

# Improving Youth SSI Recipients' Employment Outcomes through an Integrated Treatment Team Intervention in a Health Care Setting

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# **Abstract**

Youth with disabilities face challenging transition points during adolescence and young adulthood, including from school to competitive integrated employment. This paper introduces an intervention to improve the employment outcomes of youth receiving Supplemental Security Income (SSI) through the addition of intensive employment-related case management within a health care setting. The case manager serves three purposes: (1) emphasizing employment as an option for youth and their families, (2) educating the health care team about employment issues, and (3) connecting youth and their families to employment supports, including vocational rehabilitation and benefits counseling. By reducing service system fragmentation through better coordination between the private health care sector and public programs, the proposed intervention aims to improve the long-term employment and independence of youth receiving SSI. The ultimate goal is to increase the self-sufficiency of youth with disabilities in making health care and employment decisions through greater access to consistent information that emphasizes the expectation of employment.



#### I. Introduction

Youth with disabilities and their families face a variety of challenges during the transition to young adulthood. One such challenge is navigating the complex and fragmented service system, including the disconnect between health care and other services that promote employment and independence. This challenge can result in some youth with disabilities not accessing services and opportunities that could improve their long-term outcomes.

We propose a novel service intervention to improve the long-term employment outcomes of youth with disabilities—specifically, Supplemental Security Income (SSI) recipients age 14 and up who are receiving medical services for their disabilities in multidisciplinary clinics with integrated treatment teams. Such integrated treatment teams often comprise doctors, nurses, nutritionists, social workers, and a variety of therapists. Hallmarks of these teams are a high degree of collaboration and communication among team members and a focus on improving coordination among the different systems of care often faced by patients with complex medical needs.

The proposed intervention adds case managers to established integrated treatment teams in multidisciplinary clinics with the intent of coordinating care between medical providers and public benefits programs. Including an employment-focused case manager in clinical team meetings can build a shared belief by all integrated treatment team members that employment is possible for all youth who want to work. Case managers can facilitate a number of important referrals to achieve this goal. First, referrals to state vocational rehabilitation (VR) programs can help youth SSI recipients improve their access to employment-related services. Second, referrals to benefits counseling help educate and advise youth SSI recipients (and their families) about their benefits and potential work incentives. Referrals to benefits counseling, provided by Community Work Incentive Coordinators (CWICs) or Community Partner Work Incentives Counselors (CPWICs), will offer families a formalized and nuanced view of SSI to better inform them about options for employment.

To improve long-term outcomes of youth SSI recipients, the intervention focuses on the following objectives:

- 1. Increasing health care staff knowledge of competitive integrated employment (CIE) though the training of case managers in multidisciplinary clinics on employment-related supports, including VR and benefits counseling
- 2. Increasing coordination between private health care and public employment supports
- 3. Increasing referrals to VR services from multidisciplinary clinics
- **4.** Increasing receipt of benefits counseling by youth SSI recipients and their families through referrals by CWICs and CPWICs
- **5.** Increasing youth SSI recipients' knowledge about their medical condition and how it affects their ability to gain and maintain employment

The intervention intends to achieve these objectives through a coordinated service delivery approach. This approach was identified in the Promoting the Readiness of Minors in Supplemental Security Income (PROMISE) initiative as a critical component of serving transition-age youth with

disabilities (Honeycutt and Livermore 2018). Multiple partners will collaborate in the intervention, including case managers in multidisciplinary clinics, VR counselors, health care providers, and CWICs and CPWICs. We propose a pilot to be conducted at variety of the multidisciplinary clinics at Children's Hospital Colorado (CHCO) that serve youth with disabilities.

# II. Background

# A. What are the challenges with crossing transition points?

Youth with disabilities face challenging transition points during adolescence and young adulthood. These include the transitions from pediatric to adult health care, from school to CIE (Balcazar and others 2012; Berry 2000; Braddock, Rizzolo, and Hemp 2004; Davies, Rupp, and Wittenburg 2009; Office of Special Education and Rehabilitative Services 2020), from secondary school to postsecondary education (Lindsay and others 2019), and, ultimately, to independent and community living. Transitioning within and between systems can be a confusing and difficult process for youth with disabilities and their parents to navigate. These transition points require that youth with disabilities and their families move through multiple systems with varying eligibility criteria and program rules that can create disincentives for youth to seek employment and long-term independence (Fraker and others 2014). Moreover, youth with disabilities often face federal, state, and local systems that have inconsistent policies and practices (U.S. Government Accountability Office 2012). They and their parents may experience information overload about systems and services and have fears about what the future will look like after services end. This fragmentation can result in youth with disabilities not receiving services that could improve their long-term employment and independent living outcomes.

#### 1. Low employment

One of the least successful transition points for youth with disabilities is from school to CIE (Luecking and Wittenburg 2009). People with disabilities are less likely to participate in the labor force than people without disabilities. Transition-age youth with disabilities experience low employment rates, especially those with significant disabilities, including intellectual and developmental disabilities and autism (Roux and others 2017). In 2018, people with disabilities ages 16 to 19 had a labor force participation rate of 24 percent, which is significantly lower than the 36 percent rate of people without disabilities in the same age group (Bureau of Labor and Statistics 2019). The disparities increase between the ages of 20 and 24; in this age group, people with a disability have a 45 percent labor force participation rate compared with a rate of 74 percent among their counterparts without a disability. These disparities demonstrate that people with disabilities are not fully included in CIE during critical years of the transition into adulthood.

