



Health care transition quadruple aim outcomes for IDD: Scoping review

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ABSTRACT

Purpose: Structured HCT models addressing planning, transfer, and integration into adult care for adolescents and young adults with childhood-acquired chronic conditions are becoming more prevalent. However, consensus on outcome measures to assess health care transition (HCT) interventions particularly for intellectual and developmental disabilities (IDD) population is lacking. This scoping review identified potential HCT outcome measures for young adults (aged 18–26) with IDD using the Quadruple Aim Framework.

Methods: On August 6, 2021 and April 27, 2023, Medline Ovid, Embase, Web of Science, PsycINFO, and Cochrane databases were searched using the terms “young adult,” “intellectual disability,” “developmental disability,” “cognitive dysfunction,” “autism,” “cerebral palsy,” “spina bifida,” and “transition to adult care.” Searches were limited to publications in English and published from 2000 to present. Observational and experimental (qualitative or quantitative) studies were included if participants were young adults (median/mean ages 18–26) with IDD (Autism, cerebral palsy, Down syndrome, spina bifida, or other IDD-related conditions) and study outcomes addressed one of the Quadruple Aim domains (population health, patient/family experience, cost/utilization, and healthcare provider/caregiver experience). Studies were excluded if participants had attention deficit/hyperactivity disorder or learning disability only, if outcomes were primarily educational or vocational, or if publications were reviews, abstracts, or not in English.

Results: One hundred and three articles were included data extraction. Articles were categorized under the Quadruple Aim domains: Population Health (43), Patient/Caregiver Healthcare Experience included (23), Cost/Utilization (24), and Healthcare Provider/Caregiver Experience (15). Most articles were observational and utilized a variety of assessments or internally developed questions as measures.

Conclusions: While studies describing HCT outcomes for the IDD population are limited and measures are inconsistent, studies pertaining to Quadruple Aim outcomes identified in this review can further direct efforts towards consensus and standardization of HCT outcome measures to address the needs of individuals with IDD, their families, and caregivers/providers.

1. Introduction

Intellectual and/or developmental disabilities (IDD) are a group of conditions associated with impairment in cognitive, physical, learning,

language, or behavior areas. These conditions are congenital or begin during the developmental period and impact daily function usually throughout a person's lifetime.^{1,2} Examples of congenital or genetic IDD diagnoses include autism spectrum disorder (ASD), genetic conditions

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such as Down syndrome (DS) or Fragile X, and perinatal/congenital conditions such as cerebral palsy (CP) and spina bifida (SB). Individuals with IDD have a spectrum of behavioral, medical, adaptive, and home/community support needs depending on their cognitive ability, behavior concerns, mobility impairment, and/or medical complexity.

IDD-related congenital diagnoses were previously considered pediatric conditions, but with advancements in pediatric care, technology, and community support, many individuals with IDD are living well into adulthood.³ Amongst young adults ages 18–44 surveyed in the United States in 2016, approximately 16 % had a disability in hearing, vision, cognition, mobility, self-care, or independent living with 10.6 % having a cognitive disability.⁴ Unfortunately, adults with IDD have worse health outcomes compared to their peers without IDD including a more sedentary lifestyle, inadequate emotional support, increased chronic health conditions, lower preventive care rates, and higher acute care use.^{4–7}

Health Care Transition (HCT) is “the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care.”⁸ The HCT process not only refers to the successful transfer of patients from a pediatric healthcare system to an adult healthcare system but the assurance that adolescents and young adults have access to appropriate medical and behavioral healthcare and community supports to optimize their health and wellbeing and avoid preventable exacerbations and complications throughout this transition.^{9,10} Thus, implementation of a high-quality HCT process should result in improved health outcomes. While objectives and tools have been developed to support clinics in implementing the HCT process, consensus is lacking on the definition of high quality HCT and what health-related HCT outcomes should be measured, particularly true for the IDD population.⁹ The Triple Aim framework describes target outcome domains to improve care including population health, patient experience, and cost reduction and has been suggested as an framework for measuring HCT outcomes for those with chronic conditions from childhood.¹⁰ In 2014, the Triple Aim framework was revised to the Quadruple Aim to also include a healthcare provider experience domain, however the Quadruple Aim has not yet been applied to HCT.¹¹

This scoping review aimed to conceptualize potential HCT outcome measurements particularly for young adults (ages 18–26) with IDD using the Quadruple Aim framework.^{12,13} A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and JBI Evidence

Synthesis was conducted, and no current or underway systematic reviews or scoping reviews on the topic were identified. Outcome measures identified may be useful to evaluate structured HCT interventions and guide quality improvement initiatives specifically for youth with IDD.

2. Methods

This scoping review was conducted in accordance with the JBI methodology for scoping reviews to answer the question: what Quadruple Aim HCT outcome measures or concepts are described in published studies for young adults with IDD?¹⁴

2.1. Article inclusion criteria

2.1.1. Concept

Authors categorized HCT outcome subdomains under each Quadruple Aim Framework Domain based on the previously published HCT Triple Aim domains and the Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs Research Protocol and Systematic Review (Fig. 1).^{10,15} As there are fewer HCT studies for the IDD population, studies describing Quadruple Aim outcomes for young adults with IDD, but not explicitly describing HCT were included, and the authors were more inclusive IDD diagnoses that result in adaptive impairment (cognitive or physical) due to a congenital or genetic condition and begin in the developmental period (e.g. neurofibromatosis and smooth muscle atrophy, etc.).

2.1.1.1. Quadruple aim population health domain. The Population Health Domain describes a range of health outcomes for a specific population.¹⁶ The population may be defined geographically, as members of a specified insurance provider, or by a specific condition. Measures in this domain may include condition-specific biological markers (e.g., hemoglobin a1c for Diabetes Mellitus) and condition-specific screening measures (e.g., annual eye and foot screening exams for Diabetes Mellitus), general health and preventive care measures (e.g., obesity and smoking rates) and age/risk-factor screenings (e.g., mammograms or colon cancer screening), mortality rates, mental/emotional health measures (e.g., depression and anxiety screenings), and general or condition specific health-related quality of life (QOL) measures.¹⁶ For those with IDD, condition-specific biological markers are rare, however, condition-related functional and behavioral impairment measures are

Population Health
<ul style="list-style-type: none"> • General health and age-based preventive care • Condition-specific outcomes and mortality • Mental and behavioral health • Self-management/Transition Readiness • Independence • Quality of life
Youth/Family Experience of Care
<ul style="list-style-type: none"> • Patient/Caregiver Healthcare satisfaction • Access/Barriers to care
Cost/Utilization
<ul style="list-style-type: none"> • Utilization of healthcare services • Gaps in care (Healthcare Effectiveness Data and Information Set, Wellness) • Cost per capita
Provider Satisfaction
<ul style="list-style-type: none"> • Healthcare provider experience
Additional domain for this review: Family caregiving experience
<ul style="list-style-type: none"> • The experience of family members as caregivers in the community

Fig. 1. Quadruple Aim Domains and Sub-Domains for Healthcare Transition.

important to include as they may modify community participation, independent living, mental health, and QOL outcomes.^{17–19} Also important to HCT are condition-related self-management, transition readiness assessments, and medical/adaptive assistance need assessments as these measures help determine support needs.²⁰

2.1.1.2. Quadruple aim patient/family experience domain. Patient experience encompasses the range of interactions that patients have with the healthcare system including communication, access, information and decision sharing, and self-management support.²¹ Such interactions take place with medical staff and medical providers in outpatient and inpatient facilities as well as managed care organizations, home health care staff, supply/equipment companies, and other ancillary services. For those with IDD, their family caregivers experience these interactions along with their loved-one with IDD. Individuals with IDD often require increased healthcare services throughout their lives and have notable health disparities.^{22–24} Thus, understanding barriers and facilitators to care access and identifying strategies for effective communication with patients and families is important, and can guide interventions to improving patient experience in both pediatric and adult systems, particularly as they transition to adult care.^{25–27}

2.1.1.3. Quadruple aim cost/utilization domain. The Quadruple Aim framework strives to optimize health while reducing per capita costs of care for the benefit of communities while optimizing utilization, and getting the right care at the right time.¹¹ Understanding how healthcare systems are utilized by the IDD population, disparities in meeting general healthcare effectiveness measures, and the drivers of utilization patterns (e.g., reasons for emergency room utilization for chronic care condition or behavioral exacerbations) can facilitate improvement strategies to decrease high-cost, emergent healthcare utilization, and improve access to timely outpatient care.^{28–36}

2.1.1.4. Quadruple aim provider experience domain. As healthcare provider burnout and lack of care team wellbeing have been associated with poorer patient experience and health outcomes, the need to include provider experience as a healthcare quality outcome became evident.¹¹ Developing team-based communication strategies and workflows as well as having adequate and involved staff have shown to improve medical provider experience.

2.1.1.5. Family caregiving experience. While not typically included in the Quadruple Aim Framework, family caregivers are essential to providing for the on-going medical and daily living support needs of individuals with IDD, it is important to consider the family caregiving experience.^{37,38} This aspect of the caregiver's experience is different from the second domain of patient/family experience in which they are interacting with the healthcare system with and on behalf of their loved-one with IDD as under additional domain. This concept refers to the family caregiver's wellbeing as they fulfill their role in providing medical, behavior, and adaptive living support in the home and community setting for their adult loved-one with IDD.

2.1.2. Context

International studies in all geographic and setting areas (clinic and community) were included. We excluded participants solely with ADHD who can also be categorized as having an IDD diagnosis as this population often requires less decision-making and daily activity support compared to those with congenital or early-childhood IDD diagnoses. As this review is primarily focused on HCT, studies solely describing educational/vocational outcomes without reference to Quadruple Aim health outcomes were excluded.

2.1.2.1. Participants. Studies with participants (n = 5 or more) of young adults (including age range or mean/median age between 18–26

years)³⁹ with congenital or genetic IDD-related diagnoses or their parents, caregivers, and/or health providers were included.² This review included only the young adult age group to focus on HCT outcomes rather than HCT planning measures.

2.1.2.2. Types of sources. Original articles published in English from 2000 to April 2023 in peer-reviewed journals with experimental and quasi-experimental study designs including randomized controlled trials, non-randomized controlled trials, before and after studies, and interrupted time-series studies, as well as, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical or descriptive cross-sectional studies were considered for inclusion. Qualitative interviews and focus groups were also included as these designs are commonly used to describe HCT experience. Reviews, conference abstracts, and opinion articles were excluded.

