms associated with autism. Our revised search was run in ERIC, PsycInfo, Academic Search Premier, CINAHL, Medline, EconLit, and Business Search Premier databases. Our CCS included both empirical (quantitative, qualitative, and mixed methods) and non-empirical literature. For the purposes of our study, we focused on the literature that discussed work for ‘youth with autism.’

**Screening**

Following Cobb and colleagues’ procedures, literature was included in our review if it discussed work training and experiences for US youth (situated) on the autism spectrum in English-language journals between 1991 and 2012. Consistent with Cobb and colleagues’ systematic review, only articles that discussed work training or experiences which did or could occur during high school were included. We defined work broadly as employment, vocation, or participation in paid or unpaid labor and transition services as including career training or counseling. We considered youth as people between the ages of 13 and 22, and included literature about adults when it offered retrospective examinations of their work experiences as youth. Literature was excluded if it did not meet these inclusion criteria.

Our search yielded 13,076 references, of which 2738 contained the keywords ‘autism,’ ‘autism spectrum disorder,’ or ‘Asperger’s syndrome’ and ‘work,’ ‘employment,’ ‘vocation,’ ‘job,’ or ‘career.’ The abstracts of the 2738 references were screened, resulting in 252 references on which we conducted a full-text screen (read the entire article to ensure it met our inclusion criteria). We subjected the 62 articles that remained to data extraction, which resulted in the exclusion of 45 additional articles – because their focus was not on either youth with autism or work experiences. A total of 17 articles were included in our synthesis, two of which were eligible for inclusion in Cobb and colleagues’ (2013) systematic review – of these two, one met single-subject design standards for inclusion in Cobb and colleagues’ review.
Data extraction and analysis

Each of the 17 articles was extracted by at least two team members using a pro-forma to summarize features of the article and capture all statements about autism, work, and the worker with autism. The paired team members compared their extractions and reconciled differences.

We attempted to understand each of the articles through a close reading and textual analysis of their extractions, noting the ways in which the articles depicted autism, work, and the worker with autism. To do so we relied on several of Gee’s (2010b) discourse analysis tools, including the ‘significance building tool’ to note what the articles built up and lessened as significant and the identity building tool to note what identities the articles enabled and ‘disabled’ when they talked about autism and work.

This strategy borrows from Gee’s view that discursive ‘identities can be placed on a continuum in terms of how active or passive one is in “recruiting” them’ (2000, 104) and acknowledges Skiba et al.’s (2016, 224) critique that ‘deficit perspectives abound’ in the body of work on disproportionality in disability. By situating this research theoretically and engaging methodologically as described herein, we have taken seriously Skiba and colleagues’ (2016, 223) claim that what is needed is ‘an approach to disability research that is situated in social, cultural, and historical contexts’ and research that attends to the complexity of relationships.

We categorized autism and work into a matrix consisting of four quadrants created by two spectra: from simple to complex, and from asset to deficit. A simple construction ignored intersectionality (autism, class, race) and contained a unidimensional and easy-to-follow narrative of autism and work, while a complex construction contained multiple dimensions and intersections of autism and work – depicting them in a less than straight-forward narrative. Deficit constructions depicted autism or work in negative terms while the asset construction depicted autism or work more positively (involving assets).

To understand what the double constructions of autism and work said about the ‘worker with autism,’ we grouped the articles containing similar constructions of autism, people (situated) on the autism spectrum, and work, and asked whether there was a common story being built – and if so, how. This process resulted in two major stories: the intervention story and the complex story. The intervention story is named as such to illustrate the emphasis on methods and methodology given the consistency with which work and autism were treated where interventions were featured. We chose ‘complex story’ to capture the complexity with which work and autism were treated across a variety of methods/methodologies. Variants of these two stories are also presented and discussed. While we read the articles and conducted the extractions individually, we met weekly as pairs and a team over the course of several months to discuss and link the depictions of autism and work to broader socio-political (e.g. neoliberal, disability) and academic (e.g. post-positivist) discourses.

