

Short Communication

Employment of people with Down syndrome: A scoping review

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Abstract

Down syndrome is the most prevalent genetic condition contributing to intellectual disability. Advancements in medical care have significantly increased the life expectancy of people with this condition, making employment a vital component for independent living and quality of life. The aim of this study was to examine the current literature on the employability and employment experiences of individuals with Down syndrome, focusing on the evolution of the employment rate and factors influencing employment such as cognitive and personal factors, societal attitudes, challenges, and effective support systems. Using Arksey and O'Malley's methodology, a scoping review of relevant qualitative and quantitative articles from PubMed, Scopus, Web of Science (WoS), CINAHL, and Medline was conducted. The search focused on the keywords found in the title and abstract of articles from 1980 to 2023. The search strategy utilized medical subject headings (MeSH), including "work", "Down syndrome", and "employment". All articles employing qualitative, quantitative, and mixed methods that were published in English were included. Of an initial 4,296 articles, 32 full-text articles were evaluated, and nine met the inclusion criteria. The data indicated improved employment rates for people with Down syndrome, with a recent employment rate of 53%. However, jobs are often limited to sectors like food service and are underutilizing their skills. Key factors associated with employment status include cognitive abilities, family support, and social attitudes. Despite positive perceptions, significant barriers such as systemic bias persist. Effective support systems are crucial but are often hindered by limited opportunities. In conclusion, employment opportunities for people with Down syndrome have improved, but challenges such as limited job diversity and systemic barriers remain. Comprehensive policies are recommended to promote inclusive employment practices and tailored support systems.

Keywords: Down syndrome, employment, type of work, opportunity, barrier

Introduction

Down syndrome (DS), also known as trisomy 21, is a common chromosomal disorder affecting approximately 1 in 1,000 to 1,100 live births [1]. It is one of the leading genetic causes of intellectual disability [2], with incidence rates varying by region. Advanced maternal age is a significant risk factor for having a child with DS [3]. The prevalence of live births with DS has not shown a significant decline in numerous countries despite the availability of prenatal screening and elective termination options. This phenomenon may be attributed to various factors, such as



the rising age of mothers, disparities in access to prenatal care across different regions, socio-economic challenges, and the influence of religious beliefs [4,5,6]. Advances in medical care have increased the survival rates of people with DS, especially in developed countries, with life expectancy now reaching up to 60 years [7,8]. This improvement in survival rates has contributed to a higher overall prevalence, with more than six million people with DS worldwide [9].

Employment is crucial for independent living and significantly impacts the quality of life of people with DS and their families [10]. It provides opportunities for income generation, skill development, social engagement, and greater autonomy [11,12]. Employment improves the quality of life by facilitating social connections and the acquisition of technical knowledge [13]. Families also benefit through reduced financial stress and increased leisure time [14]. However, despite the advantages, employment rates for people with DS remain low, with many working in sheltered workshops or volunteer roles.

Individuals with DS are often employed in sectors such as food service and cleaning, which do not fully utilize their skills and capabilities [15]. This narrow range of job opportunities highlights the need for comprehensive studies exploring the diverse roles individuals with DS can fulfill. Societal attitudes and systemic barriers, including financial disincentives related to benefits like Medicaid and Social Security, continue to limit access to competitive employment [16]. Further analysis is needed to assess the effectiveness of support systems, such as training centers and social networks, in promoting successful employment outcomes [15]. Furthermore, longitudinal studies do not adequately assess the long-term effects of employment and the support required during and after transition planning [16]. Structured programs integrated with community resources could foster a more inclusive employment landscape, allowing people with DS to explore a wider range of employment opportunities. Therefore, the aim of this study was to identify the employability and employment experiences of individuals with DS, focusing on the evolution of the employment rate and factors influencing employment such as cognitive and personal factors, societal attitudes, challenges, and effective support systems.