2.2. Article selection

2.2.1. Search strategy

Medline Ovid, Embase, Web of Science, PsycINFO, and Cochrane databases were searched to identify articles on the topic and medical librarian assisted in developing the search strategy and conducting the search. The strategy was initially created in Medline Ovid using MeSH terms as well as keywords and phrases (see Appendix 1). Search terms used were “young adult,” “intellectual disability,” “developmental disability,” “cognitive dysfunction,” “autism,” “cerebral palsy,” “spina bifida,” “spinal dysraphism,” and “transition to adult care.” The reference lists of included articles were also screened for additional studies. The first database search conducted August 6, 2021 yielded 3705 results. A second database search to update publications was done April 24, 2023 and yielded 182 additional articles.

2.2.2. Study/Source of evidence selection

Following the search, all identified citations were collated and uploaded into Rayyan and duplicates removed.³⁹ Titles and abstracts were screened by two independent reviewers for assessment against the inclusion criteria for the review. Potentially relevant sources were retrieved in full, and their citation details imported into an excel. The full texts of the selected citations were assessed against the inclusion criteria by two independent reviewers, and reasons for exclusion were recorded. Any disagreements between the reviewers at each stage of the selection process were resolved through discussion, and/or with an additional reviewer.

2.2.3. Data extraction

Data were extracted from the articles by two or more independent reviewers for each domain including specific details about the participants, concept, context, study methods, and key findings relevant to the review questions.

2.2.4. Data analysis

As this is a scoping review, critical appraisal of individual sources of evidence was not conducted. Categorization of articles into Quadruple Aim domains and HCT subdomains was determined by two reviewers. Any disagreement was discussed and resolved with an additional reviewer.

3. Results

After de-duplication, 2556 articles were screened from both searches, and 247 were assessed for eligibility with full text review. One hundred and three articles were included for domain categorization and data extraction. Two articles were considered relevant to both the Population Health and Cost/Utilization domains.^{34,40} The results of the

search and the study inclusion process were documented in the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Fig. 2).⁴¹

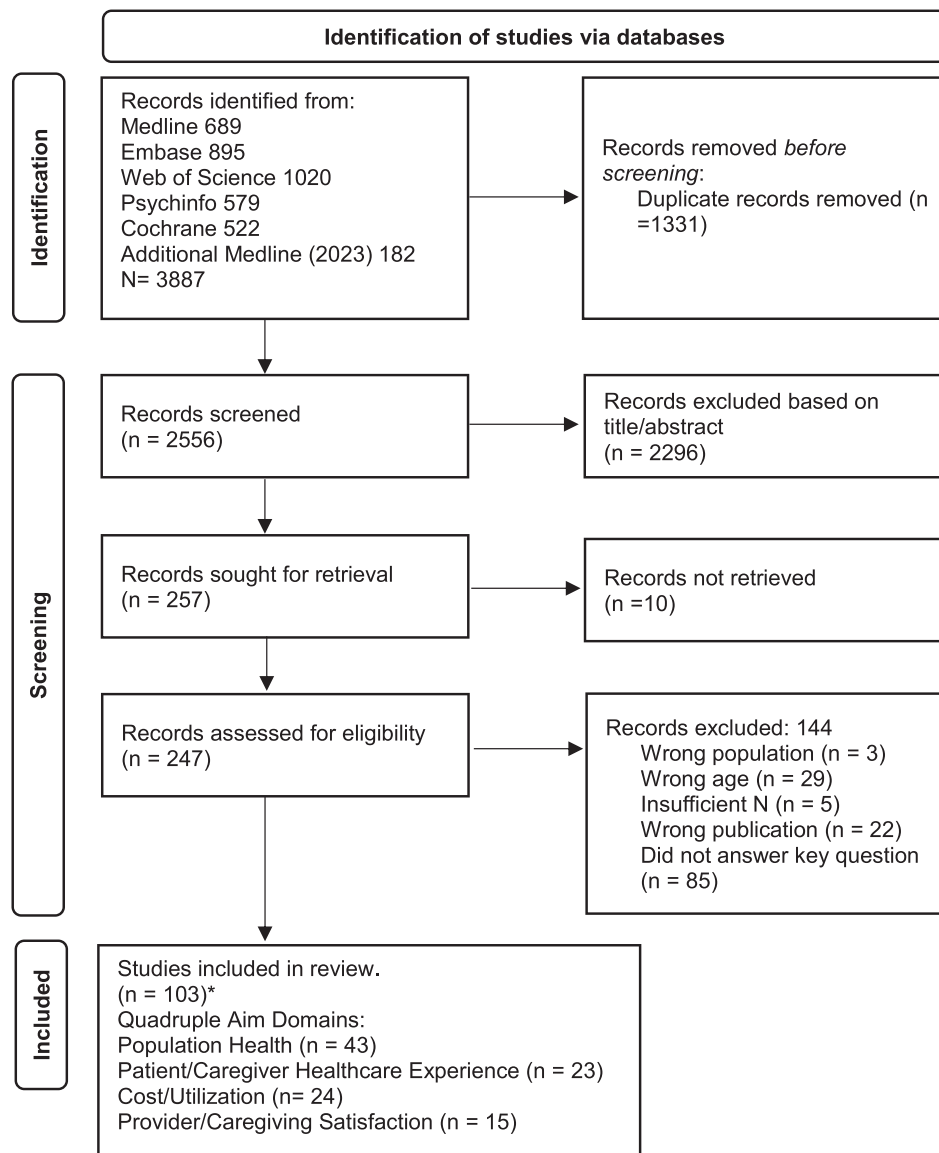
3.1. Population health

Forty-three articles were categorized under the Population Health domain (Table 1). Of these, 34 were quantitative and nine were qualitative studies from Australia, Belgium, Canada, Scotland, South Korea and the United States. Eleven described condition-related health outcomes for young adults: three for ASD,⁴²⁻⁴⁴ five for CP,⁴³⁻⁴⁷ three for SB,⁴⁸⁻⁵⁰ and one for spinal muscle atrophy.⁵¹ Two described general health outcomes⁵²⁻⁵⁴ and nine described mental health outcomes.^{44,52,55-62} Seven described quality of life outcomes,^{49,51,59,61,63-65} six discussed self-management,^{50,63,66-69} and 11 described independent living outcomes.^{46,54,59,65,71-77}

Regarding the general health subdomain, Hoyle et. al found that individuals who were transition age with IDD were likely to be obese, have a sedentary lifestyle, smoke, and have diabetes,⁵³ while McLeod found that those with ASD in college had lower rates of sleep deprivation

and drinking compared to their peers.⁵² Regarding studies describing health concerns within IDD populations, Williams found that fatigue and sleep problems were common in those with ASD, particularly females.⁴³ Davignon and Liu noted that infections, obesity, allergies, gastrointestinal, and musculoskeletal problems were common health concerns for transition-aged youth with ASD.^{34,60} Lui and McDermott also found that epilepsy was a common health concern for those with Fragile X, ASD, ID, and CP.^{34,40} Jacobson also found that individuals with CP had high rates of fatigue and sleep problems, but increased physical activity was associated with decreased fatigue.^{46,54} Additionally, pneumonia, gastrointestinal problems, fractures, and urinary tract infections were common admission diagnoses in CP.⁴⁷ Pain and mobility impairment significantly impacted quality of life and independence for those with CP and SB.^{65,70,71} Accordingly, those with CP were found to have increased medication use, particularly psychotropics and analgesics, with age.⁷² Importantly for young adult with SB, skin ulcers were associated with lower self-management, higher motor impairment, and higher hospitalization rates mortality.⁴⁸

Regarding the mental health subdomain, increased rates of anxiety and depression were reported in several IDD populations.^{43,44,52,60,62,63,}



*Two articles were considered applicable to both Population Health and Cost/Utilization

Fig. 2. PRISMA-ScR flow diagram. *Two articles were considered applicable to both Population Health and Cost/Utilization.

Table 1
Population Health Outcomes for HCT for Young Adults with IDD (Quantitative).

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Outcome Subdomain/s
Alriksson-Schmidt (2014)	CPAge: M 20.6 (n = 106)	Describe the living arrangements, educational or occupational status, and use of personal assistance in young adults with CP.	Community, Sweden	Cross-sectional	Mobility: GMFCS, MACS	GMFCS was associated with independent living, use of assistance, and employment.	Independent living
Anderson (2014)	ASDAge: M 23 (n = 605)	Examine the prevalence and correlates of living arrangements among post-secondary young adults with ASD.	Community, USA	Cross-sectional	Depression: Glasgow Depression Scale for people with a Learning Disability Depression: Glasgow Depression Scale for people with a Learning Disability Anxiety: Glasgow Anxiety Scale-IDD Coping: Brief Cope self-report, internally developed survey for achievement.	Those with ASD were less likely to live independently compared to those with learning disabilities or emotional concerns.	Independent living
Austin (2018)	IDAge: 18 –30 (n = 55)	Assess predictors of anxiety and depression in young adults with ID.	Community, Australia	Cross-sectional	Depression/Anxiety: HSCL–25, Other: Child Attitude Toward Illness Scale, Family APGAR, Patient Assessment of Chronic Illness Care QOL: World Health Organization QOL-BREF version Self-management: AMIS II Other: Family APGAR,	Insight was the strongest predictor of anxiety, and maladaptive coping skills was the strongest predictor of depression.	Mental health
Bellin (2013)	SBAge: M 22 (n = 61)	Explore the association between multi-level ecological factors and psychological symptoms in young adults with SB.	Clinics, USA	Longitudinal	Depression/Anxiety: HSCL–25, Other: Child Attitude Toward Illness Scale, Family APGAR, Patient Assessment of Chronic Illness Care	High rates of depression and anxiety. Attitudes toward SB and family functioning were strongly related with depression. Pain was associated with anxiety.	Mental health QOL
Bellin (2013)	SBAge: M 22 (n = 48)	Assess changes in QOL over 15 months and associated factors in young adults with SB	Clinics, USA	Longitudinal	QOL: World Health Organization QOL-BREF version Self-management: AMIS II Other: Family APGAR,	SB condition severity and pain were associated with decline in QOL. Family satisfaction was related to improved QOL. Attaining adult social roles varied by impairment type and severity. Activity limitations partially mediated the relationship between impairment and adult social roles. Attending postsecondary education increased attaining markers of adulthood.	QOL Self-management
Braun (2006)	IDDAge: 21 –25 (n = 635)	Assess the relationship between intellectual and physical impairment and adult social role acquisition.	Community, USA	Cross-sectional	Internally developed survey	The relationship between impairment and adult social roles. Attending postsecondary education increased attaining markers of adulthood.	Independent living
Brunton (2013)	CPAge M = 19.1 (n = 10)	Understand the physical experiences of youth/young adults with CP	Community, Canada	Structured interview	Mobility: GMFCS, CFCS, Other: Internally developed questions	Themes: fatigue with walking and prolonged activity, need to recognize signs of fatigue and/or how to adapt activities	Condition-related
Cai (2016)	SB Age M 21.5 (n = 114)	Investigate risk factors associated with death among adolescents and young adults with spina bifida during transition from pediatric to adult health care.	State health database, USA	Cohort	ICD–9 codes	Death rate 7 % Individuals with skin ulcers had significantly higher mortality than those without ulcers particularly if first ulcer was during adolescence.	Condition-related
Capriola-Hall (2021)	ASD without IDAge M 19.74 (n = 32)	Determine if cognitive behavioral therapy-based transition education program affects anxiety and depression.	Community, USA	Randomized control	Mental health: Adult Self Report, UCLA Loneliness Scale, Difficulties in Emotion Regulation Scale, American Institutes for Research Self Determination Scale	The cognitive behavioral therapy-based transition education program participants had significantly greater declines in depression, but not anxiety.	Mental Health
Cheak-Zamora (2017)	ASDAge M= 19.2 (n = 27)	Explore health-related independence experiences of youth with ASD and their caregivers	Community, USA	Qualitative, Interview	Internally developed questions	Themes: efforts toward independence, low self-efficacy for adolescents' independence, and desire for independence. There was low communication of these desires between youth and caregivers.	Independent living
Cheak-Zamora (2021)	Caregivers of youth with ASD, Youth Age M = 18 (n = 501)	Evaluate youth with ASD's knowledge and care-seeking behavior for physical and mental health conditions.	Community, USA	Qualitative, Survey	Internally developed questions	Care-seeking was higher for physical health than mental health with severity of ASD, IDD, self-care skills predicted ability to seek care.	Independent living