This employment disparity is important because employment is increasingly considered an important social determinant of health (Healthy People 2020). Employment has a direct impact on financial security, and it can improve access to benefits such as health insurance, which is important for individuals with complex medical needs and disabilities. Unemployment, which is experienced at higher rates for people with disabilities than for people without disabilities, is associated with

negative health outcomes such as depression and physical pain (Burgard and Kalousova 2015; Dooley, Fielding and Levi 1996).

#### 2. Service fragmentation and lack of access to effective services

The Individuals with Disabilities Education Act and the Rehabilitation Act of 1973, as amended by Title IV of the Workforce Innovation and Opportunity Act (WIOA), provide clear guidance on the importance of transition services for youth with disabilities. They both indicate that transition services must include collaborative partners and be outcome oriented, with a focus on activities such as CIE. The existing transition landscape comprises a variety of public services, including VR, benefits counseling, Medicaid, and education. However, some of these services are often disconnected from the private health care sector (Stange 2009). For example, medical providers do not typically provide referrals for VR or benefits counseling.

Youth SSI recipients might have difficulty understanding and navigating work incentives that are offered by the Social Security Administration (SSA) to encourage employment among those receiving federal disability benefits. This lack of understanding might lead families to undervalue the benefits of youth's employment and underuse SSI work incentive provisions (Honeycutt and others 2018; U.S. Government Accountability Office 2017). Moreover, fear of losing benefits, such as Medicaid, can be a significant barrier to employment for youth SSI recipients (Tremblay and others 2006).

As noted above, the transition from pediatric to adult health care is a critical point for individuals with disabilities and their families. However, the health preparation process often does not include other transition elements such as employment, education, community integration, and independent living. Often, the health care setting omits these perspectives. Individuals with disabilities and their families are left to navigate multiple siloed systems and transition elements without a comprehensive road map for the systems and processes that contribute to a fulfilling and healthy life in adulthood, despite multiple conversations and an involved transition planning process. Although education and employment systems have become more integrated and collaborative under the WIOA, fragmentation still exists among health care, education, community living, and employment systems. This continued fragmentation suggests a need for greater alignment among existing supports to achieve better outcomes for youth with disabilities.

#### B. What supports help improve employment?

#### 1. Case management has demonstrated benefits for youth SSI beneficiaries

According to the Federal Partners in Transition Workgroup (2015), a "coordinated application of resources and effort" (p. 4), including coordination among educators, VR counselors, and staff of other community organizations, can improve employment outcomes for youth with disabilities (Luecking and Wittenburg 2009; Honeycutt, Martin, and Wittenburg 2017). The proposed intervention in multidisciplinary clinics will build on the successful components of PROMISE that involve intensive case management and benefits counseling (Crane and others 2019).

The U.S. Department of Education, U.S. Department of Health and Human Services, U.S. Department of Labor, and SSA collaborated to jointly fund PROMISE with the goal of improving employment and educational outcomes of youth SSI recipients (Honeycutt and Livermore 2018). The funding initially supported demonstration sites and one consortium of states in 2013, the Achieving Success by Promoting Readiness for Education and Employment (ASPIRE) consortium, in which Colorado participated. Key components of the ASPIRE intervention included case management, benefits counseling, and work experiences, all of which are similar to the services included in this paper's proposed intervention. A greater number of in-person case management meetings in Years 1 and 2 of the ASPIRE intervention increased participants' probability of later employment (Ipsen and others 2019). With case management as a cornerstone of the intervention, ASPIRE also led to increases in the use of benefits counseling and employment-promoting services, including a 15 percent increase in the number of youth who applied for VR services (Mamun and others 2019).

#### 2. Benefits counseling improves earnings

With greater education, coordination, and targeted counseling on benefits and financial literacy, the fears of youth and their families can be transformed into a belief that employment can lead to a sustainable health and financial future that does not rely on SSI. Benefits counseling can be effective in improving outcomes for youth as they transition to adulthood. Studies have shown that those who receive benefits counseling have improved employment outcomes and reduced dependence on benefits, outcomes that ultimately lead to overall cost savings for SSA (Kregel 2012; Wilhelm and McCormick 2011). Additionally, benefits counseling has been found to increase mean earnings for beneficiaries and increase their use of work incentives (Tremblay and others 2006). Youth SSI recipients enrolled in the Wisconsin PROMISE initiative experienced significant improvements in employment outcomes after receiving benefits counseling—most notably, compared with those who did not receive benefits counseling, they were more than twice as likely to gain employment and more than four times as likely to earn income exceeding the SSA's substantial gainful activity threshold (Schlegelmilch and others 2019). However, these findings are correlational and may have been influenced by selection issues. Nonetheless, the literature suggests that benefits counseling can have a positive impact on employment and earnings outcomes for youth SSI recipients.

#### 3. Multidisciplinary clinics are an avenue for addressing transition challenges

Pediatric multidisciplinary clinics offer a setting where patients with disabilities, including youth receiving SSI, can obtain coordinated services designed to promote their employment. Multidisciplinary clinics (also known as multimodality clinics) are defined as "a group of health care professionals who have cognitive and procedural expertise in different areas of care delivery and can efficiently manage complex medical conditions" (Tyler and others 2015, p. 1). These clinics often comprise of a variety of clinicians, including doctors, nutritionists, nurses, social workers, psychologists, and speech, occupational, physical, and rehabilitation therapists, who work together to address the different components of patients' health and wellness, improve health outcomes, and provide cost-effective care.

