

COMPREHENSIVE SUPPORT MODELS

МОДЕЛИ ОРГАНИЗАЦИИ КОМПЛЕКСНОЙ ПОМОЩИ

Employment in Autism: Reflections on the Literature and Steps for Moving Forward

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Reflecting an address given at the Autism Challenges and Solutions International Conference in Moscow in April 2019, this paper reviews selected studies within the author's program of research as well as selected literature addressing pathways to employment for adults with autism. A range of employment support programs are considered, representing promising approaches. Attention is given to environmental elements that appear to have a bearing on individual employment experience and outcomes. These elements point to a person in environment approach which is increasingly supported by emerging evidence. This approach is conveyed as the employment ecosystem, with constituent elements that include the individual (employee or potential employee), family, employer, co-workers, work setting, community services, and embedded labor, health and disability policy. These various components of the ecosystem offer relevance in terms of understanding employment options and experiences of autistic adults. Recommendations for advancing this field are offered.

Keywords: autism spectrum, autistic, employment, quality of life, ecosystem.

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Трудоустройство людей с РАС. Анализ исследований и шаги для дальнейшего развития

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Эта статья написана по итогам VII Международной научно-практической конференции «Аутизм. Вызовы и решения» (Москва, апрель 2019 г.). В ней представлен обзор некоторых работ в рамках исследовательской программы автора, а также избранные обзорные статьи, посвященные созданию возможностей для трудоустройства взрослых с расстройствами аутистического спектра (РАС). Рассмотрен ряд программ с перспективными подходами по повышению занятости людей с ограниченными возможностями. Особое внимание уделяется элементам окружающей среды, оказывающим влияние на полученный опыт и достигнутый результат трудоустройства. Элементы указывают на использование подхода на основе учета интересов человека в окружающей среде, эффективность которого все чаще подтверждается новыми данными. Этот подход выражается в экосистеме занятости, компонентами которой являются сам человек (работник или потенци-

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альный работник), его семья, работодатель, коллеги, рабочая обстановка, социальные службы и политика в отношении труда, здоровья и инвалидности. Для понимания вариантов трудоустройства и соответствующего опыта взрослых с РАС имеют значение все компоненты экосистемы. В работе предложены рекомендации для развития данной сферы.

Ключевые слова: аутистический спектр, аутичный, трудоустройство, качество жизни, экосистема.

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Reflecting a presentation offered at the *Autism Challenges and Solutions International Conference* in Moscow on April 8, 2019, this paper reviews selected research addressing employment experiences and outcomes for adults with autism. Promising support interventions in the field are considered, with employment being positioned as reflective of an array of contributing elements within the broader community and system at large.

Background

Several recent systematic reviews have examined employment programs and interventions for adults with autism. Taylor et al. [17] examined vocational interventions for individuals with autism aged 13 to 30 years, and found only a few studies, with the authors noting them as being poor quality. A synthesis review by Nicholas et al. [8] also found a limited number of studies and concerns over methodological quality, but noted the literature addressing supported employment in community settings appeared promising. A subsequent systematic review by Hedley et al. [3] on employment programs for adults with ASD also raised concerns with study quality, with studies generally reporting positive outcomes.

Despite this emerging evidence demonstrating means to support employment in the autistic population, there continues to be overall low employment rates and reported dissatisfaction about employment prospects among autistic individuals themselves [9]. As an example, the Canadian employment rate for adults with autism is unacceptably low at only 14.3% for individuals over 15 years of age [19]. Of further concern, those who are employed are often engaged in short-term and low-paying jobs, and some may not find their work to be meaningful or satisfying [7; 12; 16].

In seeking improved employment prospects, a recent roundtable discussion consisting of expert stakeholders in the autism employment field [11], addressed proposed steps forward. Discussants recommended a strengths-based approach to employment support by acknowledging what each autistic individual offers, and their preferences, goals, and support needs to reach their potential—all while aiming to change the environment to nurture employment success. Suggested aims were the development of inclusive communities and workplaces, and recognition of how employment connects to the individual's life and wellbeing, and the importance of developing careers as opposed to focusing merely on job acquisition [11].