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Table 1 (continued)

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Outcome Subdomain/s
Cheak-Zamora (2021)	ASDAge: M 21.3 (n = 15)	Explore how autistic young adults experience and cope with stress during the transition	Community USA	Qualitative, focus group	Internally developed focus group questions	Youth with ASD experience a great deal of stress with multiple new adult responsibilities. Coping mechanisms: relaxation techniques, use of technology, and friends and family social support.	Independent living
Choi (2021)	SBAge M 19.88 (n = 108)	Identify the transitional educational needs of AYAs with SB.	Hospital system, South Korea	Cross-sectional	Self-management: TransitionClinic Study Parent/Patient Questionnaire, Other: patient demographics, clinical characteristics	Educational needs: Health insurance, SB related- urinary, nervous system, constipation, and work-life management.	Self-management
Davignon (2017)	ASD Age 14 –25 (n = 4123)	Describe the frequency of medical and psychiatric conditions in ASD.	State health database, USA	Cross-sectional	ICD–9 codes	34 % of individuals with ASD had a psychiatric condition. Common medical conditions: infections, obesity, allergies, musculoskeletal, and gastrointestinal.	General health Mental health
Dicianno (2009)	SBAge: M 21.0 (n = 61)	Determine the relationships between mobility and self-management skills, psychological health, or quality of life.	Multicenter clinics, USA	Cross-sectional	Internal scale for wheelchair use Depression and Anxiety: HSC–25 Self-management: Adolescent Self-Management and Independence Scale II QOL: World Health Organization QOL-BREF version	Full-time wheelchair use was associated with reduced QOL. psychological distress and problems with self-management were prevalent, regardless of mobility status.	QOL Self-management
Dykens(2015)	DSAge: M 21 (n = 49)	Compared psychiatric diagnoses of youth with DS to those with other IDD	Multicenter clinics, USA	Cross-sectional	Mental Health: DSM-IV-TR criteria	Psychosis and depression with psychotic features were more common in DS, especially females. All parents believed their children's sensory sensitivities impacted their transition to adulthood, developmentally, psychologically, socially, and managerially. These beliefs did not significantly differ by child characteristics.	Mental health
Hantman (2022)	Parents of ASD individuals Age of ASD individuals M 19.4(n = 77)	Determine effect of sensory sensitivities on the transition process.	Community, USA	Survey, Interview	Internally developed questions, Mental health: Parent Rated Anxiety Scale for ASD, Aberrant Behavior Checklist Other: Vineland Adaptive Behavior Scales, Adolescent/Adult Sensory Profile	All parents believed their children's sensory sensitivities impacted their transition to adulthood, developmentally, psychologically, socially, and managerially. These beliefs did not significantly differ by child characteristics.	Mental health Independent living
Hoyle (2020)	IDDAge: 18 –28, M 26(n = 206)	Determine associations of long-lasting developmental disabilities with health, behaviors, and well-being in adulthood	Community, USA	Longitudinal	Data from Panel Study of Income Dynamics survey (Child Development Study and Transition into Adulthood Supplements) (DDABRA), IDD: 3 DDABRA criteria, Woodcock-Johnson Psycho-Educational Battery-Revised	Those with serious developmental disabilities were more likely to report no high school graduation, being assaulted, criminal arrests, smoking, sedentariness, obesity, diabetes, and work disability	Independent living General Health
Jacobson (2019)	CPAge: M 21 (n = 61)	Describe social outcomes for CP and ID	Community, Sweden	Cross-sectional	Mobility: GMFCS, CFCS, MACS Social outcomes: Internal questions based on literature review (living arrangements, relationships, occupation, finances, assistance from family, ADL assistance)	20 % of young adults had moved out of family home, 43 % were dependent for ADLs, 79 % without ID were employed or in higher ed. GMFCS and ID were important determinants of social participation.	Independent living
Jacobson (2020)	CPAge: M 21 (n = 61)	Describe health-related quality of life (HRQoL), pain, fatigue, and other health variables in young adults with CP and associations with motor function and physical activity	Community, Sweden	Cross-sectional	Mobility: GMFCS QOL: Short Form 36 (v2) HRQOL, Other: Brief Pain Inventory, Fatigue Severity Scale, clinical variables	Physical QOL was lower in GMFCS III to V compared to GMFCS I to II. Mental QOL was lower in GMFCS I to II compared to GMFCS III to V. Pain prevalence was 49 % across all GMFCS. 41 % had fatigue and sleep problems. Fatigue severity decreased with increased level of physical activity.	Condition-related QOL
Kim (2021)	ASDAge: M 20.2 (n = 16)	Evaluate validity and feasibility of behavioral program to improve independence and emotional skills.	Community, South Korea	Pre/post assessment	Adaptive skills: Barkley Deficits in Executive Functioning Scale, Vineland Adaptive Behavior Scale-II, Community Integration Skills Assessment–2, Cognitive Flexibility Inventory	Behavioral support program improves ADLs, time management, organization, self-restraint, and emotional regulation.	Mental health Independent living

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Table 1 (continued)

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Outcome Subdomain/s
Lam (2020)	ASD(n = 14)	Photovoice project to understand ideas about well-being in young adults with ASD	Community, USA	Qualitative	Photos, individuals' descriptions	Young adults described themselves as uniquely and different, but they were eager to learn and adapt. They also valued their relationships with their families, friends, animals, and the community.	QOL
Liptak (2011)	ASDAge: M 19.2 (n = 725)	Describe social participation and identify factors that affect it in a nationally representative sample of adolescents and young adults with autism.	Community, USA	Longitudinal	National Longitudinal Transition Study–2 dataset	Being employed or in secondary education was associated with not being teased, not having ID, being above the poverty level, not using medications, health status, and parental involvement with school.	Independent living
Liu (2021)	ASDAge: 18 –21 (n = 10,501) Compared to younger ages	Identify of physical health risk factors specifically associated with ED utilization in ASD.	Database insurance claims, USA	Cross-sectional	ICD–9, Insurance claims	Prior physical health conditions (e.g. Epilepsy and gastrointestinal problems), particularly injuries were associated with elevated risk for ED visit.	Condition-related
Lounds Taylor (2017)	ASDAge 17 –22 (n = 36)	Examine how social activities in high school predict social activities after graduation in ASD	Community, USA	Longitudinal	Behavior: Adult Behavior Checklist Other: internally developed socialization questions	Participation in structured social activities declined after high school. More social participation in high school predicted post-graduation participation. Internalizing symptoms predicted increasing social isolation.	Independent living Mental health
Mahmood (2011)	SBAge: M 22.2 (n = 38)	Determine if self-management ability and healthcare service delivery factors were related to SB-related preventable conditions and acute care utilization.	Multi-center, US	Longitudinal	Self-management: Adolescent Self-Management and Independence Scale Other: Hospital/ Emergency room encounters, clinical variables	UTIS were associated with no shunt, lower education, higher employment, and lower self-management scores. Pressure ulcers were associated with higher motor level, higher education. Hospitalization was associated with number of wounds and lower self-management.	Condition-related Self-management
Martin (2016)	FXS Age: 20.3 (n = 34)	Determine the association with executive function and independent living.	Community, US	Longitudinal	Cognitive: Wechsler Intelligence Scale for Children, e Contingency Naming Test, Verbal Fluency test "F,A,S" Independent living: Independent Living Scales	Executive function predicted independent living.	Independent living
Mazzella(2021)	SMA Age 19 –24 (n = 41)	Evaluate QOL	Community, USA	Qualitative and Quantitative	Internally developed QOL survey	Challenges: feelings of isolation, stigma, difficulty with accessibility, dependence	QOL
McDermott(2015)	FXS, ASD, IDDAges: 15 –24 (FXS: n = 125, ASD: n = 2592, ID = 10,685)	Compare hospital encounters between adolescents and young adults with fragile X, ASD, and other IDD	Medicaid database, USA	Cross-sectional	ICD–9	Metal illness hospitalization decreased for adults with Fragile X. Those with Fragile X, ID, ASD had higher odds of hospitalization due to epilepsy in both age groups.	Condition-related
McLeod (2021)	ASDAge: M 20.8 (n = 89)	Estimate the association of ASD with six physical and mental health outcomes, accounting for comorbidity with other disabilities.	Under-graduate students in Indiana	Cross-sectional	Mental health: Center for Epidemiologic Studies–Depression Scale, Mini-Social Phobia Inventory Other: internally developed survey	Students with ASD reported poorer self-rated physical and mental health, more depressive symptoms, and more symptoms of anxiety than typical students, but lower likelihood of sleep deprivation and binge drinking.	Mental health General health
Nadig (2018)	ASD without IDAge: 18 –29 (n = 26)	Randomized control trial of a transition support program measuring effects on self-determination and quality of life.	Community, USA	Longitudinal	Condition: Autism Diagnostic Observation Schedule-Second Edition Cognitive: Raven's Progressive Matrices, Wechsler Abbreviated Scales of Intelligence Adaptive: Social Communication Questionnaire-Lifetime, Vineland Adaptive Behavior Scales, Self-Determination Scale, Social Problem-	Intervention group improved self-determination and QOL scores compared to control group.	Independent Living QOL

