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# Integrating vocational supports into a transition clinic: A pilot program

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#### ABSTRACT

*Objective:* Pilot a clinical model and study to learn more about how employment impacts health in children and young adults with intellectual and developmental disabilities.

Background: As young individuals transition into adulthood, milestones such as independent living and gainful employment become paramount. However, for those with intellectual and developmental disabilities (IDD), these milestones can diverge notably from those of typically developing peers. They often confront distinct challenges, especially during shifts from pediatric to adult health care and transitioning from school to employment. Despite the positive influence of employment on quality of life, fragmented support systems create barriers to achieving this outcome. Employment is an important aspect of overall health and wellness, and more research is needed to determine how employment supports can be integrated with health care to improve certain health outcomes.

*Design:* Self-determination theory and social ecological theory highlight the need for a comprehensive approach that considers both the internal needs and motivations of the individual with IDD and the external factors that influence their transition to adulthood. Based in these theories, our intervention offers an innovative blend of vocational support within a transition services framework at a large academic hospital. Our study introduces vocational support tailored for IDD youths within three health clinics.

Results: Initial results demonstrate the technical and scheduling feasibility of integrating the intervention within existing healthcare services. The study has enrolled several participants, showing potential in technical, scheduling, economic, and operational domains. However, upcoming long-term data and comprehensive evaluation are required for a conclusive understanding of the intervention's impact.

*Conclusions:* The program integrates vocational support into transitioning individuals with IDD from childhood to adult health care services. This intervention has potential to improve the health outcomes and quality of life for individuals with IDD, which could drive broader interdisciplinary interventions.

# Introduction

# Background

Navigating the shift from pediatric to adult healthcare is a complex process, especially for those with intellectual and developmental disabilities (IDD). In the United States, neurodevelopmental disorders (NDD) affect about one-sixth of children, with the vast majority living well into adulthood. These disorders, including Autism Spectrum Disorder, cerebral palsy, and Prader-Willi among others, impact over 7 million Americans with a variety of symptoms that commonly affect

motor skills, cognitive abilities, social interactions, and communication. As these individuals progress into adulthood, they frequently encounter significant barriers in achieving key life milestones such as independent living, employment, and the establishment of meaningful relationships. These challenges contrast with the experiences of their typically developing peers, underscoring a critical need for innovative approaches to foster their independence and enhance their overall quality of life.

One of the pivotal challenges during this transition is the shift from pediatric to adult healthcare systems. Many of these individuals, particularly those who utilize Medicaid to access health care, face

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considerable obstacles in accessing adult healthcare services. <sup>4</sup> These systemic barriers often limit the provision of care for publicly insured patients. <sup>5</sup> Beyond the medical complexities associated with their neurodevelopmental disorders, individuals with NDD are prone to leading less active lifestyles and suffer from unaddressed chronic health conditions, further complicating their transition into adult life and healthcare. <sup>6</sup> Currently, there is an evident lack of a consistent and accessible healthcare model that offers coordinated care for individuals with NDD during this crucial transition phase. <sup>7</sup>

This program is designed to investigate how targeted case management for vocational support, integrated within transition services, can positively influence health outcomes in young people with IDD at a multidisciplinary health clinic. At the core of this study is the hypothesis that effective integration of vocational support into healthcare transition services can significantly improve the health and well-being of individuals with IDD. Central to this hypothesis is the recognition of employment as a crucial social determinant of health.<sup>8</sup> Employment brings not only financial stability but also fosters a sense of purpose, belonging, and self-esteem – elements that are particularly crucial for individuals with IDD during their transition years. Previous research has consistently illustrated the positive impact of meaningful employment on the overall quality of life, including health outcomes. 10 However, the direct correlation between employment and health outcomes, specifically for those with IDD, remains insufficiently explored in current literature.

Our study takes a two-pronged approach to address this gap. The first aim is to establish an innovative model of vocational support for youth and young adults with IDD, which will be implemented within multidisciplinary health clinics. This model is designed to blend evidence-based practices and optimal employment support strategies into the healthcare setting. This integration is expected to foster greater collaboration and reduce service fragmentation, resulting in a comprehensive, individualized coordination of holistic transition services that adeptly addresses the diverse needs of this population. The second aim of the study is to evaluate the effect of engaging in employment support intiatives on various health metrics. By embedding employment support into clinical care, as established in the first aim, we propose to investigate the effects of employment and increased independence on health, fitness, and life quality during the crucial transition period for individuals with IDD.