Results

Overall our analysis revealed two major constructions of autism, work, and the ‘worker with autism’: the intervention story and the complex story. Our categorization process leading to these constructions was based on two spectra – simple (S) to complex (C), and asset (A)
We discuss our findings in terms of the two stories we identified based on our coding of the literature, beginning with the intervention story.

**The intervention story**

The intervention story literature (seven articles) depicted youth (situated) on the autism spectrum as becoming good neoliberal subjects who would gain value when they performed independently and according to expectations. The intervention story literature described interventions such as video modeling (Allen et al. 2010; Cihak and Schrader 2008), modeling and praise (Rigsby-Eldredge and McLaughlin 1992), social, vocational, or communication skills training (Alpern and Zager 2007; Burke et al. 2010; Hillier et al. 2007), and behavioral training (McClannahan, MacDuff, and Krantz 2002). This literature presented interventions as a set of bounded procedures that, if mastered, promised to transform youth on the autism spectrum into useful people. The language ‘intervention’ alone suggests that something is needed to remedy a known problem with an unquestionably desired outcome. In the following we describe how our literature told the intervention story and entailed constructions of autism, work, and the ‘worker with autism.’

In our sample of articles, the intervention story began with a biologically based, deficit construction of autism. For example, the first paragraph in Rigsby-Eldredge and McLaughlin begins:

> Autism is an organic neurological disorder that interferes with normal development of reasoning, social interaction, and communication skills (Schreibman, 1998). The prognosis for treatment of such children and youth remains quite poor (Schwartz & Johnson, 1985). (1992, 205)

Next, the intervention story narrowed autism to one or more deficits portrayed as challenges or difficulties in the workplace. That is, autism was constructed in these articles as an inherent inability to work. In their study of a vocational skills support group, Hillier and colleagues explain that the lack of ‘ability to form age-appropriate peer relationships’ amongst individuals with high-functioning autism and Asperger’s syndrome results in ‘social isolation and vocational failure’ (2007, 107). Within this simple argument, framing autism as a lacking of ability, the intervention story described the nature of work similarly – as narrow and simple. Work involved a discrete set of tasks such as copying papers (Cihak and Schrader 2008), raking leaves (McClannahan, MacDuff, and Krantz 2002), or moving the arms, tails, and eyes of a ‘Rocky Raccoon’ mascot costume:

> To wear the WalkAround costume, the participants strapped on a belt that supported a battery pack and mechanical blower that weighed about 14 lbs, then stepped inside the uninflated costume … The costume was also equipped with cloth strings hanging down from inside the head that, when pulled, could move the tongue, ears, and eyes. (Allen et al. 2010, 341–342)

Some intervention story articles explicitly described the importance of work and framed qualities of youth on the autism spectrum as desirable among employers. Burke and colleagues, for example, stated:

> Not only is employment important for people with ASD, these individuals typically have cognitive abilities and job skills that employers values such as attention to detail, trustworthiness, reliability, punctuality, the ability to follow directions, and dependability … (2010, 1232)

Although Burke and colleagues’ comments on ‘people with ASD’ were asset oriented, their skills and abilities (e.g. attention to detail) were only considered assets to the extent they
were valued by employers. Most other articles, however, appeared to assume any kind of work was a good without explicitly arguing the case.

The intervention story articles then proceeded to describe procedures consistent with the features of post-positivist inquiry (e.g. parsimonious selection of variables, exploration of causal relationships among variables, and statistical testing and/or reporting of findings). Of the seven articles, four used single-subject designs and three were quantitative program evaluations or descriptions. All articles discussed the impact of interventions on observable and/or measurable outcomes, and most drew on behavioral theory to frame the interventions.

In all articles, the interventions were found to remediate inherent deficits of autism in order to produce independent workers, even though the interventions might not be ‘cost-effective’ (Burke et al. 2010) or eliminate all deficit behaviors (for example, Allen et al. 2010). When the intervention did not work as well as expected, some authors attributed the lack of impact to imprecise measures (Hillier et al. 2007). Most, however, explained the failure of the intervention in terms of deficiencies of the person as opposed to limitations of the training or nature of work: ‘Participants would occasionally become preoccupied with one particular target skill (e.g., waving) while neglecting others, which is not surprising given the propensity for preoccupation with topics, routines or repetitive behaviors evident for this population …’ (Allen et al. 2010, 346).