Methods

Study design

This scoping review was guided by the Arksey and O'Malley framework [17]. The review process consisted of five stages: identifying the research questions, selecting relevant studies, conducting the study selection, charting the data, and finally collating, summarizing, and reporting the results. The present study focused on the following research topics: (1) the evolution of employment rates and types of employment for people with DS in different countries; (2) the factors influencing the employment of people with DS, which could be further categorized into (i) the key cognitive, functional, and personal factors that influence job outcomes for people with DS; (ii) the impact of social attitudes and perceptions toward people with DS on their employment opportunities and workplace inclusion; (iii) the primary challenges and barriers faced by people with DS in accessing competitive, community-based employment; and (iv) the support systems and facilitators identified as effective in promoting successful employment outcomes for people with DS.

Search strategy

Five electronic databases were examined: PubMed, Scopus, Web of Science (WoS), CINAHL, and Medline. The search strategy used index terms when appropriate and free text terms to capture the following population, concept, and context (PCC) framework developed by Joanna Briggs Institute (JBI) [18], including Down syndrome, employment or employability or work, and drivers and/or barriers. The search terms included work: "work"[MeSH Terms] OR "work"[All Fields] AND Down syndrome: "down syndrome"[MeSH Terms] OR ("down"[All Fields] OR "syndrome"[All Fields] OR "down syndrome"[All Fields] AND employment: "employability"[All Fields] OR "employable"[All Fields] OR "employer"[All Fields] OR "employer's"[All Fields] OR "employers"[All Fields] OR "employment"[MeSH Terms] OR "employment"[All Fields] OR "employments"[All Fields] OR "employments"[All Fields].

Inclusion and exclusion criteria

Studies included in this review were published between 1980 and 2023 and focused on the employment or employability of individuals with DS. All study designs were considered, including qualitative, quantitative, and mixed methods, as long as they were published in English. Conversely, studies that lacked original data (such as editorials and commentaries) or for which full texts were unavailable were excluded.

Data extraction

The screening process was carried out based on the preferred reporting items for systematic reviews and meta-analyses for scoping reviews (PRISMA-ScR) [19]. Two reviewers (TCH and CYY) independently selected titles and abstracts based on established inclusion and exclusion criteria. Both reviewers subsequently evaluated the full-text articles, and any discrepancies were addressed through discussion or by seeking input from a third reviewer (MMR). A data charting form was developed to systematically extract pertinent information from selected studies, including study characteristics, employment outcomes, and significant findings. The data obtained were synthesized using a narrative approach. The results were thematically organized to address the research question. Furthermore, the implications for policy, practice, and future research were discussed.

Results

Study selection results

During the initial search, a total of 4,296 articles were identified through the five online databases (PubMed, Scopus, WoS, CINAHL, and Medline). Following the elimination of duplicate studies, the remaining 3,951 articles were screened based on the titles and abstracts. Subsequently, 32 full-text articles were evaluated for eligibility. After excluding the irrelevant articles and those that were not published in English, nine articles were included in this review for data extraction (**Figure 1**).

Characteristics of the included studies

Among the nine studies reviewed, five were carried out in the United States [15,21,24,25,27], while two were conducted in European countries, specifically the United Kingdom, Scotland, and Italy [20,22]. One study took place in Australia [23] and another in Japan [26] (**Table 1**). The majority of the studies involved young adults with DS [15,20,24,25,26] as well as their families or caregivers [15,22,23,25,27]. Notably, only one study involved adults from the community [21]. Among all the studies, five were published in journals classified as Q1 [15,20,22,24,25], one in a Q2 journal [27], and the remaining three appeared in Q3 journals [21,23,26] (**Table 1**).

Employment status and trends

The employment landscape for people with DS has seen substantial progress over the years. In the late 1980s, a study reported only 2.9% of people with DS successfully obtained employment after transitioning from school placements [20]. Up to 65.7% were placed in Adult Training or Resource Centers [20]. However, more recent studies reflect a positive trend. A study in Rome found that 10% of adults with DS were employed under regular contracts, with employment rates peaking at 30% for those aged 25–30 years [22]. Another study in Australia reported that 25.0% of people with DS were in open employment [23]. Although the overall employment rate for people with DS is still relatively low, in the United States, it was notably higher, ranging from 41.9% to 56.6% [15,24,25,27].

Factors influencing the employment of people with Down syndrome

Personal attributes

The literature identifies several factors influencing employment outcomes for people with DS. Several studies have identified that personal attributes, including a friendly and cheerful disposition [20,27], self-confidence and independence [20], sincerity and passion for one's work,

coupled with a fondness for social interaction [26,27], constitute significant strengths that improve employment outcomes.