Khayatzadeh-Mahani et al. [6] reported similar findings, noting barriers for autistic individuals such as not being exposed to work as early as their peers, a lack of employer knowledge about autism, stigma, insufficient capacity, and non-helpful workplace policy. Recommendations included the alleviation of potential disincentives to work, increased employment opportunities, and more employment education in high school. Of top priority among participants, Khayatzadeh-Mahani and colleagues [6] identified the need to address, “employers’ knowledge, capacity, attitudes, and management practices” [6, p. 4]. The authors recommended employer training aimed at building knowledge around inclusion, with a suggestion to commence this training in school, which could also have a broader societal impact.

Nicholas and Klag [12] called for shifts in the focus of employment supports and related policy. They noted that many support programs focus on obtaining employment as a sign of success, which often includes shorter term employment. Despite initial positive outcomes, this can potentially lead to future concerns such as a potential cycle of short-term employment that may be seen as less desirable by future

employers [12]. Furthermore, this cycle of *on-and-off-again* employment can leave gaps in an individual's income. Seeking longer-term employment is suggested, including sculpting jobs to an individual's strengths and interests, engaging employers and co-workers in employment support, and an earlier introduction to employment opportunities. Nicholas and Klag further suggested that services need to offer greater focus on building individual capacity in soft skills (e.g., social reciprocity), and be sufficient enough to alleviate reliance on family members who currently may feel compelled to provide employment-related support due to a lack of services. Finally, a more holistic view of employment is invited, with the ultimate goal of attaining a 'good life' in terms meaningful to the autistic individual [12].

In qualitative interviews with young adults with autism and their parents, the importance of addressing family involvement along with other intersecting systems such as schools, service providers, and employers was raised by participants [1]. Anderson et al. [1] found that, "many barriers to employment had less to do with a young adult's characteristics and more to do with larger systems and external realities, including prejudice, organizational inflexibility ('we do not just hire for little niches'), and lack of services" [1, p. 11], including a need to examine young people's experiences in high school and how these experiences could be improved.

Despite advances in employment opportunities and support for people with autism, gaps and challenges exist in this field, and high unemployment rates remain. This paper documents promising developments in the literature, and highlights a broader *ecosystem* approach. Specific aims of the paper are to: 1) explore selected employment support initiatives, and 2) examine the emerging ecosystem perspective within employment in autism. Below is a review of selected literature, along with research reflections related to employment among youth and adults with autism. We seek to amplify core elements of employment and employment support that may increase the likelihood of autistic adults finding and maintaining employment.

What is the Employment Ecosystem? An Analogy for Navigating Employment

An *ecosystem* is defined as "a biological system composed of all the organisms found in a particu-

lar physical environment, interacting with it and with each other" [2]. In our program of research, participants have conveyed employment somewhat akin to a walking path on a steep ascending slope that is overgrown with encroaching foliage as well as bumps and crevices on the pathway. At one point long ago before its metaphorical and hypothetical development, there presumably was no path; rather, it was created through mutual effort on the part of many over time – by intention, design and toil which cumulatively opened space to traverse the challenging terrain. Yet the path, as constructed in this analogy, may be less than ideal; even largely impassable hence, potentially unfunctional.

Extending this image to the real and often arduous *uphill journey* to employment access and sustainability, autistic adults in our research have often conveyed the path to employment as daunting and anxiety-producing. For too many adults, the path is hewn with barriers akin to large rocks, deep crevasses and bumps that can render it impassable, with meaningful work seemingly unattainable. Un- or under-employment is borne out by population-based statistics internationally. Our pressing task, as advocates, employers, service providers and researchers, is to innovate ways to overcome and decrease barriers on the path to and within employment.