Given the large number of youth being served in multidisciplinary clinics, the high degree of trust youth SSI recipients and their families have established with their medical providers, and their interaction and engagement with coordinated care, multidisciplinary clinics provide an innovative setting to implement the proposed intervention. Medical providers represent influential agents because youth and families consider their health care knowledge and treatment planning when making decisions. Youth SSI recipients and their families develop high levels of trust in their medical providers because the relationship is "deeply personal and can be profoundly life-altering," sometimes stretching from the patient's infancy into young adulthood (Thom, Hall, and Pawlson 2004, p. 126). Therefore, promoting knowledge about and a focus on employment and self-sufficiency among medical providers might support youth and parents with those goals. Although youth SSI recipients receive transition services through their school districts, they may not have the established trust with their teachers and coordinators that they have with their medical providers. Additionally, youth SSI recipients and their families may look to their medical providers for guidance on safe and appropriate employment given the youth's health condition.

Families of youth with special health care needs desire service integration. About 40 percent of families participating in the 2009–2010 National Survey of Children with Special Health Care Needs expressed dissatisfaction with their transition services (Ciccarelli, Gladstone, and Armstrong Richardson 2015; U.S. Department of Health and Human Services 2013). A lack of multidisciplinary teams to provide transition supports contributes to that dissatisfaction. Knowing this, service delivery that connects patients with employment supports should be expanded into the private health care sector, given the large number of patients who receive SSI and Medicaid benefits. Youth SSI recipients and their families might never explore work incentives, Medicaid buy-in programs, or employment because they are highly focused on how to maintain health insurance and remain on benefits. Health care and health insurance are critical for individuals with disabilities, and many fear losing benefits during the transition to adulthood. Thus, framing information and referrals to support employment with a particular emphasis on health care and health insurance needs might be effective for promoting employment.

#### 4. Integrated treatment teams can have an employment focus

Integrated treatment teams have been used successfully in the evidence-based practice of Individual Placement and Support and rely on integrating an employment specialist into the behavioral health care team. Integration involves shared office space, collaborative care, and goal setting (Becker and others 2015). Although integrated treatment teams have become widely accepted in behavioral health settings, they have not been widely adopted in medical treatment teams. This intervention proposes the expansion of the integrated treatment team model into multidisciplinary health clinics to promote employment for youth SSI recipients.

In addition to coordinated services, expectations of employment and hands-on, practical work experience are two factors associated with employment for transition-age youth after high school (Carter and others 2012). According to the Center for the Advancement of Policy on Employment for Youth 2020, , both paid and unpaid work experiences have a high value for students with disabilities and assist them in gaining jobs with higher wages after they graduate from high school.

VR agencies are uniquely positioned to assist students with disabilities in completing paid and unpaid work experiences, thereby improving their long-term employment outcomes, but VR services might be underutilized by youth.

# **III. Proposed intervention**

The proposed intervention offers youth SSI recipients and their families case management and other services to support employment as part of their care at multidisciplinary care settings (Figure 1). It aims to reduce service system fragmentation through coordination and communication between public programs and the private health care sector, with the goal of promoting the long-term employment and independence of youth SSI recipients. Early intervention beginning at age 14 will offer youth SSI recipients the opportunity to be referred to VR services and benefits counseling and to plan for their transition from youth to adult medical care. Providing this intervention to youth SSI recipients will promote SSI as a temporary solution to financial and medical needs, and it will emphasize CIE as a favorable long-term solution.

Given the complexity of their conditions and the need to remain on Medicaid to assist with high medical costs, those with intellectual and developmental disabilities (IDDs) and significant medical conditions might be more likely to seek adult SSI benefits and remain on SSI indefinitely after a successful age-18 redetermination. Medical providers in multidisciplinary clinics report that youth SSI recipients and their families frequently ask questions regarding independent living, employment, Social Security benefits, and health insurance. While conducting research for this paper, the authors heard from medical providers that they are frequently asked about SSI benefits and encourage families to apply for adult SSI benefits on behalf of their youth. Those providers also reported that they were less knowledgeable about employment-related supports and that they encouraged their patients to apply for adult SSI benefits because their patients need Medicaid coverage to continue accessing their health care.

The following sections describe the focal population and intervention services and present a logic model illustrating how the intervention will lead to the intended outcomes.

Integrated treatment team Medical specialists Employment questions Employment-focused Integrated treatment team and providers case manager focused on employment at all appointments Youth receiving SSI Seeking care at Utilizing Medicaid Ages 14 to 17 multi-disciplinary clinics Services Monthly check-ins and Service referrals and assistance Case management care coordination Community partnerships Interagency communication Vocational Benefits Education Medicaid and coordination rehabilitation counseling

Figure 1. An integrated treatment team intervention in a health care setting

#### A. Integrated treatment teams in multidisciplinary health clinics

Multidisciplinary clinics serve people with a diverse range of disabilities, including individuals with IDDs, co-occurring disorders, and complex medical conditions. These clinics often address critical patient issues outside of health care, including independent living, employment, benefits (such as SSI and Medicaid), guardianship, and community living. The role of these clinics is broad, and they support youth with disabilities at various transition points. The framework of integrated treatment teams and the population of patients with complex disabilities they treat make multidisciplinary clinics an ideal setting for implementing the proposed intervention.