When the intervention worked well, authors attributed the success to features of the program and context. Rigsby-Eldredge and McLaughlin, for example, said: ‘It may be that the positive history that these subjects [youth situated on the autism spectrum] had with school staff allowed this intervention to be so powerful’ (1992, 216). That the tasks taught or the jobs might be menial or temporary was not always missed by the authors, but in keeping with neoliberal assumptions about the value of independent work some argued that even unpaid, part-time work prepares ‘workers with autism’ for the promise of future employment. Burke and colleagues stated:

... while ‘mascoting’ can result in full-time employment for a select few (e.g., theme park mascots, professional sports mascots, etc.), for most it will not. Still, individuals employed as part-time mascots may develop vocational skills (e.g., following directions, being prompt, preparing for work tasks) and establish a work history that can serve as a stepping stone to life-long full- or part-time employment elsewhere. (Burke et al. 2010, 1231)

What we are calling the intervention story is readily found in the post-positivist studies included in most systematic reviews and meta-analyses typically valued by policy-makers. Indeed the only studies included in both our CCS and Cobb and colleagues’ (2013) systematic review were of the intervention story type (Allen et al. 2010; Cihak and Schrader 2008). However, one study (Cihak and Schrader 2008) strayed somewhat from the pattern we described earlier. This variant of the intervention story shows how post-positivist-leaning intervention research might be written in a way that avoids deficit depictions of youth (situated) on the autism spectrum.

**Intervention story variant: focusing on assets and benefits**

In contrast to the intervention story articles we coded as SD (constructing autism in simple, deficit terms), Cihak and Schrader’s (2008) article presented a simple, but decidedly more optimistic construction of autism (SA). Their intervention story began by describing the intervention as an effective way to teach desired behaviors or skills to people with disabilities:
The use of video is a relatively new genre of visually based treatments that hold promise for individuals with disabilities (2008, 9). Because the argument for the study focused on the intervention and its potential usefulness, the authors did not need to position the intervention as remediating a problem located in people (situated) on the autism spectrum. In this variant of the intervention story, autism was not constructed as a set of deficits in need of remediation. While the article still described autism and work in simple terms, and the overall aim remained well aligned with neoliberal accounts of the useful worker, the worker (situated) on the autism spectrum was discursively produced as somewhat more asset oriented (as characterized by an affinity for visual learning). The authors suggested that video modeling may be effective for anyone who identifies as a ‘visual learner.’ By positioning autism as perhaps less ‘abnormal’ among deficit discourses (when compared with people without disabilities), the argument decreased the social distance between ‘neurotypicals’ and those (situated) on the autism spectrum.

**Intervention story variant: gesturing to the complex work environment**

In contrast to other intervention story articles whose depictions of work we coded as SA (simple, asset), Keel, Mesibov, and Woods (1997) described work with more complexity (CA), as an array of employment contexts in which the intensity of support relates to the ability of the youth (situated) on the autism spectrum to demonstrate independent performance. In the context of the Treatment and Education of Autistic and related Communication Handicapped Children and Adults (TEACCH) supported employment program:

> Job placements are based on individual strengths and interests of the clients with autism. Consequently, there was diversity in the types of work settings associated with TEACCH’s supported employment program; however, less diversity than in a group of normally developing individuals who would have a wider range of interests and skills. (Keel, Mesibov, and Woods 1997, 6)

The authors also considered different factors associated with successful work placement (jobs are predictable, employers and coworkers are willing to learn about autism, and work tasks are clearly defined with few distractions) that further constructed work as more complex than mastering a series of discrete tasks.

We read this wide array of activities in which the person (situated) on the autism spectrum might participate as a complex treatment of work, yet is tempered by the simple and deficit construction of autism. That is, while work and environment were complex, the person (situated) on the autism spectrum was portrayed as deficient in their ability to manage that complexity: ‘Most people with autism are able to handle a variety of tasks within their jobs as long as there is a predictable routine or schedule to follow and what is expected is clear to them at all times’ (Keel, Mesibov, and Woods 1997, 6).