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Table 1 (continued)

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Outcome Subdomain/s
					Solving Task. QOL: Quality of Life Questionnaire, Abridged Version		
Rehm(2012)	IDD and parents Age 14 –26(youth: n = 65, parents: n = 77)	Characterize QOL priorities during transition	Community, USA	Qualitative, interview	Internally developed interview questions	Meaning of adulthood was defined as functioning as independent as possible with appropriate supports	QOL
Roquet (2018)	CPA: 18 –24 (n = 61)	Analyze the health care usage of individuals with CP as a function of age and ambulatory status.	Clinical network, France	Cross-sectional	Internally developed questions	Medication use (particularly psychotropic and analgesic) increased with age	Condition-related
Rossetti(2015)	IDD and parents Age: M 25.7 (adults n = 23, parents: n = 23)	Determine how adults with support needs spent their time and defined meaningfulness	Community, USA	Qualitative, interview	Internally developed interview questions	Themes: Most adults spent time in the community. Meaningfulness involves community participation, individual indicators, nature of activities Patients with SB in an adult clinic had lower transition readiness scores than controls.	QOL
Roth (2019)	SB Age: Mdn 21 (n = 43)	Compare transition readiness between young adults with SB and controls	Clinic, Indiana	Case-Control	Self-management: Transition Readiness Assessment Questionnaire		Self-Management
Roth (2020)	SB Age: Mdn 25.5 (n = 96)	Identify factors impacting transition readiness.	Clinic, Indiana	Cross-sectional	Self-management: Transition Readiness Assessment Questionnaire	Only age was associated with transition readiness.	Self-Management
Rozkalne (2019)	CPA: 18 –24 (n = 54)	Identify level of participation based on GMFCS	Clinic, Latvia	Cross-sectional	Mobility: GMFCS General Independent Living: Rotterdam Transition Profile, WHO Disability Assessment Schedule 2.0	21 % (education and employment), 56 % (intimate relationships), and 59 % (sexuality). GMFCS had negative associations with autonomy in social activities, sexuality, and transportation	Condition-related Independent Living
∞ Sienko (2018)	SB Age: M 23.8 (n = 97)	Examine ambulatory decline, pain, emotional concerns, QOL	Clinic database, USA	Cross-Sectional	Motor: GMFCS Behavior: Behavioral Risk Factor Surveillance System QOL: Multidimensional Health Locus of Control Other: Brief Pain Inventory, Fatigue Assessment Scale	Pain contributed to variance in health status and emotional health to life satisfaction	QOL
Van de Woestyne (2021)	Chromosome 22q11 deletion Age: M 23.6(n = 33) ID Age: M 27.6 (n = 26)	Determine the role of resilience and QoL in young Adults with 22q11.2DS and behavioral problems, in comparison with those with ID without an identified genetic syndrome.	Clinic, Belgium	Case-control	QOL: WHO QOL-BREF and WHO QOL-DIS (for ID) Mental health: young adult behavior checklist and young adult self-report Other: Dutch Resilience Scale, Internally developed questions	Young adults with a 22q11.2DS show less resilience compared with both the general population norms and young adults with ID. Only the “acceptance of self and life” subscale contributed to QOL.	QOL Mental health
White (2022)	ASD without ID Age: M 18.8 (n = 59)	Determine if self-reported ASD severity and depressive symptoms independently predict self-determination	Community, USA	Cross-sectional	Mental health: Anxiety Disorders Interview Schedule, Beck Depression Inventory Other: American Institutes for Research Self Determination Scale, Social Responsiveness Scale-Second Edition-Adult: Self-Report, Wechsler Abbreviated Scale of Intelligence Mental Health: Patient Health Questionnaire–15 (somatic symptoms), General Anxiety Scale–7, Beck Depression Inventor QOL: WHOQOL Other: Social Responsiveness Scale-Second Edition-Adult: Self-Report, demographics	After controlling for ASD-related social impairment severity, depression did not significantly predict self-determination.	Condition-related Mental Health
Williams (2022)	ASD (independent adults) Age: M 23.1(n = 290)	Assess the prevalence, impact, and clinical correlates of somatic symptoms in ASD.	Community, USA	Cross-sectional		Somatic burden was higher in ASD adults than reported in the general population. Most common symptoms: fatigue, sleep problems, menstrual problems. Females endorsed symptoms 2 –4 times greater than males.	Condition-related Mental health
Young (2011)	CPA: M = 26.3 (n = 477)	Identify the most common reasons for acute care hospital admissions among youth and young adults with CP	Hospital database, USA	Cross-Sectional	ICD–9	Epilepsy and pneumonia were the top reasons for admission. Followed by mental illness, followed by lower GI or constipation problems, malnutrition or dehydration, upper GI problems, fractures, and UTIs.	Condition-related
Young-Southward (2017)	IDD Age: 13 –24 (n = 5556)	Compare health during transition for IDD versus not.	Census data, Scotland	Cross-Sectional	Census data	Those with IDD were more likely to have mental health concerns	Mental Health

Abbreviations: Autism Spectrum Disorder (ASD), cerebral palsy (CP), Diagnostic and Statistical Manual of Mental Disorders, 4th edition-TR (DSM IV-TR), Fragile X Syndrome (FXS) Glasgow Anxiety Scale for people with Intellectual Disability (GAS-ID), Glasgow Depression Scale for people with a Learning Disability (GDS-LD), Gross Motor Function Classification System (GMFCS), IDD (Intellectual and/or Developmental Disabilities) mean (M), median (Mdn), Manual Ability Classification System (MACS), Spina Bifida (SB), Spinal Muscle Atrophy (SMA)

⁷³ Bellin et. al found high rates of depression and anxiety in young adults with SB with family function being associated with depression and pain being associated with anxiety.⁶³ For those with ASD, increased insight predicted anxiety whereas poor coping skills predicted depression.⁵⁵ Kim et. Al, demonstrated that behavioral support programs for young adults with ASD improved independence skills and emotional coping, and Nadig demonstrated that group interventions for those with ASD during transition improved self-determination and QOL.^{64,74}

In qualitative studies describing independent living and QOL, young adults with IDD emphasized the importance of supports for living independent living and the meaningfulness of community participation.⁷⁵⁻⁷⁷ However, rates of independent living were low and attaining social roles and independence were attenuated by intellectual disability, executive function, behavioral concerns, and physical disability across multiple populations.^{45,51,78,79,71,80-82} For those with ASD, high school social participation predicted young adult participation whereas internalizing symptoms predicted isolation and coping techniques and social support were helpful in coping with adult responsibilities.^{58,83}

3.2. Patient/family experience of care

Of the 23 articles categorized under the Experience of Care domain (Table 2), two were cross-sectional studies, and 16 were qualitative studies employing interviews or focus groups from Canada, Hong Kong, Scotland, South Korea, and the United States. Thirteen articles studied IDD populations in general,⁸⁴⁻⁹⁶ followed by three studying ASD,⁹⁷⁻⁹⁹ four studying spina bifida,¹⁰⁰⁻¹⁰³ two studying cerebral palsy,^{104,105} and one studying neurofibromatosis populations.¹⁰⁶ Ten studies included both parents and youth,^{66,88,93,95,97-100,102,103,106} with four studying only youth,^{91,101,104,105} and eight studying only parents.^{84-87,89,90,92,96}

Studies identified facilitators and barriers to successful/positive HCT at the level of the individual, the family, and the healthcare/community. Individual level facilitators of HCT were acceptance of diagnosis, higher cognitive function, and strong interest in independence/self-determination while barriers were lower cognitive and physical abilities, lower self-perception.⁹⁸⁻¹⁰¹ Family facilitators were parents fostering independence, family resourcefulness/advocacy, and parental hope while barriers were lack of parental knowledge about HCT needs and overly protective parenting style.^{86,96,100,101} Healthcare/community level facilitators were patient-centered care practices (addressing various cognitive, sensory and behavioral/mental health needs), care coordination including a structured transition process, community supports/resources, and defined adult care provider roles whereas barriers were lack of coordination and patient-centered care, strong dependence on pediatric care coordination, transportation, and negative experiences with adult providers.^{84,87,90,98,100,105}

Common themes of HCT experience in qualitative studies were loss of relationships with pediatric providers, lack of sufficient healthcare and community support, need for more structure during transition, and lack of adult providers who are knowledgeable about their condition and accommodating healthcare systems.^{85,91,97,106} Neece et.al and Stewart et. al found that HCT satisfaction was related to multifaceted individual, family, and environmental factors.^{92,95} While most studies found negative HCT experiences, Fremion et al. found that patients with IDD and their families who participated in structured HCT clinic programs had improved satisfaction and preparation compared to those who did not have structured HCT preparation.⁸⁸ Similarly, Sawin et. al found that patients with SB engaged in a HCT preparation program benefited from developing trust and communication with the team, however barriers to finding adult care remained.¹⁰³

3.3. Cost/Utilization

Twenty-four articles were categorized under the cost/utilization domain (Table 3). Three articles pertained to cost,^{36,110,111} 23 articles

Table 2
Experience of Care Outcomes for HCT for Young Adults with IDD.