This study arises from a compelling need to bridge the gap between the healthcare transition and employment support systems for individuals with IDD. We seek to offer novel insights into how integrated vocational support within healthcare services can potentially transform the transition experience for these individuals, leading to improved health outcomes and a higher quality of life. The outcomes of this research are expected to provide a substantial contribution to the field, offering a model that can be replicated and adapted in various healthcare settings to improve the transition process for youth with IDD. At this point, we demonstrate the feasibility of the integration of employment supports into existing healthcare services.

## Theoretical framework

The theoretical framework for this intervention draws from two central concepts: self-determination theory and social ecological theory. These frameworks provide a comprehensive understanding of the dynamics at play in supporting individuals with IDD during their transition to adulthood, especially in the context of vocational support and healthcare.

Self-determination theory (SDT) is instrumental in this intervention, focusing on the psychological needs for autonomy, competence, and relatedness. In the context of individuals with IDD, SDT emphasizes the importance of fostering a sense of autonomy and control over their lives, enhancing their ability to make choices and decisions regarding their employment and health. This theory posits that when individuals feel a

sense of ownership over their decisions, they are more motivated and engaged, leading to better outcomes. The application of SDT in the intervention aims to empower youths with IDD by involving them in the decision-making processes related to their employment and healthcare. This empowerment is expected to increase their engagement in and commitment to the transition process, thereby improving their ability to achieve meaningful employment and better health outcomes. Additionally, this intervention aims to reduce fragmentation between systems and elevate expectations of employment from multiple perspectives, including providers, families, and individuals. Self-determination theory helps us conceptualize the individual's autonomy, while a complementary systems-level approach grounds that individual experience in a larger conceptual framework.

Social ecological theory provides a framework for understanding how various systems and environments influence an individual's behavior and development. This theory recognizes the complex interplay between individual, interpersonal, organizational, community, and policy-level factors. In the context of this intervention, social ecological theory helps to conceptualize how various factors - from personal skills and family support to healthcare systems and employment policies interact and impact the transition experience of youths with IDD. <sup>11,12</sup> By adopting this perspective, the intervention is designed to not only address the individual needs of these youths but also to engage with and potentially modify the systems and environments. This includes creating collaborations among healthcare providers, vocational services, and educational programs to ensure a seamless transition.

The integration of these two theories in the intervention aims to create a comprehensive approach that considers both the internal needs and motivations of the individual with IDD and the external factors that influence their transition to adulthood. This dual approach is expected to facilitate a more effective and holistic transition process, leading to improved vocational and health outcomes for these individuals.

# Development of the intervention

The intervention central to this study was developed at Children's Hospital Colorado (CHCO), in response to the identified need for enhanced vocational support for youth with intellectual and developmental disabilities (IDD) during their transition from pediatric to adult healthcare. This intervention represents an initial effort to integrate vocational support within the framework of healthcare services, acknowledging the multifaceted nature of transition for this demographic.

Children's Hospital Colorado has long been at the forefront of providing comprehensive care for children and adolescents with various health needs, including those with IDD. Recognizing the unique challenges faced by this group during transition phases, CHCO aimed to create an intervention that not only addresses health concerns but also encompasses vocational and educational aspirations. This initiative aligns with the hospital's broader commitment to holistic care and support for all its patients.

The development of the intervention involved a crucial partnership with the Colorado Office of Employment First (COEF). This collaboration ensured that the intervention was grounded in the principles of Employment First, a philosophy advocating for the prioritization of competitive integrated employment (CIE) in the lives of people with disabilities. States are increasingly committing to the Employment First initiative, which recognizes CIE as the only acceptable employment goal for individuals with disabilities. <sup>13,14</sup> The Workforce Innovation and Opportunity Act (WIOA) defines competitive integrated employment as having three components: (1) competitive earnings (e.g., at or above minimum with benefits similar to those without disabilities performing the same work), (2) integrated location (e.g., located in the community, interacting with coworkers and customers without disabilities), and (3) opportunities for job advancement commensurate with coworkers without disabilities in similar positions. <sup>15</sup> In addition to federal policy

under WIOA, more than 30 states have established Employment First policy, and almost every state has some form of an Employment First initiative. These initiatives support CIE as the first outcome considered for people with disabilities who receive state services such as Vocational Rehabilitation or Medicaid waiver supports. Employment First represents a commitment by states, and state IDD agencies, to the idea that all individuals with IDD (a) are capable of working in typical integrated employment settings; (b) should receive, as a matter of state policy, employment-related services and supports as a priority over other facility-based and non-work day services; and (c) should be paid at minimum or prevailing wage rates. 16-18 While Employment First has been widely accepted across states, there has not been a coordinated effort to train health care providers on the philosophy and its integration in clinical settings. COEF's expertise in this area was instrumental in shaping the vocational aspects of the intervention. Fig. 1 demonstrates potential funding streams to support CIE.