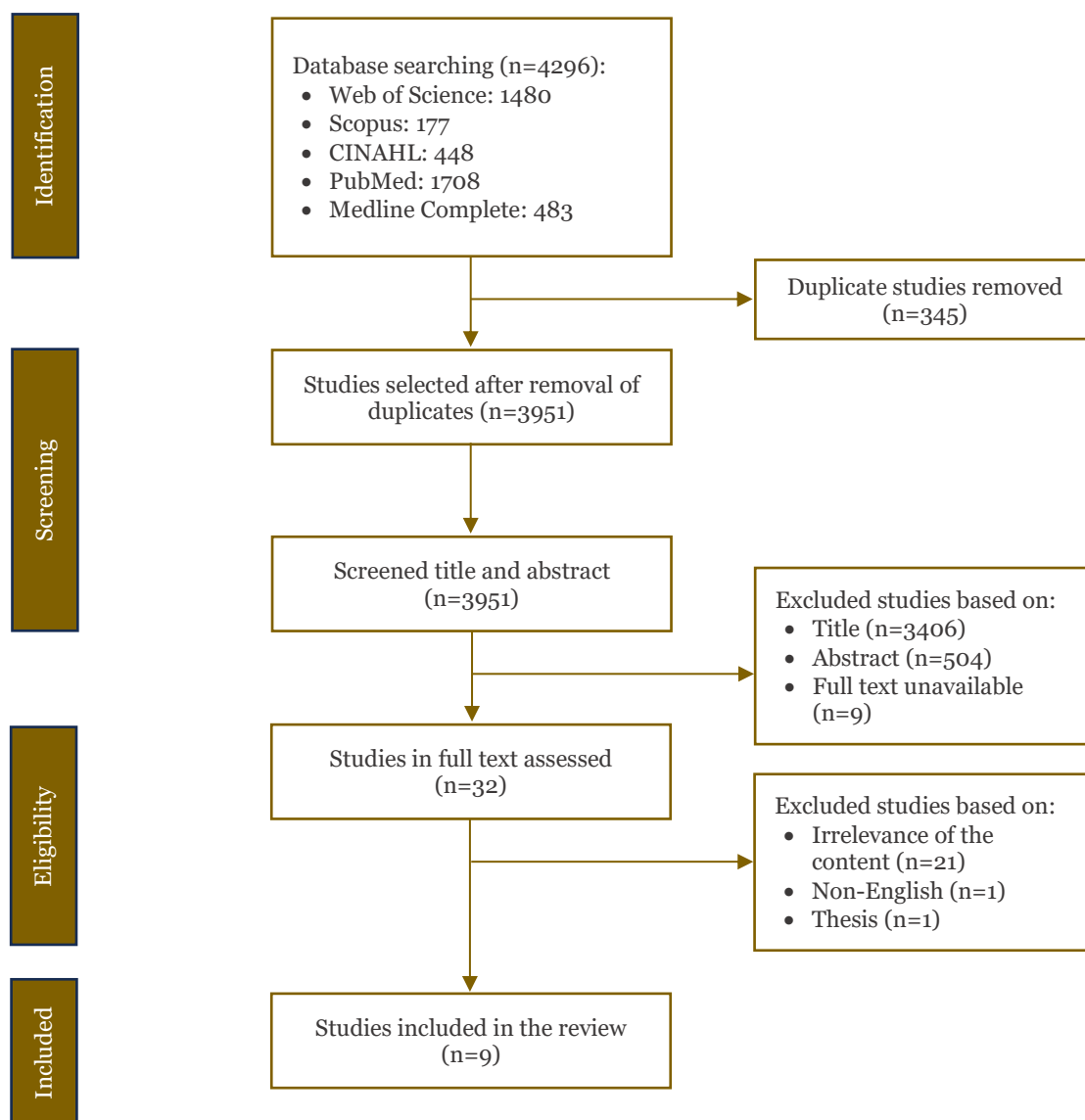


Figure 1. PRISMA flowchart of the study selection.