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Subdomain (s)
Benson (2021)	Parents of youth with IDD Ages: 16 –22 (n = 11)	Explore the experiences of parents of youth with IDD transitioning to adult care	Community, USA	Qualitative	Internally developed interview questions	Facilitators: positive team collaboration, person-centered practices Barriers: lack of person-centered practices, communication from team, frustration with progress, feelings of defeat, gaps between programming, Facilitators individual factors: higher cognitive functioning, strong interest independence; family factors: parents fostering independence; service factors: success negotiating primary care responsibilities with adult healthcare providers. Barriers Individual factors: lower cognitive ability, impaired physical ability; family factors: lack of parent awareness of transition needs; service factors: strong dependence on pediatric provider care coordination, and negative experiences with adult specialists perceived as not anticipating their needs Themes: deep sense of loss, overwhelming process, parents making transitions happen, shock to the adult healthcare system and unbearable pressure	Facilitators to care Barriers to care
Berry (2013)	Youth with SB and parents Age: M 18.0 (youth: n = 15, parents: n = 14)	Understand barriers and facilitators of transition to adult care for youth with SB	Community, USA	Qualitative	Internally developed interview questions	Themes: loss of relationship with provider, lack of support, lack of provider knowledge and managing medical care Facilitators: understanding and acceptance of SB, acquiring self-management skills, parenting styles encouraging autonomy, parents' emotional support, schoolteachers' thoughtful consideration, and participation in self-help groups. Barriers: overprotective parenting style, experience of being bullied by peers, damaged self-concept, concealing one's chronic condition from others, and the lack of privacy in school restrooms	Facilitators to care Barriers to care
Brown (2020)	Parents of youth with IDD Ages: 18 –30 (n = 10)	Explore the experiences of families of young adults with IDD	Community, Scotland	Qualitative	Internally developed interview questions		Family healthcare satisfaction
Cheak-Zamora (2015)	Youth with ASD and families Ages: 15 –22 (ASD: n = 13, family: n = 19)	Explore the experiences of youth with ASD and their families during transition to adult services	Clinics, USA	Qualitative	Internally developed focus group questions		Patient healthcare satisfaction Family healthcare satisfaction
Choi (2023)	Young adults with SB Age: M 20.6 (n = 16)	Explore the experiences of Korean young adults with SB to identify the facilitators or barriers to adulthood	Clinic, South Korea	Qualitative	Internally developed focus group questions		Facilitators to care Barriers to care
Cox (2011)	Young adults with SB and parents Age: M 26.9 (n = 105)	Assess Transition to adult care experience	Clinic, Canada	Cross-sectional	Survey SF–36 Ambulatory Care Experience Transition of Care Survey	Urologic and neurosurgical outcomes did not correlate with patient experience	Patient healthcare satisfaction Family healthcare satisfaction
Davies (2011)	Parents of youth with IDD Ages: 18 –21 (n = 17)	Explore parent perceptions about transition to adult care	Clinic, Canada	Qualitative	Internally developed interview questions	Facilitators: parent's resourcefulness, family support, relationships in the adult care system Barriers: lack of coordination; and lack of resources in the adult care system	Facilitators to care Barriers to care
First (2016)	ASD and family caregivers Age: 15 –22	Explore perspectives ASD and parents on	Community, USA	Qualitative	Internally developed	Facilitators: support from community, self-	Facilitators to care Barriers to care

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Table 2 (continued)

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Subdomain (s)
	(youth: n = 13, caregivers: n = 19)	transition to adulthood			focus group questions	determination Barriers: accessing services, managing multiple responsibilities, and vocation and higher education challenges Facilitators: Parent-peer coach, hope despite uncertainty	
Franklin (2019)	Parents of young adults with IDD Age: 18 –33 (n = 16)	Explore experiences of parents of transitioning youth with IDD	Clinic, USA	Qualitative	Internally developed interview questions	Barriers: Silos between medical educational, vocational, community; inadequate resources	Facilitators to care Barriers to care
Fremion (2022)	Young adults with IDD and parents Age: Mdn 20 (n = 408)	Determine factors associated with health care transition preparation satisfaction	Clinic, USA	Cross sectional	HCT Feedback Survey 2.0	Those who participated in a structured HCT program before transferring to adult care had higher transition preparation satisfaction.	Patient healthcare satisfaction Family healthcare satisfaction
Gauthier-Bodraeu (2017)	Parents of youth with IDD Age: 18 –26 (n = 14)	Explore needs of parents with profound ID transitioning to adulthood	Clinic, Canada	Qualitative	Internally developed interview questions	Material, informative, cognitive, emotional needs are not met	Barriers to Care
Gauthier-Bodreau (2018)	Parents of youth with IDD Age: 18 –26 (n = 14)	Propose realistic solutions to meet the needs of youth with profound ID	Community, Canada	Qualitative	Internally developed interview questions	Facilitators: implementation of transition document, plan, process to address the needs of those with profound/severe ID; training for providers, support for families Themes: fear and apprehension, lack of cooperation or communication between providers and feelings of abandonment	Facilitators to care
Lariviere-Bastien (2013)	CP Age: M 20.9 (n = 14)	Explore the perspectives of youth with CP transitioning to adult care	Community, Canada	Qualitative	Internally developed interview questions	Priorities: Transition to Adulthood, insurance/ financial resources, professionals' competence, understanding the experiences of people who communicate Differently, hospitalization, medication, alternatives to medication, and social supports. Facilitators: Self-Advocacy, Self-Acceptance, Community openness, Finding personal support though acceptance. Barriers: Lack of understanding of sensory needs, etc. by adult medical professionals.	Patient healthcare satisfaction
Kramer (2019)	IDD Ages: 18 –30 (n = 76)	Determine priorities for young adults with IDD and mental health needs	Community, USA	Qualitative	Internally developed questions	Facilitators: Self-Advocacy, Self-Acceptance, Community openness, Finding personal support though acceptance. Barriers: Lack of understanding of sensory needs, etc. by adult medical professionals.	Patient healthcare satisfaction
Lee (2022)	ASD , parents, coordinators Age: M 21.6 (adults: n = 6, parents: n = 7, coordinators: n = 11)	Explore the role of acceptance during transition to adult care	Community, USA	Qualitative	Internally developed focus group questions	Transition satisfaction was related to family and environmental factors	Facilitators to care Barriers to care
Neece (2009)	Parents of adults with IDD Age: (n = 128)	Examine parent perspectives of transition	Community, USA	Qualitative	Internally developed interview questions	Theme: need for structured clinical transition service	Family healthcare satisfaction
Pin (2016)	IDD and parents Age: M 19.6 (youth: n = 13, parents: 22)	Explore experiences in transitioning to adult care	Community, Hong Kong	Qualitative	Internally developed interview questions	Themes: need for more information, access to NF1 experts, daily living support, care for mental health and socioeconomic participation, and closer communication between health-care providers	Patient healthcare satisfaction Family healthcare satisfaction
Rietman (2018)	Parents and young adults with Neurofibromatosis , (adults: n = 30, parents: n = 12)	Understand the full spectrum of worries and care needs in medical, psychological, social, and economic domains of adults with NF-1 and their parents	Community, The Netherlands	Qualitative	Internally developed interview questions	Barriers: contextual (e.g. ill-adapted health care, lack of specialized public transport) and relational (e.g. attitudes towards parental involvement in decision making)	Patient healthcare satisfaction Family healthcare satisfaction
Racine (2013)	CP Age: 18 –25 (n = 14)	Characterize perspectives towards autonomy in health care	Community, Canada	Qualitative	Internally developed interview questions		Barriers to care

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Table 2 (continued)

Author Last Name (Date)	Population	Concept/Aim	Context	Study Design	Measures	Key Findings	Subdomain (s)
Sawin (2015)	SB and parents Age: M 23 (adults: n = 24, parents: n = 16)	Evaluate experiences of patients in a SB transition program	Clinic, USA	Qualitative	Internally developed interview questions	Benefits of the program: positive experience, developing trust, unexpected benefits, communication, desire to engage in transition earlier. Concerns: accessing adult specialists and supports Barriers: crisis sparking transition, turmoil, waiting	Patient healthcare satisfaction Family healthcare satisfaction
Schultz (2013)	Parents of young adults with IDD and seizures Age: 20–30 (n = 7)	Understand the HCT experiences of parents of individuals with IDD and epilepsy	Community, USA	Qualitative	Internally developed interview questions	Facilitators: Webs of information (advocacy groups, health care providers), parent advocates HCT is complex with personal experiences and abilities as well as community/healthcare supports and policies influencing the HCT experience.	Facilitators to care Barriers to care
Stewart (2014)	Youth with IDD, parents/ caregivers and service providers Age: 19–30 (n = 50)	Explored the meaning of the lived experiences of youth with disabilities in transition to adulthood	Community, Canada	Qualitative	Internally developed questions		Patient healthcare satisfaction Family healthcare satisfaction

*Age describes that of young adults with IDD.

Abbreviations: autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome (DS), intellectual/developmental disability (IDD), mean (M), median (Mdn), spina bifida (SB)

pertained to utilization of services,^{27,32–34,36,40,72,107–122} and five articles identified gaps in services^{27,35,117,119,123} (some articles covered more than one subdomain). Studies were from Canada, France, Poland, Latin America, and the United States. Overall studies identified increased emergency department (ED) and hospital utilization in young adults with IDD compared to those without IDD.^{40,109,120} Benevides et. al found that for young adults with ASD and Medicare, having ID, psychiatric diagnoses, increased number of chronic conditions, white ethnicity, female gender, Medicare/Medicaid eligibility were predictors of ED use.¹²¹ Additionally, Lunsky et. al found that greater ASD severity, having a family in crisis, and not being involved in structured day activities predicted ED use in young adults with ASD.¹¹⁴ Blaskowitz et. al, who studied young adults with IDD in New York City, found that older age; having CP, a neurological condition, additional chronic conditions, mental illness, using five or more meds, and residing in a supported apartment were associated with increased ED use.³² Common reasons for ED visits for young adults with ASD included psychiatric issues, medication management, injuries, epilepsy, respiratory concerns, and gastrointestinal problems.^{34,114,121}

Regarding outpatient care, Ames reported that youth with ASD had higher primary care, mental health, and neurology utilization but lower gynecology utilization than young adults without ASD.³⁶ Ishler found that those with ASD who had a home and community-based waiver had increased case management and mental health use.¹¹¹ In the CP population, Cornec et. al reported decreased use of multidisciplinary rehabilitation in France as individuals with CP entered adulthood, and Liljenquist similarly found decreased use of physical therapy for adults with CP in the US.^{110,113} Similar declines in service utilization were seen in young adults with ASD and ID¹¹⁸ and young adults with SB.³³ Lastly, insurance,¹²³ difficulty in identifying adult providers,¹¹⁷ general lack of services for adults,¹¹⁹ and access barriers particularly for low income, Latino, and rural families lead to gaps in regular outpatient care.^{27,118}

While cost intervention studies were sparse, Alain et. al demonstrated that a clinic providing primary care and transition services specifically for ASD reduced overall health care cost as well as mental health, outpatient, hospitalization utilization for those with ASD who had Medicare coverage.¹⁰⁷ Additionally, this clinic demonstrated an increase in meeting preventive care goals.¹²² Similarly, Maeng reported that enrollment in a comprehensive care clinic decreased acute care utilization and cost per month for youth with IDD.¹⁰⁸ Kingsnorth found that individuals with CP and SB engaged in a structured transition had

increased successful transfer to adult care services.¹¹²

3.4. Healthcare provider experience

Six studies described the experience of healthcare providers in Australia, Canada, France, and the United States (Table 4).^{124–129} No articles described the experience of non-family home health care providers or direct support personnel. Healthcare providers surveyed about HCT stated that transfer to adult care should occur between 18–21 years; multidisciplinary teams were needed to provide comprehensive care in pediatric and adult settings; and structured HCT should include developing medical summaries, providing adult care and community resources, and care coordination/hand off to adult providers.^{124–126} Australian service coordinators for young adults with IDD described the following challenges to delivering HCT: difficulty accessing and communicating with services, insufficient knowledge about services, and cultural considerations; structural challenges of separate mental health and intellectual disability agencies for dual diagnoses; excessive focus by services on crisis response rather than prevention and early intervention.¹³⁰ Lindsay et al. interviewed SB healthcare providers involved in implementing structured HCT who identified enablers for the program: leadership, advocacy, funding, inter-agency partnerships, and cross-appointed pediatric and adult care staff as enablers; as well as challenges to implementation: gaps in adult specialty services, geographic catchment of adult services, engagement of frontline staff, and gaps in communication and role clarity.¹²⁷ Similarly, pediatric and adult epileptologists as well as combined focus groups of healthcare providers and caregivers identified that lack of preparation, lack of adult provider knowledge and available clinic support for patients with and IDD, and collaboration between adult and pediatric providers were HCT barriers.^{128,129}

3.5. Family caregiving experience

Six studies described the experience of family caregivers from Australia, Israel, Spain, the United Kingdom, and the United States (Table 5).^{131–136} Caregiving experience studies found that family caregivers struggled with the balance of relinquishing control while keeping their young adult child safe.¹³¹ Additionally, parents experience the stress of decreasing social support in adult care while they and their child with IDD are aging.¹³² Uniquely, Rawson interviewed siblings of

Table 3
Cost/Utilization Outcomes for HCT for Young Adults with IDD.