Adding employment-focused case managers to an existing integrated health team improves the feasibility of care coordination and communication, which is critical to the proposed intervention because of the intervention's focus on integrating private health care with public programs. Strategic partners of this intervention include VR agencies, benefits counselors, schools, and Medicaid agencies.

The specific components of the intervention are as follows:

- 1. The integrated treatment teams within multidisciplinary clinics add case managers to the team. Case managers have knowledge of employment resources and state-specific public programs.
- 2. Starting at age 14, patients are assigned to a case manager.
- **3.** The case manager provides ongoing support, referrals, and assistance to the youth SSI recipients and engages them at least once per month. The case manager also provides referrals, coordinates care, and maintains communication between state agencies and programs (including VR, Medicaid, education, and CWICs and CPWICs).
- 4. The integrated treatment team maintains engagement with youth, their families, and other team members on health and employment issues. The standard appointment questionnaire will include questions on employment and transition services or resources to determine the use of employment supports. This assessment will encourage all members of the treatment team to remain engaged with the youth's employment progress.

Thus, the proposed intervention will embed an employment-focused case manager into an existing integrated treatment team. The case manager and multidisciplinary clinic providers will work together to support the youth SSI recipient in managing complex medical needs through the framework of supporting the youth's goals in the transition to adulthood, which can include independent living, employment, higher education, and community living. Those staff will work collaboratively with other treatment team members to assist with setting goals for employment. The employment-focused case manager who assists youth SSI recipients will be trained specifically on the Employment First philosophy, CIE, Medicaid waivers and VR funding for supported employment services, benefits counseling, and pre-employment transition services.

In this intervention, patients will receive care as usual in multidisciplinary clinics, and their families will meet with the medical providers who are involved in their care for their medical diagnosis and/or disability. For example, CHCO holds many multidisciplinary clinics for diagnoses such spina bifida, osteogenesis imperfecta, and Turner syndrome. Visits to multidisciplinary clinics are triggered when the patient turns 14 years old and typically follow a one-day model, in which multiple specialists meet with patients and their families to discuss the transition from pediatric to adult health care. During the initial visit, youth and families address health maintenance and management issues with various providers and specialists. The intervention will leverage that one-day model to initially identify youth SSI recipients and will provide intensive case management and care coordination after the initial visit. As part of the initial visit, patients and their families will meet with a case manager to address access to and coordination of the different systems that are available in the state for people with disabilities to promote independence and transition to employment, and the case manager will discuss employment as a social determinant of health.

# B. Population of interest

The population of interest for the intervention is youth SSI recipients between the ages of 14 and 18 who use Medicaid as their primary insurance for medical appointments in multidisciplinary clinics, such as children's hospitals. One in 20 hospitals in the United States is a children's hospital, and an estimated 7 percent of all children seen in children's hospitals are SSI beneficiaries (Children's Hospital Association 2020). The intervention would add a question on the standard health screening

questionnaire that is administered in pediatric multidisciplinary clinics at the start of each visit to ask patients if they receive SSI. Identification and selection of participants would proceed as follows to ensure the identification of all potential youth SSI recipients:

- 1. Before the appointment, if Medicaid is listed as the patient's insurance source, scheduling staff will be prompted to ask about and verify the youth's SSI status. Youth ages 14 to 18 who are being served in multidisciplinary clinics are asked if they are "receiving SSI benefits" during the routine health screening questionnaire at the beginning of their medical appointment.
- 2. If they answer "yes" to receiving SSI benefits, they will be referred to a case manager for additional services.
- **3.** If they answer "no" to receiving SSI benefits, they will still be asked this question during all future visits to ensure their inclusion in the intervention if their circumstances change.

#### C. Intervention services

During the initial and subsequent meetings, the case manager will share with the youth and family the available resources and referrals to benefits counseling, VR, and other state services that will help streamline the youth's transition into an adulthood that includes employment. Intensive case management will follow, with contact occurring with youth SSI recipients and their families at least once a month for 30 minutes. The monthly case management will occur through telehealth visits, and ideally, the integrated treatment team will meet once every quarter with the youth and their family either through telehealth visits or in person. Outside of the one-day multidisciplinary clinic, members of the youth's integrated treatment team will maintain collaborative communication through the online patient portal to share notes.

The following sections provide more detail about the intervention's service components.

#### 1. Case management

Medical providers are not knowledgeable about public programs related to employment and SSA. A case manager who is skilled in assessing youth's nonmedical needs and knowledgeable about the services available to meet those needs can provide integrated treatment teams with this expertise and ability to navigate the broader service system. Engagement from youth SSI recipients and their families will be critical to the implementation of case management strategies and, thus, to the success of the intervention. Fortunately, youth SSI recipients and their families are already engaged in the health care setting where they will receive initial information from case managers. As a trusted member of the integrated treatment team, the case manager will provide referral information and help facilitate engagement in the subsequent steps of the intervention, with the intent of sustaining engagement outside of the health care setting where the referral is being provided.

As in the ASPIRE case management intervention (Ipsen and others 2019), case managers will provide intensive case management and meet with youth SSI recipients in their multidisciplinary clinics or at VR appointments at least once per month for 30 minutes. Case management appointments will address goal setting for employment and follow up on referrals.