Attitudes and perceptions towards Down syndrome

The research on attitudes and perceptions toward employment for people with DS reveals a complex landscape. The community demonstrated a willingness to embrace and assist people with DS in the workplace [20]. Notably, women, individuals possessing higher educational qualifications, and those with prior relationships with people with DS were strongly associated with favorable attitudes toward their inclusion in the workforce. A particular study highlighted that 65.7% of respondents believed the majority of adults with DS should be able to work, whereas 18% expressed concern about an increased accident risk in the workplace [21].

Challenges and barriers to employment for people with Down syndrome

The literature identifies numerous challenges and barriers to employment for people with DS. On an intrapersonal level, cognitive impairments, including intellectual difficulties [20], limited speech abilities, reduced independence, and shifting and working memory difficulties [25], alongside physical, mental, and behavioral difficulties [22], present significant hurdles.

Table 1. Study characteristics and main findings of the included study

Author(s), year	Country	Participants and sample size	Study design	Main findings
Thomson <i>et al.</i> , 1995 [20]	United Kingdom and Scotland	Young people with DS aged 16–20 (n=35)	Mixed quantitative and qualitative prospective cohort study	<ul style="list-style-type: none"> • Only one participant (2.9%) succeeded in obtaining employment post-school, although this position was not maintained for an extended period. • Majority (65.7% to 74.3%) can sustain placement at Adult Resource/Training Center. • Personal attributes: friendly and cheerful disposition, self-confidence, and independent • Community attitudes and perceptions: acceptance by others, readiness to offer support • Barriers: severe learning difficulties, limited speech abilities, insufficient independence skills, parents' disapproval of the training center opportunities, unplanned future • Facilitators: attended training and resource center, access to supervised voluntary jobs, availability of resources and connections, and flexible working hours
Pace <i>et al.</i> , 2010 [21]	United States	Adults over 18 years old in the community (n=5,399)	Cross-sectional	<ul style="list-style-type: none"> • Community attitudes and perceptions: 18% agreed that people with DS are prone to accidents. 65.7% agreed adults with DS should be able to work. Females, people with higher levels of education, and previous relationships with people with DS were strongly associated with positive attitudes toward their workplace inclusion.
Bertoli <i>et al.</i> , 2011 [22]	Italy	Families of individuals with DS (n=518)	Cross-sectional	<ul style="list-style-type: none"> • 10% of adults with DS were employed with regular contracts and the majority (30%) were aged 25–29. • Barriers: medical issues, severe behavioral changes, lack of transport, lack of support services
Foley <i>et al.</i> , 2013 [23]	Australia	Parents of young people with DS aged 15–30 (n=164)	Cross-sectional	<ul style="list-style-type: none"> • Type of post-school day occupation involved: <ul style="list-style-type: none"> ○ Open employment: 25.6% ○ Sheltered employment: 39.0% ○ Attending alternatives-to-employment (ATE): 25.0% ○ Attending training 10.4% • Facilitator: better levels of overall functioning in activities of daily living (ADL), including self-care, community, and communication skills, increased the probability of securing open employment or training compared with those in sheltered employment or ATE (OR=1.14; 95%CI: 1.06–1.22)
Kumin and Schoenbrodt, 2016 [15]	United States	Adults with DS (4.5% completed by self; 16.6% completed with assistance) aged 18–61 and parents of adults with DS (78.8%) (n=511)	Cross-sectional	<ul style="list-style-type: none"> • Nature of employment: <ul style="list-style-type: none"> ○ Paid job: 56.6% ○ Volunteer job: 25.8% ○ Self-employed: 2.8% • Barriers: inadequate transportation, health problems, not interest in working, lack of programs to teach job skills, fear of losing Supplemental Security Income (SSI) • Facilitators: received job training, network from friends and family, support from rehabilitation agency, community organizations, and employment agency, assistance from job coaches, possess computer skills at work