Supported employment in this intervention story variant emerged as the *dues ex machina* through which the complexity of work can be managed:

> Even when clearly defined work tasks and work areas do not exist naturally at the job site, TEACCH staff are often able to restructure tasks and work areas to meet the needs of the person with autism if an employer is supportive. (Keel, Mesibov, and Woods 1997, 6)

Our analysis of this variant suggests to us that any hopeful, expansive construction of the ‘worker with autism’ depends on complex and asset constructions of work and autism, and a de-emphasis of the god-like nature of The Intervention. We found these more hopeful constructions in the complex story and its variants. Before introducing the complex story
variants, we show how the literature told the complex story and entailed constructions of autism, work, and the ‘worker with autism.’

**The complex story**

In contrast to the intervention story and its variants, the ‘complex story’ depicted both autism and work complexly and as assets, whose value was mediated in context amid various intervening factors and conditions. Autism was depicted as a condition involving unique and varied skills and interests, whereas work was also depicted complexly – as a job or a career that changed over time and was affected by the social environment of the workplace. The complex story was featured in articles on program evaluations and reviews of literature but most often in articles using the descriptive case-study method (Furniss 2009; Nuehring and Sitlington 2003) or crafting a conceptual argument (Chappel and Somers 2010; Grandin 2006; Hurlbutt and Handler 2010; McDonough and Revell 2010).

**Autism**

Different from the intervention story, the complex story articles suggested to us that educational programs and trainings could build on unique strengths of people (situated) on the autism spectrum, and their inclusion in the world of work could benefit them and those with whom they work. Even the information authors extracted from medical reports focused on abilities beneficial and relevant to work expectations:

> he has fair muscle strength and he could walk independently. He is able to lift heavy objects, walk long distances, twist, stoop, and climb. He has some fine motor skills but works better with larger objects and gross motor movements. (McDonough and Revell 2003, 98)

Across these seven articles, attributes associated with autism were described without using medical terminology.

Unlike the intervention stories that emphasized autism as a condition inherent in people, the complex stories focused on transition services and barriers to receiving them. Complex stories treated autism as a state of arrangements, affected by relationships (between people, conditions, and expectations), and negotiated rather than accepted as inherently a condition of deficit and asset. However, the deficit perspective avoided by McDonough and Revell (2003) was evident in the other articles coded as complex stories (Chappel and Somers 2010; Furniss 2009; Grandin 2006; Hurlbutt and Handler 2010; Nuehring and Sitlington 2003).

**Work**

In the articles labeled as complex and asset (CA), discussions of work resembled the definitional continuum described by Prideaux and colleagues (2009) in which work was defined singularly at one end of the continuum (as purely contractual) and multiply at the other (as including the range of ways in which humans make effort an endeavor). To expand the construction of ‘work’ beyond the industrial type (aimed at gain through exchange), Prideaux and colleagues added progressive, majority world, and post-welfarist types. These types of work were useful to understanding how work was constructed alongside autism.

For instance, Nuehring and Sitlington (2003) conducted a multi-case study of high school students engaging in two forms of transitional work, community-based and center-based (facility/in-house provider), which occurred along a continuum of sites offering a range of supports from sheltered (vocational learning) to competitive employment. They described
some forms of transitional work as learning experiences rather than exchanges of labor for payment. Likewise, Furniss (2009) described an art career as one that can involve public advocacy. She further positioned art and advocacy as a social good and the participant (Benjamin as artist) whose relationships with galleries and sponsors could entail economic arrangements, as capable of exchanging of labor for wages. Her suggestion that Benjamin should be supported to continue participating in art exhibitions aligned with Prideux and colleagues’ post-welfarist and majority world types of work involving social exchanges and a range of informal and formal activities. Resembling post-welfarist type of work, Furniss discussed art exhibitions as potentially being accompanied by gallery contracts that are fulfilled through the artist’s abilities ranging from producing works of art (for social and/or economic exchange) to raising social awareness through advocacy.