Case managers will receive training on employment (reflecting an Employment First philosophy), CIE, and public employment supports for youth SSI recipients. According to the U.S. Department of Labor, Employment First is a framework founded on the idea that all individuals, regardless of their severity of disability, can experience full participation in their community and in integrated employment. The knowledge gained from training will help the case managers provide necessary referral information to youth SSI recipients to connect them to supports that provide resources to gain employment. Case managers will become trusted members of integrated treatment teams by building a therapeutic relationship with their patients (Coffey 2003; Neale and Rosenbeck 1995). In combination with their Employment First training, case managers will use principles of self-determination to encourage youth's involvement in their vocational journey.

#### 2. Service referrals and assistance

The case manager's emphasis on ensuring that youth SSI recipients have access to employment-related supports will center on referrals to and coordination with state VR services and benefits counseling.

#### a. VR services

A foundation of the proposed intervention is maximizing the use of the VR system as a framework for delivering job development supports for youth SSI recipients. People who receive SSI, including students and youth with disabilities, are presumed to be eligible for VR services. Presumed eligibility for VR services can expedite access to employment- and disability-related VR services, such as job development and placement supports, that improve CIE outcomes (Alsaman and Lee 2017). This access, though, depends on the availability of services from the VR agency; some agencies impose an order of selection to limit applications when their resources are scarce (Hager 2004). In addition to VR services, youth SSI recipients may be eligible to access pre-employment transition services from VR agencies or schools while they are still in high school. These services support early job exploration, self-advocacy, counseling on postsecondary education, workplace readiness training, and work-based learning experiences.

Case managers will provide comprehensive referral services that include initial outreach to the referral source and ongoing coordination and assistance. Initially, the case manager will determine which VR office will serve the youth SSI recipient. (In Colorado, the youth's zip code determines their VR office.) Additionally, the case manager will assist the youth in gathering all necessary documents for the VR eligibility process. This includes medical records with appropriate releases and SSA letters or other documents verifying receipt of benefits. The case manager will also help the youth SSI recipient and his or her family complete the VR application and schedule an intake appointment. At VR appointments, the case manager will be available to help describe medical needs, management strategies, and other medical information related to helping the youth SSI recipient gain and maintain employment. After those VR appointments, the case manager will consult with the integrated treatment team to discuss any changes in medical needs and treatment that relate to employment and will collaboratively discuss progress toward employment outcomes.

#### b. Benefits counseling services

Benefits counseling is fundamental to the desired outcomes of the intervention. Certified benefits counselors (CWICs and CPWICs) will provide benefits counseling services that are designed to maintain health care and support employment by increasing youth and families' knowledge of underutilized SSI work incentive provisions and other resources. Incorporating benefits counseling that recognizes the necessity of health care, alternative means for obtaining coverage, and the importance of employment for specialty adult medical care will encourage youth to pursue employment.

Case managers will provide referrals to CWICs and CPWICs throughout Colorado, depending on the youth SSI recipient's location. Benefits counseling is provided as a no-cost service for individuals determined eligible for VR services and for SSI recipients who are not VR clients through the Work Incentives Planning and Assistance (WIPA) program. Once a referral to VR has been made and the case manager has helped to coordinate the youth SSI recipient's required documents to determine eligibility, he or she will assist with the referral and coordination for benefits counseling. The case manager will assist the youth SSI recipient and his or her family with gathering the necessary

# SSI work incentive provisions (SSAB 2019)

- Plans to Achieve Self-Support can be used to plan for future employment goals and purchase items that support those goals.
- Impairment-related work expenses and blind work expenses are disability-related items purchased by the worker and needed to work; the expenses are deducted from countable income when computing SSI payments.
- Sections 1619(a) and (b) allow SSI recipients to maintain Medicaid eligibility after their earnings exceed the threshold that makes them ineligible for cash benefits.
- The Student Earned Income Exclusion excludes income from work in calculations of SSI payments for students.
- Section 301 allows for continued payment of SSI and Social Security Disability Insurance benefits to recipients who have been medically ceased because they are participating in an appropriate program of VR, employment, or other support services.

Other supports available to youth ages 14 to 17

- Medicaid buy-in (age 16)
- Medicaid waiver services
- Achieving a Better Life Experience accounts
- Individual development accounts

documents for the CWIC or CPWIC to complete their benefits counseling.

The benefits counselor will focus on work incentive provisions and other supports, shown in the call-out box, to develop a detailed benefit summary and analysis (BSA) for the youth. The BSA will be used to increase the youth's knowledge of how work affects benefits, with the intent of decreasing fear of losing benefits after gaining employment. In addition to providing guidance on underutilized work incentive provisions, CWICs and CPWICs are able to provide health insurance planning. Currently, a large portion of the transition information that is disseminated to patients at multidisciplinary clinics such as CHCO relates to the pediatric-to-adult health care transition and how to maintain coverage while still seeing specialty providers. The expertise that CWICs and CPWICs have in navigating health insurance systems is a needed addition to those discussions. With permission from youth and their families, the BSA will be shared with the case manager. The case manager will communicate BSA information related to health insurance options with other members

of the integrated treatment team to ensure that all members of the team understand the insurance options as they relate to the pediatric-to-adult health care transition. Because the population of interest ranges from 14 to 18 years old, benefits counselors will tailor BSAs depending on the youth SSI recipients' age. For recipients between 14 and 16 years of age, the benefits counselors will aim to raise expectations of employment by decreasing youth and their families' fear about working while on benefits. As youth age, BSAs will incorporate more information about work incentives. For example, as youth get closer to age 18, their BSAs will be more focused on work incentives such as Section 301 and the Student Earned Income Exclusion.