Accentuating the urgency for rapid advancement in employment access for autistic adults, the first-hand experiences of autistic adults, their family members and service providers in Canada were collated and reported elsewhere [9]. In that study, participants conveyed the need for further resources and service shifts related to greater employment access and integration in their community, including the need for ancillary resources (e.g., transportation, mental health support, housing). Our research to date, as well as that of others in the field, has identified similar needs for enhanced employment-based service to autistic youth and adults along with additional elements such as community and workplace supports – all integral for sustained employment success. Below are some examples of promising employment support initiatives reported in the literature and discussed in the Moscow session, followed by a reflection on broader community factors that cumulatively may advance employment options for adults with autism.

Promising Employment Support Programming

As reported and reviewed by others [3; 10], we briefly reflect on international examples described in the literature; two programs from the United States, one program from the United Kingdom, and one program from Canada:

Based in the United States, the TEACCH Program® offers training and job coaching in the environment in which employment is occurring. Over a period of approximately 10 years, over 100 individuals were served, with 96 placed in jobs and an 89% job retention rate [5].

Project SEARCH® is an internship program for youth in the final year of high school that offers a range of supports including environmental support. It has been offered at multiple sites in North America. Eighty-eight percent of the youth evaluated in these reviews went on to competitive employment versus 6% of youth who received basic services according to a more standard education plan called an *Individualized Education Plan* [13; 18].

Based on an early report from the United Kingdom in 2005, the National Autistic Society (NAS) Prospects Program reflects a supported employment service model. A 68% success rate was reported, through job placement in 192 jobs over an 8-year period, along with employer capacity building [4].

An integrated support approach was implemented by a Canadian program entitled, *Employment Works* (EW), an employment support resource aimed at improving job readiness for individuals with autism, while also supporting the capacity of employers and communities [10]. Positive program outcomes included individual skill development, capacity building among employers, and bolstered engagement and receptiveness of coworkers. Autistic individuals and their coworkers/employers were engaged together in onsite experiences and mutual learning, and these relationships were reported to be pivotal to capacity building. Engagement of employers in the program reportedly led to shifts in thinking, and provided the space to confront preconceived negative notions and stereotypes, which led to increased intention to hire autistic individuals [10].

Cumulatively, the reported outcomes of the various initiatives across world regions demonstrate that working with individuals and colleagues in the aim of supporting employment appears promising, although in some cases, more robust evaluation is advised [3; 8; 17].

Seaman and Cannella-Malone [14] reviewed vocational skills-based interventions that offer employment-related skills that enable individuals with autism to become more ready for employment. They described 3 groups or types of intervention. The first group was focused on pre-employment services (all 3 interventions were based at universities, and not at workplaces). The second reviewed group of 14 studies consisted of programs that supported capacity in completing tasks of work, and of these, 13 studies used technology such as handheld devices that electronically cued or reminded the individual about aspects for success in the workplace. Of these studies, 7 studies were based at universities/schools while 7 were in workplaces. The third group in Seaman and Cannella-Malone's [14] review consisted of 4 studies that focused on job retention, with several using technology applications. An important distinctive feature of this work is its focus not only on *finding* a job, but also *keeping* a job.

Gaps in employment support based on this review were noted [14]. Specifically, there was an identified lack of pre-employment skill development (e.g., core skills, resume writing, interviewing, occupational focus, motivation) and fewer resources that support job retention. A challenge for many people with autism that warrants greater support in service delivery was reported as the navigation of social interaction such as social reciprocity and engaging in dialogue [14]; indeed, requisite skills in many jobs.

In summary, we are learning from emerging studies and secondary reviews of the literature, that acquiring the skills for success in the workplace for some with autism requires a range of supports and other structures. Time to try varying jobs and workplace experiences may allow greater opportunity to consider what types of employment or employment sectors and fields, best suit and appeal to the individual. This collective work cautions against individuals being slotted into a particular job; and rather, supports an approach of methodically planning and sculpting jobs based on who the individual is and in what role and setting they may vocationally thrive.