#### Methods

#### Overview

The pilot program presented in this paper is part of a larger study entitled "Growth in Youths with Intellectual/Developmental Disabilities – Assistance Navigating Competitive Employment" or "GUIDDANCE." GUIDDANCE represents a multifaceted approach to vocational support for youth with intellectual and developmental disabilities. It is structured to integrate seamlessly with the existing healthcare services provided at CHCO. GUIDDANCE aims to integrate targeted vocational case management within the healthcare transition services for youth with

IDD. The intervention focuses on two key components: enhancing employment outcomes and improving health metrics. The initial stage of the study demonstrates the feasibility of integrating this intervention into existing transition services.

# **Population**

The intervention draws patients from several specialized clinics within CHCO each addressing unique aspects of care for individuals with IDD. At the Prader-Willi Clinic, the focus is on genetic and endocrine concerns, where patients receive comprehensive care that includes occupational and physical therapy, social work, and specialized medical services. Meanwhile, the Transition Clinic provides a dedicated half-day service monthly, offering intensive transition support through a multi-disciplinary team. Additionally, the Adult Special Care Clinic is tailored to adults with IDD and complex medical needs, ensuring a seamless continuation of care beyond pediatric services, thus addressing the full spectrum of patient needs within the CHCO system.

# Referral process

The referral process for GUIDDANCE is inclusive and straightforward. Patients aged 15–25 receiving care in the clinics, or on their waiting lists, are identified as potential candidates. Clinic physicians and staff inform these patients and their families about the intervention, emphasizing its voluntary nature and additional benefits to standard care. Interested individuals are then contacted by a Research Services Professional (RSP) associated with the GUIDDANCE study to discuss enrollment.

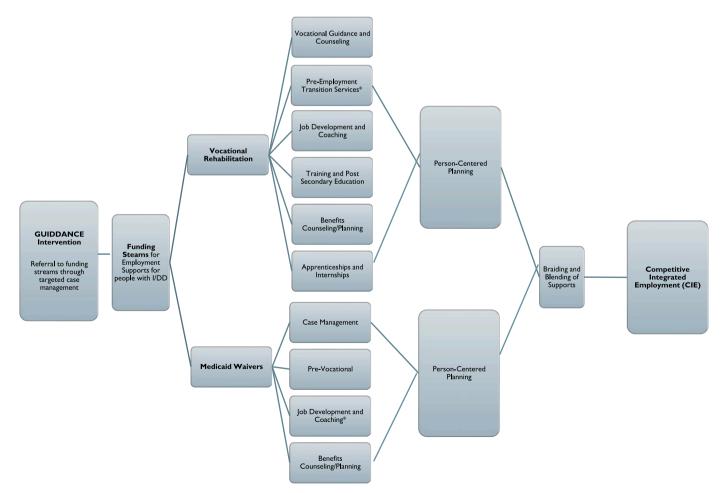


Fig. 1. Funding Streams for GUIDDANCE.

#### Intervention steps

The intervention is structured into three stages to ensure comprehensive and tailored support for participants. The first stage begins with an initial assessment, where the RSP performs a thorough review of each participant's chart, gathering data on demographics, diagnoses, and social determinants of health. In cases where recent assessments of adaptive behavior are not available, these are conducted to ensure a complete understanding of each individual's needs. The second stage, employment-focused intake, involves participants completing an intake form that provides detailed information about their vocational history, service utilization, and employment goals. This crucial step allows the intervention to be specifically tailored to each participant's unique requirements.

Following this, the intervention moves into the third and final stage:

ongoing case management. Here, the RSP offers continuous support, including facilitating referrals to vocational rehabilitation and other relevant services. Regular check-ins are scheduled to monitor each participant's progress and to adjust strategies as needed, ensuring responsive and dynamic case management.

#### Future analysis

While this pilot publication focuses on feasibility, we have already planned our future analysis. The focus of the analysis will be on identifying changes in health and employment outcomes, both before and after the intervention. Initially, the analysis will begin with descriptive statistics, summarizing key demographic information such as age, gender, disability type, race, and ethnicity, along with prior service utilization details, including vocational rehabilitation and Medicaid



Fig. 2. Process Map for GUIDDANCE.

waivers. Healthcare utilization, measured through emergency department visits, will also be measured.