#### 3. Monthly check-ins and case management

The integrated treatment team will maintain engagement with the youth, family, and other team members through intensive case management during monthly check-ins. Youth engagement will be measured by attendance at case management appointments, completion of referrals, progress in VR services and benefits counseling, and changes in employment outcomes. The initial interaction with the youth will occur in the multidisciplinary clinic in combination with his or her medical appointments, with the goal of improving engagement. As part of the integrated treatment team model, future case management appointments will occur at the same location as the youth's medical appointments, but employment case management may not.

The case manager will advocate for inclusion in medical appointments to complete employment-related case management if it is agreed upon by other members of the integrated treatment team. If a youth SSI recipient is not using the services he or she has been referred to, the case manager will collaborate with other members of the integrated treatment team to encourage additional team members to discuss employment supports with the youth. Families may choose not to access a service for a variety of reasons. The case manager will ask the family why they chose not to use the service and can potentially provide additional information about it. For example, if a family is hesitant to use benefits counseling because it involves disclosing financial information about Social Security payments, the case manager can provide reassurance about confidentiality and security. However, the family's preferences and comfort will always be a priority, and their choice to access or not access services will be respected.

#### 4. Community partnerships

The intervention is predicated on relationships of the case manager and other members of the integrated treatment team with various community partners. Potential partners include not only VR agency staff and benefits counselors, as discussed above, but also secondary and postsecondary education agencies, Medicaid administrators, and workforce development centers. These entities will need information about the intervention and its intended outcomes, knowledge about the structure and services of multidisciplinary clinics, and an understanding of common aspects of SSI and SSA work incentives. In addition to providing services to the focal population, they might refer youth to the clinics for possible inclusion in the intervention. Case managers will therefore conduct outreach to various community entities about the intervention and develop consistent and regular processes for interagency communication and coordination. These processes will promote referrals for youth

to ensure they receive intended services and will facilitate ongoing connections between the multidisciplinary clinic and individual providers as they work toward the youth's goals.

#### 5. Diverse care needs

The intervention relies on a therapeutic relationship developed through rapport building between the case manager and the youth SSI recipient and his or her family. For that reason, it is critical that the needs of diverse families are considered in case management so that disengagement does not occur because of cultural or linguistic differences. Accommodations, resources, and language interpreters are readily available in the multidisciplinary clinic setting and will be available for the population of interest in the intervention. The integrated treatment team will discuss the cultural considerations of the families to ensure that the most appropriate care is being provided.

# D. Theory of change

The conceptual model shown in Figure 2 summarizes the intervention inputs, outputs, and short-and long-term outcomes that youth SSI recipients might experience as a result of participating in the intervention. Case management delivered through the proposed intervention will support youth SSI recipients and their families in obtaining benefits counseling and VR services. Most importantly, an integrated treatment team will consistently encourage employment as the preferred option, which aligns with the Employment First philosophy. Through these efforts, youth and families will become more informed about employment supports and opportunities and less concerned about the consequences of employment for continued Medicaid or other health insurance coverage and SSI payments. This in turn will lead to CIE in the long term, greater use of work supports, and, ultimately, reduced reliance on SSI.

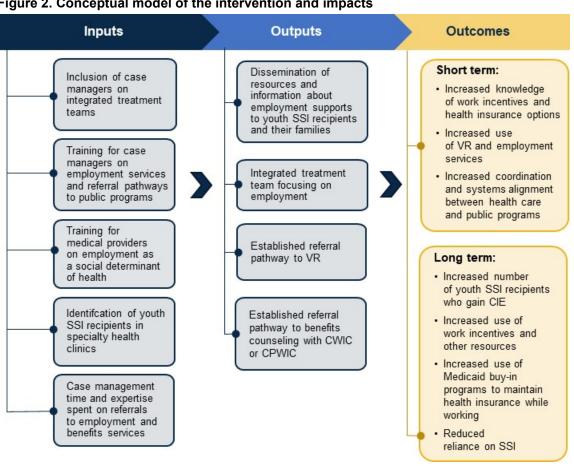


Figure 2. Conceptual model of the intervention and impacts

CIE = competitive integrated employment; CPWIC = Community Partner Work Incentives Counselor; CWIC = Community Work Incentive Coordinator; SSI = Supplemental Security Income; VR = vocational rehabilitation.

# IV. Piloting and evaluating the intervention

# A. Pilot implementation

The intervention will be piloted at CHCO in various multidisciplinary clinics that serve youth SSI recipients. In CHCO, the multidisciplinary clinic model allows patients to see a variety of specialists and providers without needing to make multiple visits to the hospital for their care. Furthermore, the care is streamlined and coordinated for patients who have complex medical diagnoses and often have a difficult time managing multiple health visits and specialists (Meguid and others 2015). Therefore, incorporating an employment focus in the medical case management is feasible and appropriate.

CHCO has multidisciplinary clinics that serve youth with autism spectrum disorders, IDDs, and other complex medical conditions. These clinics serve an average of 100 patients per year, with most patients using Medicaid to access services. Providers suggest that most of the patients are also

receiving SSI benefits. The authors estimate that a pilot intervention will identify and serve approximately 50 SSI recipients across three to five multidisciplinary health clinics at CHCO.