Author Last Name (Date)	Population	Concept/ Aims	Context	Design	Measures	Results	Outcome Domain
Alain (2022)	ASDAge: Mdn 21 (Center for Autism Services and Transition (CAST): n = 490, Medicare-enrolled ASD: n = 980)	Examine the impact of CAST on healthcare utilization and expenditures.	Clinic and Medicare database, USA	Cross-sectional	Expenditures and utilization for primary care; ED visits; inpatient hospitalizations; mental health admissions; and outpatient visits	CAST patients had the highest primary care utilization and expenditure but significantly lower expenditures in mental health, outpatient, and total expenditures as well as 57 % fewer hospitalizations. Youth with ASD had higher primary care, mental health, and neurology and lower gynecology utilization. Youth with ASD had higher inpatient psychiatric visits than diabetes and general population but lower than youth with ADHD. Costs for youth with ASD were higher than those for ADHD and general population peers and lower than for diabetes. 43–54% had an ED visit past year. Predictors of increased ED utilization were ID, a psychiatric diagnosis, increased comorbidities, white ethnicity, female gender, dual-eligibility for Medicare/Medicaid. ASD-only and ASD+ID had fewer annual ED visits versus with ID-only after controlling for demographics and comorbidities. Reason for ED visits: 18–28% from injury and 18–25% psychiatric. Residing in a supported apartment increased odds of ED visits for a medication issue.	UtilizationCost
Ames (2021)	ASDAge: 14 –25 (n = 4123)	Examine differences in healthcare utilization and costs among youth with ASD, ADHD, diabetes, and general population	Healthcare system, USA	Cross-sectional	Utilization of care (outpatient, inpatient, ED); cost of care	Olderage; having CP, a neurological condition, additional chronic conditions, mental illness, and using five or more meds were associated with increased ED use. 80% had a usual source of care. Compared to typical youth, those with IDD utilized emergency care at higher rates (27% vs 42%).	UtilizationCost
Benevides (2020)	ASD, IDAge: 18 –25 (ASD: n = 3499, ASD+ID: n = 2048, ID: n = 13,178)	Identify rates of ED utilization among transition-age young adults with ASD vs those with ASD/ID and those with ID and examine predictors.	Medicare data claims, USA	Cross-sectional	ICD–9-CM dx, Healthcare Common Procedure Coding System/Current Procedure Terminology (HCPCS/CPT)	Residing in a supported apartment increased odds of ED visits for a medication issue. Olderage; having CP, a neurological condition, additional chronic conditions, mental illness, and using five or more meds were associated with increased ED use.	Utilization
Blaskowitz (2019)	IDD Age: 18 –24 years (Total: n = 597)	Identify Predictors of ER utilization and hospitalization for adults with IDD residing in agency-supported settings	Hospital system, USA	Cross-sectional	Clinical and environmental characteristics. ED use and reason for visit.	At study entry, 22% of the young adults with disabilities were uninsured. During the 36-month follow-up period, 56% of the young adults with disability reported gaps in insurance coverage with a mean of 15 months of	Utilization
Blomquist (2006)	IDD Age: Mdn 21.1 (n = 650)	Evaluate transition outcomes for those with IDD one year post discharge from pediatrics	Community, USA	Cross-sectional	Survey questions regarding usual source of care, insurance, employment		Utilization
Callahan (2007)	IDD Age: 16 –25 (n = 599)	Compare the continuity of insurance coverage for young adults with and without disabilities.	Community, USA	Cross-sectional	Data from the 2001 Survey of Income Program and Participation		Gaps in care

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Table 3 (continued)

Author Last Name (Date)	Population	Concept/ Aims	Context	Design	Measures	Results	Outcome Domain
Cornec (2021)	CPAges: 18 –25 (n = 111), multiple additional age groups		Community, France	Cross sectional	Data from the French ESPaCe survey	uninsurance. The proportion of uninsured subjects did not significantly differ by disability status. Multidisciplinary rehabilitation decreased sharply from adolescence and was halved at adulthood. Satisfaction with the MR program decreased from childhood into adolescence and adulthood.	Utilization
Hand (2021)	ASDAge: Mdn 21 (CAST): n = 490, Medicare-enrolled ASD: n = 980	Compare the receipt of preventive services by patients at an ASD patient-centered medical home	Clinic, USA	Cross sectional	Receipt of any preventive service; receipt of specific preventive service types	CAST patients were significantly more likely to receive preventive care services than national ASD samples.	Utilization
Ishler (2022)	Family of ASDAge: M 20.9(n = 174)	Determine predictors of service use and use of specific services.	Community, USA	Cross-sectional	Number of services used in past 6 months and type of service: medical, mental health, vocational, case management, and social skills. Helpfulness of services, Independent Behavior-Revised Short Form	Having a Medicaid waiver and attending high school were the strongest predictors of service use. Medicaid waiver status predicted of use of case management and mental health services.	Utilization
Kingsnorth (2021)	CP, SBAge 16 –19 (intervention group n = 132, control n = 21)	Evaluate continuity of care and utilization for clients enrolled in LIFEsplan	Clinic, Canada	Case-control	Engagement in health care services after establishing adult care	LIFEsplan model increased successful transfer from pediatric to adult services.	Utilization
Liljenquist (2018)	CP Ages: 13 –26 (n = 35290)	Identify factors contributing to physical therapy utilization during/ after secondary school.	Community, USA	Cross-sectional	General Access to Disability Support Services Scale Items on national survey	59.4% of the youth utilized physical therapy in secondary school; only 33.7% post-school.	Utilization
Liu (2021)	ASDAges: 18 –21 (n = 10501) Compared to younger ages	Identify physical health risk factors associated with ED utilization.	Database insurance claims, USA	Cross-sectional	ED utilization during a calendar year using insurance claims data	Prior injuries were the highest risk of ED utilization. Epilepsy, respiratory, and gastrointestinal problems were associated with increased ED utilization. In the year prior, 18.4% visited the ED at least once. In a 2-months, 12.6% used at least one emergency service. Reason for visit: medical 65.4% (injury was 58.8% of cause) and mental health 34.6%. Emergency service use was associated with greater ASD severity, having a family in crisis, not being involved in structured day activities, and presence of medical comorbidities. CCC enrollment was associated with 78% reduction in hospitalizations, 60.3% in ED visits, and 28% cost reduction per member per month.	Utilization
Lunsky (2015)	Parents of ASD Age: M 18.4 (n = 284)	Describe emergency service use amongst youth with ASD and examine predictors.	Community, Canada	Cross-sectional	Parent-reported emergency service use.	Those with FXS, ASD, or ID were more likely to have hospital encounters	Utilization
Maeng (2017)	IDDAge: older than 15 (44% were 18 –21)	Examine impact of a comprehensive care clinic (CCC) on cost and utilization	Clinic, USA	Cross-sectional	Medicaid claims, ED and hospital encounters	Those with FXS, ASD, or ID were more likely to have hospital encounters	Cost Utilization
McDermott (2015)	FXS, ASD, ID Ages: 15 –24 (FXS: n = 125,	Compare hospital encounters between adolescents and	Medicaid database, USA	Cross-sectional	ICD–9		Utilization

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Table 3 (continued)

Author Last Name (Date)	Population	Concept/ Aims	Context	Design	Measures	Results	Outcome Domain
	ASD: n = 2592, ID = 10,685)	young adults with fragile X, ASD, and other IDD.				than unaffected youth. Mental health hospitalizations decreased in adulthood from adolescence. Epilepsy was designated as an ambulatory care sensitive condition for those with FXS, ASD, and ID. Youth with ASD received less services with age in each setting other than the ED. Youth with ID experienced a faster decline in service utilization. 74.3% used at least one therapeutic service in the prior 12 months, most in non-public settings. Over 93% of parents indicated that there were desired, but unmet services. Low-income families living in rural areas faced the highest risk for access barriers. With age, medication use increased whereas orthotic use, therapy use, and follow up with a physiatrist decreased for ambulatory patients. Non-ambulatory patients did not show a significant decrease in follow up with psychiatry, but psychotropic meds increased with age. Each year of CAST enrollment was associated with a 33% reduction in ED visits for any reason, 31% reduction for mental health. Children had an average of 7.25 visits per year versus fully transitioned adults with 5.33 visits per year. The distribution of visit types changed with age. Use of therapy services remained stable. 21.16% of all pediatric clinic visits are to neurosurgery which dropped to 8.45% of adult visits. 8.85% of pediatric visits were to urologists but 10.36% for adult visits. 6.86% of pediatric visits were for primary care but were 15.29% of adult visits.	
Nathenson (2017)	ASDAge: 16 –23 (n = 16,338)	Examine how healthcare utilization patterns change as youth with ASD transitioning.	Claims Database, USA	Cross-sectional	ICD–9, health service encounters		Utilization
Platos (2019)	ASD Aged 12 –38 (n = 311)	Understand of service use, unmet needs for services.	Community, Poland	Cross-sectional	Polish Autism Survey		Utilization Gaps in Care
Roquet (2018)	CP Age: 18 –24 (n = 61)	Analyzehealthcare use by age and ambulatory status.	Community, France	Cross-sectional	Internally developed survey questions		Utilization
Schmidt (2019)	ASD Age: Mdn 22(n = 77)	Evaluate if primary care center designed for adults with ASD (CAST), would reduce ED utilization over time	Clinic, USA	Longitudinal cohort	Number of ED visits per year, ED visits for non-emergent and mental health conditions based on diagnosis code.		Utilization
Shepard (2018)	SB Ages: 18 –25(adults n = 293)	Examine ambulatory health care visit use of children, transitioned, and adults who continued in pediatric care.	Clinic, USA	Cross-sectional	ICD–9, Encounters in EMR		Utilization
Szymanski (2017)	SBAge: M 19.1 (n = 77)	Assess rates and predictors of successful transition from a multidisciplinary SB clinic to adult urology.	Clinic, USA	Cross-sectional	% of pts who attended an appointment with adult provider within 24 months of discharge from clinic.	40.3% successfully transitioned. Patients without urological follow-up were most likely to visit the ED.	Utilization Gaps in Care