Following this, a comparative analysis will be conducted, which involves contrasting the baseline data with the information gathered at the 6-month midpoint and upon completion of the 12-month intervention. Moreover, individual-level changes will be scrutinized to evaluate the intervention's effect on each participant and any confounding or mitigating effects related to demographic information or diagnoses. This phase of analysis will include reviewing changes in health outcomes, such as Body Mass Index (BMI) and Adaptive Behavior Assessment System (ABAS) scores, as well as employment outcomes, including referrals to employment supports such as Vocational Rehabilitation, and placements in competitive integrated employment.

Finally, the study will involve a group-level analysis to discern broader trends and patterns across the entire participant population. This step is integral to the intervention's overall effectiveness and its impact on the group. Through this multi-layered analytical approach, the study aims to provide a comprehensive understanding of how the GUIDDANCE intervention influences both individual participants and the wider group in terms of health and employment outcomes.

#### Process mapping

A detailed process map is provided, illustrating the flow of the intervention from initial referral to post-intervention follow-up (Fig. 2). This visual representation aids in understanding the comprehensive nature of the intervention and its integration within the healthcare setting.

# Ethics and IRB compliance

All aspects of GUIDDANCE adhere to ethical guidelines and have received full approval from the Colorado Multiple Institutional Review Board (COMIRB). Participation in the study is voluntary, with informed consent obtained from all participants or their guardians. The study's design ensures that participants' standard medical care is not affected by their decision to participate or not in the intervention.

# Results

#### Overview

While we hypothesize GUIDDANCE will demonstrate feasibility in technical, scheduling, economic, and operational domains, we are still in the stages of initial enrollment, and have demonstrated technical and scheduling feasibility. As the study progresses and more data becomes available, a comprehensive evaluation of the economic and operational feasibility will be conducted, providing a clearer understanding of the intervention's impact in other areas.

#### Initial enrollment

GUIDDANCE has reached 42 potential participants for the study and will continue to enroll patients. The 42 potential participants are referred to GUIDDANCE by one of three different clinics, 3 of the 42 are from Prader-Willi Clinic, another 3 of the 42 are from specialty clinics, and 36 of the 42 are referrals from the Transition Clinic. Of the 42 contacted, 3 have returned signed consent forms and the others are contacted a second time to schedule an initial or second consent meeting.

The Transition Clinic sees between 1 and 5 patients per month, and most of those appointments result in a GUIDDANCE study referral. There are currently 108 individuals on the waitlist for the Transition Clinic. As the GUIDDANCE study expands, we hope to include clinics from the associated university hospital to reach more potential participants.

#### Technical feasibility

The technical feasibility of the GUIDDANCE intervention is evident in its successful integration within the existing healthcare framework. Utilizing the current infrastructure in multidisciplinary health clinics, the intervention seamlessly aligns with the technological capabilities already in place. This integration includes leveraging established electronic health records (EHR) systems for efficient data management and patient tracking. The data collected in GUIDDANCE, such as ABAS, BMI, and relevant diagnoses, are already in use in these clinics. By utilizing data collected as part of routine care, we have allowed for a more successful integration of GUIDDANCE into the existing clinic.

# Scheduling feasibility

The intervention is designed to align with existing healthcare appointments, allowing vocational support sessions to be conducted alongside routine medical visits. This alignment maximizes resource utilization and minimizes the need for additional time commitments from participants. This approach also ensures that each participant receives focused attention while preventing overextension of resources. Additionally, the intervention includes routine check-ins from the RSP, which assists in maintaining adherence to the intervention and allows for necessary troubleshooting.

A central aspect of the scheduling feasibility is the commitment of the multidisciplinary teams, including healthcare providers, vocational counselors, and administrative staff. These teams collaborate to deliver the intervention efficiently, adhering to the planned patient schedule while accommodating the evolving needs of participants. As some patients will require more time on medical topics and some will require more time on employment topics, flexibility with intervention's scheduling underscore its feasibility in a dynamic healthcare environment.

# Economic and operational feasibility

Regarding the economic and operational feasibility of the GUID-DANCE intervention, several hypotheses have been formulated. Economically, it is hypothesized that the integration of vocational support within healthcare services will lead to long-term cost savings. These savings are expected to arise from reduced reliance on emergency services, decreased dependency on social services, and potentially lower healthcare costs due to improved health outcomes. Operationally, the intervention is anticipated to enhance service delivery efficiency by reducing the fragmentation of care and streamlining the transition from pediatric to adult services.