The pilot will cover a 24-month period, which allows sufficient time for youth SSI recipients to receive integrated case management services, complete referrals to various agencies, participate in employment-related activities, obtain benefits counseling, and achieve early employment outcomes, including work-based learning opportunities. All of these represent opportunities to gauge the success of the intervention and improve upon the service model.

The intervention requires three initial preparation activities.

- 1. CHCO will hire case managers, who will be current CHCO employees in either case management or patient navigator positions. They will have previous training working with patients with disabilities and will have knowledge on coordinating and aligning referrals and systems. The case managers will receive 40 hours of initial training along with opportunities for ongoing training and technical assistance. That training will focus on the intervention processes, public support programs and referral pathways, the basics of benefits counseling, and other employment-related information; therefore, the case manager will be comfortable discussing the importance of employment with youth SSI recipients and their families.
- 2. After being hired, case managers will coordinate with other members of the integrated treatment team. Case managers will hold an initial meeting with representatives from the different multidisciplinary clinics participating in the pilot, the training entity (Colorado Office of Employment First [COEF]), and the section head of developmental and behavioral pediatrics to discuss the pilot, intervention, and evaluation.
- 3. Case managers will conduct initial meetings with local VR offices and benefits counseling providers to confirm the referral pathway. These meetings will also offer an opportunity to set clear expectations about the partners' respective involvement in the meetings and in medium-and long-term follow-ups. According to the Centers for Disease Control and Prevention (n.d.), strategic partnering should include common goals and priorities. Partnership building between CHCO and various agencies will identify the common goals and priorities that are shared in serving youth SSI recipients.

#### B. Costs of implementing the pilot

Because the intervention relies to a large extent on existing services, its potential costs mostly lie in the required staffing needed to successfully implement the case management component of the intervention. The authors estimate that case managers will need to be 1.0 full-time equivalents (FTEs) to complete the job duties necessary for the intervention at the proposed scope and size at one clinic in CHCO.

Case manager training represents no cost to CHCO because it will be obtained through COEF, which is housed in the JFK Partners program within the University of Colorado School of Medicine's Department of Pediatrics. COEF receives funds to provide training and technical assistance on Employment First principles, supported employment models, and benefits counseling

to a variety of stakeholders. The COEF staff hold state licenses and national certifications, including CPWIC certification for benefits counseling, and are qualified to provide the training to case managers in the pilot. (Although the training for the proposed pilot will not have a cost for CHCO, this option cannot be assumed for other states and multidisciplinary clinics implementing the intervention.)

Another potential cost is in the time needed to train health care team members on employment services for youth SSI recipients. Training the entire integrated health care team on the addition of case management and referrals to services such as VR and benefits counseling will increase knowledge about employment services for youth with disabilities, with the desired outcome of increasing overall expectations for employment. Following training, all members of the integrated treatment team should understand Employment First principles and expect that CIE is not only possible but the preferred option for youth with disabilities, including youth SSI recipients.

#### C. Evaluation

The small number of potential youth SSI recipients who will be served in the pilot suggests that a rigorous experimental or quasi-experimental evaluation using a comparison group to assess outcomes would not be feasible. Nonetheless, a small proof-of-concept evaluation of the pilot would demonstrate the potential for incorporating employment-oriented case management and referrals in the health care delivery setting and allow for an assessment of the processes involved. Table 1 lists examples of the types of questions the pilot could address. The primary sources of data to address the questions would be (1) interviews of staff from CHCO and its partner organizations, including VR and benefits counseling staff; (2) data collected for purposes of managing the intervention and tracking youth services and outcomes; and (3) periodic interviews with youth and their families using brief, standardized questionnaires administered by mail, email, or phone or in person during clinic visits. Because of the limited duration of the pilot, the evaluation could assess only short-term outcomes.

Table 1. Example research questions a pilot could address

	Data source		
Research question	Staff interviews	Program administrative data	Youth and family surveys
Implementation			
How were case managers hired and trained? How difficult was it to identify qualified staff?	Х		
How were providers trained on the intervention?	Х		
What external partners were recruited and what challenges did CHCO encounter in recruiting and collaborating with external partners?	Х		
What changes to clinic forms were needed to identify youth receiving SSI? How successful was the identification approach?	Х		
How receptive were staff to the training and intervention? What challenges did they experience in implementing the intervention? How were those challenges resolved? Were any changes to the original intervention model required?	Х		
Service outputs			
How many youth receiving SSI did the intervention serve?		Х	
What percentage of youth received referrals to VR services?		Х	
What percentage of youth received VR services?			Х
What percentage of youth received referrals to benefits counseling?		Х	
What percentage of youth received a BSA?			Х
Outcomes			
How knowledgeable are youth and families about work incentive provisions and employment options?			Х
Have youth engaged in employment preparation activities?		Х	Х
Have youth engaged in paid, competitive employment?		Х	Х
Have youth used SSI program provisions to support employment?		Х	Х

BSA = benefit summary and analysis; CHCO = Children's Hospital Colorado; SSI = Supplemental Security Income; VR = vocational rehabilitation.

# V. Potential implementation challenges

Youth and family engagement in the intervention, particularly with case management, will be the primary challenge to implementation. During case management appointments, youth and family participation in VR and benefits counseling will be encouraged through referrals. In informal discussions with the authors, families have shared that it is incredibly difficult to navigate multiple systems, attend different appointments, and organize the paperwork and billing for each agency. The multidisciplinary clinic model aims to reduce this burden on families by bringing a variety of providers together to see the youth SSI recipient and family at a single appointment, then providing ongoing supports.