‘Worker’ with [(situated) on the] ‘autism’ [spectrum]

Among the complex story examples, four forwarded a conceptual argument supported by descriptions of the program, services, or skills associated with work performance. Whether through first-person (Grandin 2006) and/or pedagogical accounts (Grandin 2006; Hurlbutt and Handler 2010), relationships were central to the construction of the ‘worker with autism.’ For instance, relationships among people, school systems (Chappel and Somers 2010), or community-level and state-level resources (McDonough and Revell 2010) were instrumental in setting the conditions for work and therefore how workers (situated) on the autism spectrum relate. While work was generally presented in this literature as an asset, the experience of working was contextual and responsive to a multitude of factors that shaped ideas about how and why work mattered for a broad network of actors (gallery owners, transition specialists, vocational rehabilitation partners, community liaisons, school district administrators, state-level politicians). The complex story variants differed from the complex stories in that each featured a case-study approach that provided detailed contextualization, centered on the learner/student, or attended to diversity in practice.

Complex story variant: detailed contextualization using case-study methodology

Of the complex stories only one was a case-study report (Precin 2010). Inherent in a case-study approach is contextualization, which challenges singular and simple accounts of people as a compilation of strengths or limitations. We coded it as CD (autism), CA (work), and CA (worker on the autism spectrum) – with CD noting that a deficit view (of autism) was relayed through the repeated use of the term ‘deficit’ as in ‘Individuals with ASD also have been shown to have deficits in mental flexibility …. ’ (Precin 2010, 373). The author framed work for the worker on the autism spectrum amid a variety of conditions and a complex set of attributes, interventions, and relationships. For instance, visual imagery was described as helping ‘S’ properly sequence and focus on the task as well as increasing his boss’s tolerance of his work performance (Precin 2010). By describing the multiple conditions and attributes involved in S’s improved performance (i.e. social relationships, self-reporting, programming, medication, training, tolerance), the author challenged the construction of autism as a condition inherent in the individual preparing to work.

Complex story variant: center on the learner/student

Our analysis of the article by Geller and Greenberg (2010) resulted in both autism and work being coded as relying on an asset and deficit perspective, with autism coded as CA/D and
work coded as SA/D. Additionally, this coding reflects complex treatment of autism and simple treatment of work that in combination we perceived as positioning the worker on the autism spectrum within a complex and asset-oriented narrative. Straddling between an asset and deficit perspective, and a simple to complex story, is illustrated by a quote depicting life on the autism spectrum as difficult due to contrasts in characteristics and unevenness in assets and deficits: ‘It is these contrasts, this uneven profile of strengths and impairments that make the transition to adult life so difficult (Grandin and Duffy 2004)’ (Geller and Greenberg 2010, 93). This quote draws on Temple Grandin, an author whose publication from 2006 is part of this sample and included as an example of a complex–asset narrative. In citing Grandin, the authors drew support from someone (Grandin) describing their personal experience of being a worker (situated) on the autism spectrum. They therefore modeled their core argument, which was to ‘start where the client is’ – the individual learner/student.

**Complex story variant: pay attention to diversity in practice**

We coded two articles in the sample (Geller and Greenberg 2010; Hendricks and Wehman 2009) as having both/and constructions (C/SA: complex and simple assets) for the three areas: autism, work, and the ‘worker with autism.’ In the literature review by Hendricks and Wehman (2009) the inquiry was similar to that of Geller and Greenberg’s (2010) treatment of youth transitioning into the workforce, citing the second author (Wehman) from an earlier publication: ‘Effective transition planning provides the opportunity for adolescents to learn about themselves and plan for their futures. This requires student involvement as an active, respected participant and preferably as a team leader (Wehman, 2006)’ (Hendricks and Wehman 2009, 79). This quote suggested to us that a learner-centered approach to transition was being recommended by calling for the inclusion of multiple perspectives in efforts to support the transition of youth into the workforce (focus on achievement, planning, supports and services, goals, and implementation). Repeatedly, the authors encouraged diverse approaches from an asset perspective. For instance, they wrote: ‘Because there is not one single most effective method that works for all individuals on the spectrum (Helfin and Simpson, 1998; NRC, 2001), rigorous research on a variety of practices is needed’ (Hendricks and Wehman 2009, 83).