(continued on next page)

Table 3 (continued)

Author Last Name (Date)	Population	Concept/ Aims	Context	Design	Measures	Results	Outcome Domain
Torres (2021)	Caregivers of ASD Age: M 24 (n = 295)	Identify the use of services for Latin Americans with ASD.	Community, 6 Latin American Countries	Cross-sectional	Internally developed survey questions	Most of our sample was not receiving health services, almost half had access to medication, and neurologists were the most consulted health care providers. Adults with ASD receive fewer services as compared to younger children and adolescents. Significantly more adults reported an unmet need for speech/language therapy, one-to-one support, occupational therapy, and social skills training. 95% of the sample visited a physician at least once per year, and 24% had a primary care physician. Adults visited physicians 11.5 times per year (approximately once per month) and were admitted to hospital once every 6.8 years.	Utilization
Turcotte (2016)	Parents of ASD Age: M 25.5 (adults: n = 467) compared to younger age groups	Examine reported service use and needs.	Community, USA	Cross-sectional	Pennsylvania ASD Needs Assessment survey		Utilization Gaps in Care
Young (2005)	IDD Age: M 21.9 (n = 345)	Explore health care utilization, among adults with complex physical disabilities	Database, Canada	Cross-sectional	Health care encounters		Utilization

*Age describes that of young adults with IDD.

Abbreviations: autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome (DS), intellectual/developmental disability (IDD), mean (M), median (Mdn), spina bifida (SB)

youth with IDD finding that they were challenged by the lack of HCT knowledge and the role dilemma of being a sibling versus a caregiver.¹³⁵ Three studies focused on the ASD population. Lounds et. al found that better well-being of mothers of emerging adults with ASD was associated with their child having less behavior concerns and being prescribed more psychotropic medications, exiting from high school, being female, and having both ASD and ID, as well as better maternal health.^{58,135} Similarly, Wong et. al found that ASD severity, behavior/mental health, and the feeling of filial obligation were stressors for parents of youth with ASD whereas social supports, HCT planning, and various coping mechanisms predicted better caregiving experience.¹³⁶ Pozo et. al found that for parents of children and adults with ASD parental stress and psychological well-being were similar across age groups, whereas depression and anxiety were lower in parents of adolescents/adults than in parents of young children.¹³⁴

4. Discussion

This scoping review sought to identify Quadruple Aim outcomes measures for HCT for young adults with IDD.¹¹ Overall, studies used a variety of measure types amongst various IDD populations and many, particularly for qualitative studies, used internally developed questions. Despite the lack of measurement consistency, common topics for measurement emerged for each domain and were agreed upon by the authors as recommendations for measurement of future HCT initiatives for the IDD population (Fig. 3).

4.1. Population health

Disparities in health outcomes and preventive care amongst children and older adults with IDD have been well documented and are important to measure to assure high-quality HCT.^{5,24,137-141} While only two articles discussed general health outcomes (both in young adults with ASD), measuring general health outcomes (e.g., obesity rates, substance use

rates, and completion of recommended preventive care activities) is important to improving overall health, preventing common adult conditions leading morbidity and mortality. Common co-occurring conditions across IDD populations of fatigue, pain, epilepsy, pneumonia, gastrointestinal concerns (e.g., constipation), mobility impairment and musculoskeletal concerns, skin ulcers, and urinary tract infections are also important measures for health optimization.^{34,40,48-50,54,71,142} From the articles reviewed, only skin ulcers were identified as a mortality risk factor for SB, thus more studies are needed to identify other mortality risk factors for SB as well as other IDD diagnoses.⁴⁸ In addition to these findings, condition-based guidelines have emerged for several adult IDD populations (e.g., SB,¹⁴³ DS,¹⁴⁴ ASD,¹⁴⁵ CP¹⁴⁶) which can serve as references to develop diagnosis-specific health outcome measures.

Mental health emerged as a common and important topic to address in HCT across multiple populations as it impacts independence, socialization, development of adult skills, and leads to increased acute care use.^{34,44,52,55,60,61,73} Notably, studies used variety of depression/anxiety assessment questionnaires. Further determining which tools best screen for mental health concerns for specific IDD populations and intellectual ability levels is important to guiding clinic care and research.

Self-management is a core element of HCT.⁸ However, all self-management studies in this review were done in the SB population revealing the need for further study to understand the developmental trajectory of health-related self-management skills and how they can be optimized for individuals with IDD of varying mobility and cognitive levels. Related to self-management is independent living. Amongst these studies, living arrangements (with family, alone, roommate, etc.), use of assistance, and employment status were used to assess independence.^{45,53,58,70,78,147,79,82,83} However, physical disability, intellectual disability, functional assessments, and supportive assistance for medical care should be considered as modifiers to independent living outcomes for the IDD population.

As patients' perception of and goals for their health and function can be different from healthcare providers' judgement, QOL is an important

Table 4
Provider/Caregiver Experience Outcomes for HCT for Young Adults with IDD.

First Author (Date)	Population/Age*	Concept/Aims	Context	Study Design	Measures	Key Findings	Subdomains
Agrawal (2019)	Urology physicians of youth with SB (n = 70)	Summarize perceived best practices for the urologic care of adult patients with SB.	Professional organization, USA and Canada	Cross-sectional	Internally developed survey questions	Nearly half of providers believed that transitioning to adult care should occur between 18- 21 years; identified a need for multidisciplinary teams. Themes: Ideal care setting is comprehensive, multidisciplinary adult clinic in adult hospital/ clinic with primarily adult providers. Barriers to successful transition: limited adult providers willing to accept CP patients, concern about level of care in adult health care system, and lack of financial resources.	Healthcare providers' experience
Bolger (2017)	Healthcare providers of adolescents with CP (n = 11)	Identify and describe current transition practices and beliefs among physician providers of adolescents with CP.	Clinics, USA	Cross-sectional	Internally developed survey questions	Recommended interventions: provide families with medical summaries for adult providers, compile lists of adult providers or community resources, coordinate care and communication between pediatric and adult providers, hold transition-specific appointments, and use checklists to track HCT progress.	Healthcare providers' experience
Kuhlthau (2015)	Healthcare providers of youth with ASD(n = 19)	Identify strategies for success for transition for ASD	Clinics, USA and Canada	Qualitative	Internally developed survey questions	Enablers: leadership, advocacy, funding, inter-agency partnerships, cross-appointed staff; Challenges: gaps in adult specialty services, geographic catchment of adult services, engagement of frontline staff, gaps in communication and role clarity.	Healthcare providers' experience
Lindsay (2016)	Healthcare providers of youth and young adults with SB(n = 32)	Understand challenges and enablers to implementing transition model for youth with SB	Adult and Pediatric clinics, Canada	Qualitative	Internally developed interview questions	Factors delaying transfer: attachment to child neurologists, lack of adaptation of adult neurology facilities Facilitators: intractable epilepsy, pregnancy. Barriers: lack of information about daily life, weak transition preparation in pediatric system, lack of knowledge of pediatric epilepsy syndromes, and the lack of support for patients with ID and multidisciplinary care needs in adult system. Both groups proposed joint clinics and development of care networks between pediatric and adult care and courses on transition.	Healthcare providers' experience
Nabbout (2020)	Neurologists of youth with IDD and epilepsy (child neurologists: n = 39, adult neurologists: n = 29)	Understand pediatric and adult neurologists' experience of transition in epilepsy	Medical association, France	Qualitative	Internally developed survey questions		Healthcare providers' experience

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Table 4 (continued)

First Author (Date)	PopulationAge*	Concept/Aims	Context	Study Design	Measures	Key Findings	Subdomains
O'Connell (2003)	Patients, caregivers, health care providers of IDD Age: 16 –26 (n = 12 focus groups of 8 –10)	Examine issues relating to transition that hinder or enhance delivery of care to young adults with a disability	Community, Australia	Qualitative	Internally developed focus group questions	Themes: lack of coordination and communication of services, continuity of care between providers, knowledge, support. Role of supportive, coordinating pediatrician. Need for policy to address problems. Themes: difficulty accessing and communicating with service; insufficient knowledge about services, cultural considerations; structural challenges of separate mental health and intellectual disability agencies for those with dual diagnosis; excessive focus by services on crisis response rather than prevention and early intervention.	Healthcare providers' experience Caregiving experience
Son (2019)	Service coordinators for adults with IDD (n = 126, ages 21 –30: n = 17)	Identify gaps and challenges in HCT delivery for youth with both intellectual disability and mental health disorders	Service providers, Australia	Qualitative	Internally developed focus group questions, evaluation of a pilot specialist health service for people with IDD	Three stressors (i.e., autism severity, mental health crisis/challenging behaviors, and filial obligation), four resources (i.e., general social support, HCT planning, parent-teacher alliance, and parenting efficacy), and three coping styles (i.e., problem-focused coping, avoidance-focused coping, and optimism) predicted parents' outcomes (i.e., burden, transition experience, subjective health, and quality of life).	Healthcare providers' experience
Wong (2020)	Parents of youth with ASD Age: 15 –27(n = 13)	Assess parent stressors, resources, coping and adaptation	Community, Midwest USA	Qualitative	Internally developed survey questions		Caregiving Experience

*Age describes that of young adults with IDD.

Abbreviations: Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Down Syndrome (DS), Intellectual/Developmental Disability (IDD), Mean (M), Median (Mdn)

balancing measure for in the population health outcome domain.¹⁴⁸ Similar to mental health measures, there were several assessments used for QOL amongst studies reviewed. In qualitative studies, young adults with IDD defined “meaningful adult life” as functioning as independently as possible and participating in the community with necessary supports.^{75,77} Relatedly, addressing adaptive needs for physical disability and accessibility and pain management are important to supporting independence and participation goals and QOL for those with mobility impairment.^{50,51,65} Further collaboration with individuals with IDD is needed to align QOL assessments with their perspectives of meaningful adult life and develop HCT interventions to best support these goals and address pain, immobility, accessibility, and self-acceptance that may challenge these goals.