As part of the intervention, rapport building between case managers and the youth SSI recipients and their families will be critical for continued engagement. Case managers should be seen as trusted members of the health care team, such that youth and families hold their case manager in as much esteem as they do their doctors and nurses. The initial case management interaction will occur at the collaborative multidisciplinary clinic appointment to eliminate the challenge of attending a separate appointment for the start of case management services. However, ongoing engagement in case management and referrals may be a constant challenge. Case managers will conduct outreach to youth SSI recipients and their families at least once a month to encourage engagement and follow up on referrals to various agencies and services.

Integrated treatment team coordination can be difficult to initiate and sustain. It requires systems alignment and collaborative communication across settings and specialties. The proposed intervention aims to mitigate this barrier by implementing the intervention within existing structures with demonstrated success in collaborative service delivery. Changing culture and attitudes can be achieved through the sharing of success stories, peer mentorship, and continuing education for providers on integrated treatment teams. These aspects are anticipated to be positive spillover effects of the intervention.

Another potential challenge is the lack of CWICs and CPWICs who provide benefits counseling under the WIPA program. Access to benefits counseling and completion of BSAs are critical components of the intervention and will be successful only if CWICs and CPWICs have the capacity to deliver benefits counseling to youth SSI recipients. For example, in Colorado, CWICs and CPWICs can be accessed through VR, but there may be waiting lists and prioritization of SSI recipients who are currently employed over SSI recipients who are looking for employment. Average wait times are currently between 30 and 90 days. Because the intervention begins when youth SSI recipients are 14, it allows time even for those on a waiting list to complete benefits counseling services and receive a BSA before they turn 18. Accessing and receiving VR services can be a challenge depending on location and wait times when a VR agency operates under an order of selection that prioritizes services. Order of selection is not currently in effect in Colorado, but it might be in other states.

A final potential challenge is that VR counselors might not be aware of youth's health issues. This problem can be resolved through additional training and exposure. Multidisciplinary clinics at CHCO serve a variety of patients with complex medical needs and a variety of diagnoses. For example, one multidisciplinary clinic at CHCO is the Prader-Willi Syndrome Clinic. Prader-Willi syndrome is not a common disability, and VR counselors receiving referrals from the clinic may need additional information on the condition. Although VR counselors are knowledgeable about many medical aspects, they may not be familiar with every condition associated with referrals from the multidisciplinary clinics.

# VI. Replicability and sustainability

If the evaluation of the pilot suggests that the proposed intervention holds promise, this intervention could be replicated in other multidisciplinary clinics at children's hospitals across the

United States. The setting was initially chosen for the intervention because it offered an existing structure of integrated treatment teams working collaboratively to achieve desired outcomes for youth with disabilities. Any other setting that includes an integrated treatment team with a focus on transition could implement and replicate the intervention. For example, in reviewing multidisciplinary clinics with transition resources, the authors identified Seattle Children's Hospital as having services similar to those at CHCO.

Replication also seems feasible because the intervention relies heavily on existing systems that are present and accessible in all states, include state VR agencies and benefits counseling services funded by SSA or other organizations. For example, the Ticket to Work and Work Incentives Improvement Act of 1999 authorized SSA to award grants, contracts, or cooperative agreements to provide community-based work incentives expertise to SSI beneficiaries with disabilities. SSA currently has 82 cooperative agreements throughout all 50 states, the District of Columbia, and the U.S. territories. These cooperative agreements establish WIPA programs, which are responsible for providing what is commonly referred to as benefits counseling or benefits planning services. These services are free to those eligible. A WIPA program is available to recipients of disability-related SSI or Social Security Disability Insurance ages 14 through 64. Transition-age youth are a priority category for service provision under the WIPA programs, and progress on the employment continuum does not factor into service provision priority.

With improved communication, coordination, and training on the benefits of employment and the availability of public programs for youth with disabilities, the private health care setting can add referrals to employment-related supports and benefits counseling in their transition planning with integrated treatment teams. The sustainability of the intervention will rely on the ability to fund the case management and training components and develop the needed community partnerships. The potential for the intervention to be adopted and sustained could be enhanced if the intervention's case management services can bill Medicaid under state waivers. Many case management services are currently included in Medicaid fee schedules, and the approval to bill for services in the intervention will contribute to its sustainability and replicability in other settings and states.

#### VII. Conclusion

Unemployment and underemployment for youth with disabilities can lead to a variety of negative outcomes, including poor health and financial insecurity. The World Health Organization's Commission on Social Determinants of Health (2008) has listed employment as a determinant of health, which highlights the critical intersection between employment and health outcomes. The proposed intervention aims to expand knowledge of and access to key employment-related supports—VR and benefits counseling—among youth SSI recipients and their families by adding case managers to integrated treatment teams in multidisciplinary health clinics at CHCO. Case managers will receive specialty training in employment-related supports and work closely with youth SSI recipients and their families, providing them with referrals and ongoing support to navigate employment systems. The short-term effects of the intervention will include increased knowledge of work incentives and health insurance options, increased use of VR and other employment services, and increased coordination and systems alignment between health care and public programs. In the

long term, the intervention can lead to increased CIE and decreased use of public supports for youth SSI recipients.

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