While substantial gains have been made in the last decade, there seemingly is a long way to go. Attaining substantial and sustained gains in employment rates for this population will likely not only require the work of employment support personnel, but also a range of mutually supportive ecosystem components applying collective effort.

Dr. Paul Shattuck and Anne Roux [15] astutely argued, “Unemployment is not just an individual predicament, it is a social problem. Social problems cannot be solved entirely through a focus on modifying individual behaviors and abilities, although this is certainly an important pursuit. We also need to examine the social environment and the impact of interventions targeting a community or policy level” [15, p. 246].

As conveyed in this literature, proactive action at individual, employer, community and societal levels is invited. If parts of *the whole* are lacking, it is suspected that the path to sustained and generative employment may be that much more challenging – just as the rocks and debris on the metaphoric ascending pathway can block and impede steps forward.

Stakeholders on the Path to Employment

As illustrated in *figure*, the employment ecosystem has increasingly been identified in recent research [1; 6; 10]. It variably consists of the job seeker or employee as well as community resources, employment support assistants, employers, coworkers, and informal supports including family members and the community. Beyond these individual

and community-level factors, the suite of education, labor and disability policy and societal values within a jurisdiction, may foster or conversely impede a pro-employment, inclusive context. It seems that if we are to substantially increase job access and retention, we need to pay attention to the complementarity versus dissonance of needs relative to resources within a given jurisdiction. As noted at the bottom of *fig.*, elements of time and context (e.g., earlier exposure to employment options, economic conditions, geopolitical considerations, housing sufficiency and affordability) may impose facilitative and/or impeding influencers that may have a bearing on employment prospects. As an example, at the time of the writing of this manuscript, the COVID-19 pandemic had dramatically impacted countries around the world. Consequent closure of many workplaces and services, as well as requirements of social distancing and other pandemic-related restrictions, are vivid examples of a global contextual condition, with impacts on employment prospects and experiences for autistic individuals and others.

The layered and intersecting components of the employment ecosystem lead us to conclude that the achievement of employment is not *just getting a job*. Rather, it entails contributing factors such as people, services, systems and broader conditions that play a role in the achievement of sustained em-