Additionally, we coded work as both/and (simple/complex asset: S/CA) because the authors described work as a physical and cognitive task, and as a social experience. They stated: ‘According to self-reports, vocational success is not contingent on completing job duties but lies in the social aspect of employment (Hurlbutt and Chalmers, 2004; Müller et al., 2003)’ (Hendricks and Wehman 2009, 81). They cited Hurlbutt whose 2010 article we coded as a complex story but with instances of a simple narrative operating in the treatment of work – as simple and complex.

**Conclusion and discussion**

In her 2002 book The Body Multiple: Ontology in Medical Practice, Annemarie Mol details how atherosclerosis shifts and takes on different meanings when subject to the varied gazes of medicine. Rather than signaling a fragmented body, Mol shows how the disease is recouped in a body multiple, made to cohere through the transportation of documents, viewing of images, and conferences. Our analysis revealed a similar phenomenon of the ‘worker with
autism’ in academic literature – depending upon the purpose, methods, and focus of the article, a different kind of autism was constructed, entailing a different kind of worker and support for transition to work. The unifying feature of these constructions was found in the argumentative structure of the academic articles. Characteristic of the intervention story was how the ‘worker with autism’ was made to cohere by centering autism as the problem or issue at hand, in need of specialized support, treatment, and/or understanding in order to render the worker with autism useful, productive, and/or happy in the work setting. The more complex accounts of autism invited broader notions of work, yet some were steeped in a neoliberal discourse – associating work with independence and privileging ‘competitive’ employment over ‘sheltered’ and ‘supported’ employment. Notable was the absence of literature that avoided pitting independence and support in opposition.

Whether identified as an ‘intervention’ story or a ‘complex’ story (or variant), most of the articles in our review unproblematically advanced neoliberal assumptions about the moral obligation of citizens to become less dependent on, and therefore present less of a burden to, the state (Ben-Moshe et al. 2009). Only a handful of articles (for example, Furniss 2009; Hendricks and Wehman 2009; Hurlbutt and Handler 2010; Precin 2010), all of which were identified as ‘complex’ stories (and variants), advanced notions of the worker (situated) on the autism spectrum in ways that avoided depicting (state-supported) independent work as a regulatory ideal. These articles described work competence as constructed in social interactions beyond mere efficiency or productivity.

In McKenzie’s (2013) terms, the articles understood work competence through (poss)ability; as a continuous search by multiple supportive actors for enabling contexts in which competence could emerge. The enabling context associated with (poss)ability is not inherently impervious to being co-opted in support of an enabling state. However, its emphasis on interactive discourse troubles singular and simplistic accounts of worker’s competence and compensation. Additionally, its emphasis on context and actors challenges the fixity of constructs (i.e. work, autism) as either conditions or (enabling) states. One might preface responses to the question of what works in transition research with statements such as ‘under these conditions’ and ‘with the support of,’ and provide rich description of the context (Donmoyer 2012), to further challenge understandings of work as individual labor (for pay) and transition to work as the practice of reducing (human, capital) deficits.

Alongside Mallett and Runswick-Cole (2012) we worry about the increasing academic fascination with and commodification of autism. Our CCS of the literature about work for youth (situated) on the autism spectrum did little to assuage our concerns. Of the 17 studies included in our CCS, only two were part of Cobb and colleagues’ (2013) systematic review. We coded both as intervention stories. We suggest that Cobb and colleagues’ exclusion of complex story accounts forwards a limited understanding of autism and advances neoliberal accounts of work as task oriented, ideally (state) independent, and involving monetary exchange. It positions youth (situated) on the autism spectrum as bad neoliberal subjects – unreliable, unsociable, and low-quality workers in need of training to render them useful, productive, and accountable. Policy-makers and educationalists looking for answers to ‘what works’ to transition youth with autism from school to work in that report will find answers narrowly constrained to the structure and assumptions of the intervention story that are unlikely to advance complex accounts of personhood and labor or to conclude, for example, ‘what works’ is supported or unpaid work as a human right (Tororei 2009).