Author(s), year	Country	Participants and sample size	Study design	Main findings
Bush and Tasse, 2017 [24]	United States	Individuals with DS aged 18–75 (n=1,857)	Cross-sectional	<ul style="list-style-type: none"> • Nature of employment: <ul style="list-style-type: none"> ○ Unemployed: 54.3% ○ Paid facility work: 30.1% ○ Paid community jobs: 15.6% • Facilitators: lower severity levels of intellectual disability, taking fewer medications for mental and behavioral health conditions, short-term choice-making ability
Tomaszewski <i>et al.</i> , 2018 [25]	United States	Young adults with DS aged 18–43 and their parents or caregivers (n=31)	Cross-sectional	<ul style="list-style-type: none"> • 41.9% of people with DS were employed • Barriers: greater shifting and working memory difficulties • Facilitators: stronger daily living skills
Takataya <i>et al.</i> , 2022 [26]	Japan	Young adults with DS aged 20–38 (n=11)	Qualitative group and individual interview	<ul style="list-style-type: none"> • Personal attributes: sincere attitude toward work, enjoy socialization, easily contented • Barriers: interpersonal issues among colleagues, little salary despite working hard • Facilitators: encouraging and caring workplace, being assigned tasks of interest
Channell <i>et al.</i> , 2023 [27]	United States	Primary caregivers to young adults with DS aged 18–27 (n=101)	Qualitative study	<ul style="list-style-type: none"> • 53% of people with DS were employed: <ul style="list-style-type: none"> ○ Community work: 69% ○ Sheltered vocational work: 31% • Personal attributes: enjoy working, passionate about pursuing dreams, enjoy socialization • Barriers: limited job opportunities, lack of job fit • Facilitators: support in finding jobs by parents and family, job training services, rehabilitation agencies, and employment agencies, flexible working hours, a short distance from home, good employer and workplace

DS: Down syndrome

Additionally, caregivers often express skepticism regarding the efficacy of the training center opportunities and unplanned future [20], as well as concerns about losing social welfare benefits [15], thereby discouraging employment pursuits. The limitation of job opportunities and job fit [27], along with the lack of programs to develop job-related skills, further complicate the employment landscape for these individuals [15]. Moreover, inadequate infrastructure, particularly in transportation and support services [22], contributed to the low employment rates among people with DS.

Support systems and facilitators for the employment of people with Down syndrome

The existing literature highlights various support systems and facilitators that enhance employment opportunities for people with DS. Key determinants of employability include a good level of daily living skills [23,25] and choice-making ability, coupled with reduced medical and mental health issues [24].

Additionally, training programs offered at adult training centers, resource centers, and rehabilitation agencies play a crucial role in fostering employability [15,20,27]. Proficiency in computer skills [15] and communication skills [23] further increase their opportunities to secure employment. Factors related to the work environment, such as better job fit, flexible working hours, proximity to home, and supportive employers, also significantly influence both employment rates and job satisfaction [20,26,27]. Furthermore, the support provided by parents and assistance from various networks and agencies is essential in facilitating employment for people with DS [15,27].

Discussion

Our analysis found that the employment status of people with DS has improved over the years, but significant challenges remain. The literature underscores the need for continued efforts to promote inclusive employment practices and address systemic barriers hindering people with DS from achieving their full potential in the workforce. The employment types and settings for people with DS often do not reflect the full range of their skills and capabilities. This gap in opportunities that leverage their potential is evident from the low percentage of DS adults using computer skills in paid work. The challenges people with DS face in securing competitive employment are compounded by societal attitudes and systemic barriers, emphasizing the need for individualized approaches to care and support for adults with DS [28]. These findings suggest that while progress has been made, there is still considerable work to be done to ensure equal employment opportunities and representation across various sectors for people with DS.

The analysis emerges a complex interplay of factors influencing employment outcomes for people with DS. An ecosystemic approach is recommended for employment, considering personal abilities alongside external factors such as family support and community resources [29]. This perspective is consistent with the findings that underscore the importance of family attitudes and strategic planning, which are highlighted in the results. Furthermore, the role of cognitive abilities extends beyond general intellectual functioning, indicating that targeted cognitive skill development could improve employment prospects [25]. Job satisfaction is also a critical factor influencing the transition to self-employment, implying that individuals with strong cognitive skills may be better positioned for such opportunities [30]. Additionally, the value of positive interactions in the workplace highlights the need for inclusive and supportive work environments [27,31]. Perceived employability and personal initiative are also essential for achieving job satisfaction, pointing out that family support can play a pivotal role in fostering these attributes [32]. The detrimental impact of job insecurity on job satisfaction and overall well-being further emphasizes the need for a proper alignment between individual capabilities and job requirements [33]. Collectively, these insights suggest that a comprehensive approach, which considers both individual characteristics and environmental factors, is essential for enhancing employment outcomes for people with DS.