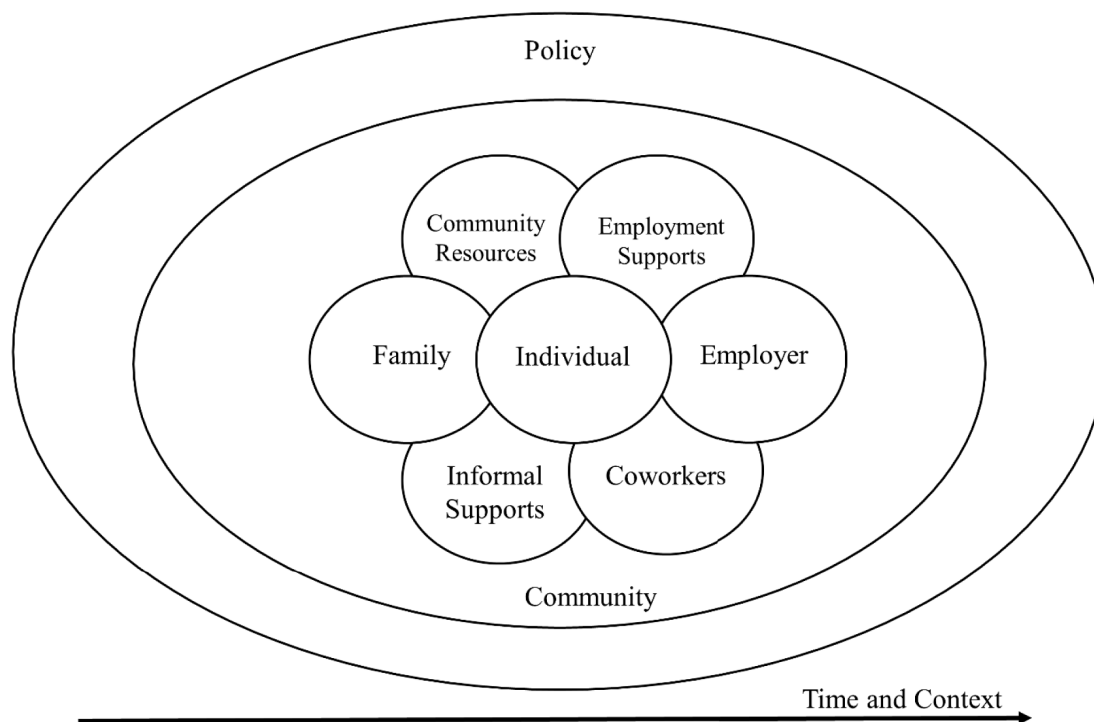


Fig. The Ecosystem: Components Nurturing Employment

ployment (or lack thereof). Adding to these components, social and ancillary conditions associated with the Social Determinants of Health, such as poverty, transportation challenges, a lack of social support, and co-existing mental health or health issues, may impede prospects of employment, thereby warranting concerted supportive strategies at individual, community and population levels [12].

Some Considerations and Recommendations in Moving Forward

This research invites action at individual, community and societal levels. At the individual support level, sufficiency of resources for employment access and career planning as well as assistance *in the workplace* for autistic youth and adults are needed. Within the employment sector, training of employers and co-workers may heighten understanding and ultimately work opportunity for autistic employees. Pro-diversity organizational and societal policy may need bolstering to ultimately achieve infrastructure supporting inclusive employment. Proactive policy and resources such as health and mental health coverage and services to encourage wellness and quality-of-work-life are important features of a sustained inclusive employment workforce.

Research Implications

Emerging from this review, greater engagement with autistic youth and adults seems warranted in better understanding their *first-person* needs and priorities for advancing inclusive employment, supportive work environments and broad-based systemic change. Examining autistic adults' work and life journeys both in moving toward, and within, employment, importantly may amplify facilitative and impeding factors that ultimately can be proactively calibrated in practice and program supports. We need to develop valid measures and methods for evaluating the various intersecting elements of the employment ecosystem. Granular analysis is further recommended, including sample distinctions across the autism phenotype (as well as potential co-existing conditions), employment/industry sectors, and support approaches/models.

Many potential research questions remain unanswered. For instance, we need to better understand specific mechanisms that advance outcomes, including how they may be linked with contextual elements such as region (e.g., locale, urban versus rural region), economic conditions, culture and policy structure. There is yet limited research that focuses on how employment supports and services moderate outcomes. In considering the impact of employment on well-being, potential questions for further inquiry emerge such as, 'how do employment services affect employee identity, self-esteem and quality of life?'. It is anticipated (and hoped) that advancing this line of research may assist in supporting autistic individuals' quality of life by determining *if* and if so, *how* employment and the range of possible supports therein, can enrich one's life course.

Interventional and longitudinal studies are needed that address employment support initiatives and trajectories across varying industry/employment sectors. Lastly, population-based impacts from the employment of autistic people are needed in determining economic and other societal outcomes (e.g., gross domestic product [GDP], population-level attitudes and values) which in turn, may heighten awareness and justify further proactive employment opportunity.

Conclusion

Research in this field suggests that meaningful and long-term employment is an important aim, yet one that may be challenging, anxiety-producing and/or elusive for many adults with autism. Employment supports are recommended to be catalytic in seeking broad level inclusion of autistic individuals in employment and community at large via ecosystem transformation. As we move forward, building partnerships amongst private and public sector stakeholders seems pivotal to sustainable change. Multi-level strategy development is invited in the aim of individual, workplace, community and societal capacity building. Advances over the last decade demonstrate that employment prospects can be improved for adults with autism. However, formidable shifts are yet needed. Working together to improve employment possibilities emerges as an endeavor worthy of pursuit in the aim of advancing outcomes and quality of life for autistic adults. ■

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