We conducted a CCS to bring to light and critique tacit assumptions about work and autism in the academic literature to show the productive power of academic writing, the
dangers of some ways of writing-up accounts of research, and to potentially identify connections between research methodologies and constructions. Intervention stories were most often told to communicate the results of single-subject or group design studies, but at the same time our analysis identified promising variations. While quantitative research is often criticized for post-positivist ontological assumptions that separate ‘researchers’ and ‘subjects,’ we noted some examples of positivist research that resisted narrow and deficit constructions of students situated on the autism spectrum (for example, Cihak and Schrader 2008). We therefore do not suggest that the types of stories we identified in our CCS are inherent to the types of studies conducted. Given these findings we recommend that academics experiment with alternative ways of conceptualizing autism, interrogating its assumptions about work, and framing discussions in a way that expands, rather than limits, the work and career possibilities for youth and adults (situated) on the autism spectrum. The matrix and types of stories offer some guidance on how types of writing can be created regardless of the type of study conducted.

At the same time, we recognize that the discursive assumptions about disability and work advanced in scholarship are both produced by and productive of an article’s writing style. Manuscripts most likely to challenge neoliberal accounts of work, offering more positive and complex accounts of work for youth (situated) on the autism spectrum, are those that draw their understandings of work and disability from scholars such as McKenzie (2013) who theorize disability and work through poss(ability), rather than promote disability as a unitary, deficit status. We hope our CCS, and the literature we drew on to frame our critique, serve as a reminder to academics involved in the study (and construction and commodification) of autism of the complexity of personhood and labor, even as neoliberal reforms and globalization press us for a simple narrative of work as necessary, desirable, and natural.

We acknowledge we have fashioned a story about the worker (situated) on the autism spectrum enabled by a social constructionist understanding of disability advanced in ‘critical disability studies’ literature. Others might analyze our article for its contribution to the discourse about transition for youth, autism, and work. The type of story this is can be determined in part by analyzing what we have framed as a problem (the academic literature), the variations or alternatives in the methods we used (discourse analysis, matrices, systematic review processes), and to what we attributed asset and deficit perspectives (constructions of autism and work). One might also consider our intent. In that regard, our aim was clear: to contribute to the expansion of work and career possibilities for youth and adults situated on the autism spectrum and ensure that such possibilities offer them a wide range of opportunities, supports, and benefits. To that end we have modeled how the CCS can promote an interactive discourse of (poss)ability to help policy makers rethink their what-works questions through contextualizing them (Donmoyer 2012); by asking who works, works for what, works for/with whom, and how (academic) work(s) work?

Notes

1. For example, educational research exerts its influence through the US Department of Education’s What Works Clearinghouse (WWC) whose goal is, although synthesizing studies it deems credible and reliable, to be ‘a central and trusted source of scientific evidence for what works in education to improve student outcomes’ (Institute of Education Sciences 2016, para. 2).

2. Articles that discussed work in the context of post-secondary education, for example, were not included in our review (see, for example, VanBergeijk, Klin, and Volkmar 2008).
Acknowledgement

The authors would like to acknowledge Deann Trevathan for her editorial assistance.

Disclosure statement

No potential conflict of interest was reported by the authors.

References


Review articles, types and categorizations

*(S=Simple, C=Complex, D=Deficit, A=Asset)*

**Intervention stories**


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SA


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SA


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SA


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SA


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SA


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SD/A

**Intervention story variants**


Work=SA, Autism=SA, Worker (situated) on autism spectrum=SA


Work=SD, Autism=SA, Worker (situated) on autism spectrum=SA

**Complex stories**


Work=CA, Autism=CA, Worker (situated) on autism spectrum=CA


Work=CA, Autism=CA, Worker (situated) on autism spectrum=CA


Work=CA, Autism=CA, Worker (situated) on autism spectrum=CA
Work=CA, Autism=CA, Worker (situated) on autism spectrum=CA
Work=CA, Autism=CA, Worker (situated) on autism spectrum=CA
Work=CA, Autism=CA, Worker (situated) on autism spectrum=CA

Complex story variants

Work=CA, Autism=C/SA, Worker (situated) on autism spectrum=CA
Work=CA/D, Autism=SA/D, Worker (situated) on autism spectrum=CA
Work=CD, Autism=CA, Worker (situated) on autism spectrum=CA