We found a discrepancy between generally positive attitudes towards the employability of people with DS and the actual employment outcomes. This disparity can be attributed to persistent societal biases and inadequate support systems, emphasizing the importance of job fit and socialization opportunities for job satisfaction [28]. The role of external factors, such as

family attitudes and social perceptions, in shaping employment opportunities for people with DS is significant [20,28]. The interaction between personal attributes, external perceptions, and systemic barriers creates a complex environment that facilitates or impedes employment opportunities for people with DS. Although studies have pointed out positive perceptions of their personal traits and work ethic [26,34], the low percentage of adults with DS using their skills in paid employment suggests that significant challenges remain in translating positive attitudes into actual employment outcomes.

Our analysis reveals a complex interplay of educational, cognitive, and societal factors contributing to employment barriers for people with DS. The low employment rates and limited job accessibility underscore the urgent need for targeted interventions and support systems. The importance of functional skills and cognitive abilities in securing and maintaining employment suggests that early intervention and ongoing support could improve employment outcomes. As reported, the perception of being undervalued in the workplace points to the need for better job matching and workplace education to ensure meaningful and satisfying employment for people with DS [26]. Additionally, other studies [24,35] highlighted systemic barriers related to financial incentives and benefits, suggesting that policy changes may be necessary to remove disincentives to work. These findings collectively indicate that addressing employment barriers for people with DS requires a multifaceted approach involving education, workplace accommodations, societal attitudes, and policy reforms.

We also found a multifaceted nature of support systems and facilitators for the employment of people with DS. Two studies [20,21] noted that the importance of social networks suggests that familiarity and exposure can create supportive environments for people with DS seeking employment. The role of volunteer work and post-secondary programs indicates the value of preparatory experiences in improving employability [15,36]. The critical role of family involvement, particularly parental support, in facilitating early employment opportunities aligns with Carter *et al.* [36] findings. However, despite these facilitators, limited job opportunities remain a challenge, particularly in paid and community work [27]. This suggests a need for ongoing advocacy and policy changes to improve job accessibility and support for people with DS, as implied by Garza *et al.* [28] call for individualized care approaches in employment support.

The study effectively integrates qualitative and quantitative research literature, providing deep insights into the experiences of people with DS and their caregivers in the workforce. Qualitative narratives complement quantitative analyses, enriching our understanding of employment dynamics. The study identifies research gaps, advocates for comprehensive census-type studies to address realistic needs, and longitudinal studies to evaluate long-term employment effects and support requirements. It emphasizes that education and social inclusion during childhood do not ensure the quality of life in adulthood, highlighting the need for a comprehensive and inclusive policy. This approach aims to help people with DS navigate persistent employment challenges.

However, this scoping review of the employment of people with DS has several limitations. The uneven distribution of study regions in our review necessitates careful consideration when interpreting our findings. Also, the lack of homogeneity among the variables and study samples in the majority of research studies complicates the interpretation process. Most research primarily collects viewpoints from people with DS and their caregivers. To achieve a more holistic understanding of employment experiences for people with DS, it is essential to incorporate perspectives from the broader workplace ecosystem, including employers and colleagues, to enhance the overall insight.

Conclusions

The employment status of people with DS has improved, yet significant challenges remain. The literature highlights the need for inclusive employment practices and addressing systemic barriers. The outcomes of employment are influenced by cognitive, functional, personal, and environmental factors, which require a multifaceted approach. Key facilitators include training centers, social networks, and parental support, but systemic barriers and limited job opportunities persist. Addressing these challenges requires individual support and larger societal changes to create inclusive employment environments.

Ethics approval

Not required.

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Conflict of interest

The authors affirm that they have no financial or personal conflicts of interest related to any of the scientific papers cited in this article, ensuring that the integrity of the research remains unaffected.

Underlying data

All data underlying the results are available as part of the article and no additional source data are required.

How to cite

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