However, conclusive evidence on the economic and operational feasibility of the GUIDDANCE intervention cannot be provided at this current stage. This is due to the need for long-term data collection and analysis to fully assess the intervention's impact on healthcare costs and operational efficiencies. Additionally, variables such as fluctuating healthcare policies, participant adherence rates, and evolving economic factors may influence the final outcomes.

# Discussion

One of the most striking challenges in the healthcare landscape for individuals with intellectual and developmental disabilities (IDD) is the gap in care during the transition from pediatric to adult services. <sup>19</sup> This transition period is fraught with complexities, as these individuals often face a discontinuity in care, which can lead to exacerbated health issues and diminished quality of life. <sup>20</sup> The current healthcare system, primarily designed for typically developing individuals, frequently fails to address the unique needs of those with IDD, particularly in the realms of vocational support and independent living skills. <sup>7,21</sup> The disjointed nature of transition services often leaves young adults with IDD and their families navigating a labyrinth of services with varying eligibility

criteria and program rules.  $^{22}$  This complexity can result in missed opportunities for these individuals to develop vocational skills and gain meaningful employment, which are crucial for their independence and well-being.  $^{9,10}$ 

The significant length of the waitlist for specialized clinics in our study highlights the high demand for tailored healthcare and transition services for individuals with IDD. This waitlist not only indicates the need for more comprehensive services but also points to the potential risks associated with delayed access to care. Prolonged wait times can exacerbate health problems, hinder the development of essential life skills, and delay vocational opportunities. The waitlist length also underscores the necessity for scalable and replicable models of integrated care that can be implemented in various healthcare settings to reduce wait times and improve accessibility for this underserved population.

The GUIDDANCE intervention, with its focus on integrating vocational support into healthcare transition services, has the potential to significantly impact the lives of young adults with IDD. By providing targeted vocational case management, the intervention aims to bridge the gap between healthcare and employment services, thereby facilitating smoother transitions to adulthood. Potential impacts include improved health outcomes, as prior research has confirmed vocational engagement can enhance self-esteem, social interaction, and financial independence, which collectively contribute to better mental and physical health. Furthermore, gainful employment may lead to reduced dependency on social services and healthcare systems, thereby diminishing the overall societal and economic burden.<sup>7,9,19,23</sup>

Future research should focus on developing and evaluating integrated models of care that encompass vocational support within the broader framework of health services for individuals with IDD. It is essential to explore how such integrated models can be effectively implemented in different healthcare settings and for diverse populations with varying levels of IDD. Additionally, research should aim to understand the long-term impacts of such interventions on health outcomes, employment stability, and overall life satisfaction. Specific populations that warrant further investigation include individuals with non-verbal or limited communication abilities and those with severe levels of IDD, as they often face the most significant barriers to employment and independent living.

#### Limitations

While the study provides valuable insights into the integration of vocational support in healthcare transitions for youth with IDD, it is not without limitations. One significant limitation is the relatively small sample size of the study, which is limited to patients within specific clinics. This may affect the generalizability of the findings. This limitation underscores the need for future research employing randomized control trials to provide more robust evidence of the intervention's efficacy. Additionally, conclusive evidence on the economic and operational feasibility of the GUIDDANCE intervention cannot be provided at this current stage. This is due to the need for long-term data collection and analysis to fully assess the intervention's impact on healthcare costs and operational efficiencies.

#### Conclusion

In conclusion, the GUIDDANCE intervention represents a novel approach to addressing the significant gaps in care for individuals with IDD transitioning to adult services. By integrating vocational support into healthcare services, this intervention has the potential to improve the health outcomes and quality of life for this population. However, future research is needed to further validate these findings, explore long-term impacts, and extend these practices to broader populations and settings. Despite its limitations, this study lays the groundwork for a more holistic and integrated approach to care for individuals with IDD, ultimately paving the way for their successful transition into adulthood

and independent living.

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We have no funding to disclose.

#### **Ethical statement**

We have no ethical considerations to disclose. This work was approved by the Colorado Multiple Institution Review Board.

#### CRediT authorship contribution statement

Elijah W. Hale: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. Aryn Taylor: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. Marlee Elton: Project administration, Investigation, Data curation. Melanie Honsbruch: Writing – review & editing, Resources, Project administration, Investigation. Cordelia Robinson Rosenberg: Supervision, Methodology, Conceptualization. Jessica Solomon Sanders: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Conceptualization.

#### **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### **Data Availability**

No data was used for the research described in the article.

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