4.2. Experience of care

Studies ascertaining patient and/or family HCT experiences described that young adults with IDD and their families experience high stress and anxiety, often feel frustrated and overwhelmed, and lack sufficient communication and support services as they enter adult

care.^{85,91,97,104,106} Like HCT experience studies for youth with non-IDD chronic conditions, structured preparation supports were linked with better HCT experiences.^{88,103} However, current literature regarding HCT patient experience for the IDD population lacks standard measures that incorporate these themes. This lack of consensus makes combining multiple study results and quantifying patient/caregiver experience challenging. Thus, identified themes of patient/caregiver experience in this review can be used to develop and/or modify standardized measurement tools for the transitioning IDD population. IDD-specific HCT patient experience measures should assess: (1) patient/caregiver anxiety and stress regarding HCT, (2) communication between patients/families and pediatric/adult healthcare teams about accommodations for behavioral/adaptive needs, (3) supports for ability-appropriate independence and self-management, and (4) connection to community and social supports. Improved patient/caregiver experience measurements can facilitate future HCT intervention studies and program development to determine best practices to improve HCT satisfaction for this population.

Table 5
Family Caregiver Experience.

First Author (Date)	PopulationAge*	Concept/Aims	Context	Study Design	Measures	Key Findings	Subdomains
Goodwin (2020)	Parents of youth with 22q deletion		Clinic, Australia	Qualitative	Interviews	parental ability to relinquish control while keeping children safe	Caregiving experience
Gur (2020)	Caregivers of individuals with IDD Age: < 21, 21 – 30, > 31 (n = 301)	Examine the social, psychological, and financial differences among caregivers	Community, Israel	Cross-Sectional	Household income and expenditure; services use; stress; social participation; social support; subjective well-being	HCT is associated with social disadvantages for families such as lack of social services, shrinking social support, and aging. Better maternal well-being was associated with their child having less behavior problems and more prescribed psychotropic medications, exiting from high school, being female, and having ID and ASD, as well as better maternal health.	Caregiving experience
Lounds (2007)	Mothers of youth and adults with ASD Age: 11.3 – 21.3 (n = 140)	Investigate how change in characteristics of adolescents and young adults with ASD predicts change in maternal well-being and in the quality of mother-child relationship	Community, USA	Qualitative	Internally developed interview questions		Caregiving experience
Pozo (2015)	Parents of individuals ASD Children Age: M 8 Youth Age: M 15.8 (n = 30) Adults Age M = 27.2 (n = 26)	Examine parental well-being in parents of adults, adolescents, and young children with ASD	Community, Spain	Cross-sectional	Childhood Autism Rating Scale (CARS), Behavior Problems Inventory (BPI), the Checklist of Supports for Parents of the Handicapped (CSPH), the SOC Questionnaire and the Parental Stress Index Short Form (PSI-SF).	Parental stress and psychological well-being similar across groups; depression and anxiety were lower in parents of adolescents/adults than parents of young children.	Caregiving experience
Rawson (2010)	Young adult siblings of individuals with IDD (n = 14)	Explore needs of siblings of individuals with IDD as they age	Community, United Kingdom	Qualitative	Internally developed interview questions.	Themes: Lack of knowledge of transition, sibling vs caregiver dilemma Three stressors (i.e., autism severity, mental health crisis/ challenging behaviors, and filial obligation), four resources (i.e., general social support, HCT planning, parent-teacher alliance, and parenting efficacy), and three coping styles (i.e., problem-focused coping, avoidance-focused coping, and optimism) predicted parents' outcomes (i.e., burden, transition experience, subjective health, and quality of life).	Caregiving experience
Wong (2020)	Parents of youth with ASD Age: 15 – 27 (n = 13)	Assess parent stressors, resources, coping and adaptation	Community, Midwest USA	Qualitative	Internally developed survey questions		Caregiving Experience

*Age describes that of young adults with IDD.

Abbreviations: Autism Spectrum Disorder (ASD), Cerebral Palsy (CP), Down Syndrome (DS), Intellectual/Developmental Disability (IDD), Mean (M), Median (Mdn)

4.3. Cost/Utilization

Both cost and utilization are known to be higher for children and adults with IDD and medical complexity and thus cost, utilization, and potentially preventable condition ED and hospital admission are important outcome measures.^{22,149,150} As expected, studies in this review demonstrated that young adults with IDD had higher cost and utilization, particularly for ED encounters compared to the general population with increased medical complexity and psychiatric care needs being associated with higher acute care utilization.^{32,35,36,40,72,109,114} Intervention studies targeting potentially preventable conditions and acute care utilization for young adults with IDD are sparse, but

preliminary studies have demonstrated that condition-specific adult primary care clinics and structured HCT care coordination increase rates of successfully establishing with adult outpatient care and decrease overall costs particularly through decreasing acute care use.^{107,108,116} However, access to comprehensive HCT, adult primary care, and community support services for IDD population remain limited.^{27,78,113,114,116,118,122,126} Further studies are needed to evaluate interventions to decrease acute care utilization for young adults with IDD for potentially preventable medical and mental health conditions and address unmet health and community support needs implementing the successful condition-specific outpatient clinic models and care coordination strategies described in studies included in this review. Further

Quadruple Aim Domains	HCT Outcome Measurement Recommendations
Population Health	
General Health	<ul style="list-style-type: none"> Rates of age-based preventive care should be measured (i.e., health screenings, vaccinations, reproductive care per general health guidelines) and general health measures (i.e., body-mass index, participation in adaptive physical activity, nutrition status, and substance use).
Condition-specific	<ul style="list-style-type: none"> Measures should evaluate the optimization/exacerbation of co-occurring conditions amongst IDD populations such as fatigue, pain, epilepsy, pneumonia, gastrointestinal concerns (e.g., constipation) immobility, skin ulcers, and urinary tract infections. Measures should include recommendations from condition-specific guidelines. Further study is needed to identify risks for mortality in this age group with IDD.
Mental and Behavioral Health	<ul style="list-style-type: none"> Depression, anxiety, and behavior concerns are important outcome measures. Consensus is needed on best depression and anxiety assessments for individuals with various conditions and intellectual ability.
Self-management/ Transition Readiness	<ul style="list-style-type: none"> Self-management measures should be adapted to various IDD populations considering physical and cognitive disabilities.
Independence	<ul style="list-style-type: none"> Living arrangements (with family, alone, roommate, etc.), use of assistance, employment status are recommended to assess independence. Physical disability, intellectual disability, functional assessments should be considered as modifiers.
Quality of life	<ul style="list-style-type: none"> Further studies are needed to align QOL measures with QOL goals identified by individuals with IDD. QOL measures should address self-acceptance, immobility, pain, adequate support and access for independence and community participation.
Experience of Care	
Health care satisfaction	<ul style="list-style-type: none"> Satisfaction measures should evaluate patient/family anxiety and stress regarding HCT, communication between patients/families and pediatric/adult healthcare teams about behavioral/adaptive accommodations, adequacy of supports for ability-appropriate independence and self-management, and adequacy of connection to community and social supports.
Access to care	<ul style="list-style-type: none"> Measures should evaluate patient/family access to healthcare and ancillary providers to meet medical, mental health, and adaptive support needs.
Cost/Utilization	
Utilization of health care services	<ul style="list-style-type: none"> Measures should evaluate utilization of outpatient, ED, and hospital pre/post transfer to adult care.
Gaps in care	<ul style="list-style-type: none"> Measures should evaluate utilization/cost for ED/hospitalizations for potentially preventable conditions, insurance coverage changes between pediatric/adult health care plans, and differences in service access based on underlying IDD diagnosis and demographic variables (e.g., race/ethnicity, rural/urban, insurance, home and community-based waiver status).
Cost per capita	<ul style="list-style-type: none"> Measures should evaluate total cost and changes in cost with engagement in HCT services, care coordination, clinic, and community-based interventions.
Healthcare Provider Satisfaction	
	<ul style="list-style-type: none"> Measures should evaluate adult provider knowledge in caring for adults with IDD, access to necessary information and subspecialty/home care supports, hand-off from pediatric teams.
Additional Domain: Family Caregiving Experience	
	<ul style="list-style-type: none"> Measures should evaluate family caregiver stress, wellness and adequacy of home medical and behavioral health support to provide care for their adult child/family member with IDD.

Fig. 3. Quadruple Aim HCT Measurement Recommendations for Young Adults with IDD.

demonstrating the impact of structured HCT programs and adult care models on cost and utilization for the IDD population could inform the development of shared cost-saving reimbursement agreements between payors and providers that make such interventions feasible and sustainable.

4.4. Healthcare provider

Healthcare provider and family caregiver experience providing care studies found that structured HCT processes, integrated care coordination particularly across pediatric and adult care systems, and adequate support services in the healthcare system and community were desired and deemed helpful by healthcare providers, service coordinators, and family caregivers.^{124–126} In reviewing these limited studies, measuring the effect of structured HCT processes, care coordination, and community or clinical resources on healthcare provider well-being and satisfaction is important to HCT quality.

4.5. Family caregiving experience

Family caregivers often described the stressful experience of caring for their emerging adult child while both changing and often losing healthcare resources and community supports.^{128,129,131,132,130} Siblings also described the reality of needing to take on increasing care support roles as their parents and siblings with IDD aged.¹³⁵ Topics of family caregiving not addressed in the studies identified in this review are long-term care planning including where the adult with IDD will live as their parents age and may not be able to care for them, interfamily relationships in providing in-home care, and interventions to support caregiver wellness and prevent burnout. In collaboration with families of individuals with IDD, strategies to address these topics may be adapted from the Geriatrics literature.

4.6. Limitations

The body of literature addressing HCT outcomes particularly for the IDD is mostly limited to observational and qualitative studies with most qualitative studies including parents and few including young adults with IDD. Additionally, due to the heterogeneity of measures used in the identified studies, further analysis of the articles was not feasible. While these studies are valuable to begin to identify priority physical and mental health as well as community support concerns, further studies are needed to compare various HCT models and strategies in addressing these topics with input from young adults with IDD and their families. Additionally, after the initiation of this scoping review, the Institute for Healthcare Improvement revised the Quadruple Aim to become the Quintuple Aim including advancing health equity as a priority healthcare quality outcome.¹⁵¹ We acknowledge that this domain was not included in this scoping review and that both further study and incorporation into HCT outcomes of this domain is important.

4.7. Conclusions

Reaching consensus on HCT outcome measures for all patients, but particularly those with IDD, is an increasingly important priority as there are increasing numbers of individuals with IDD entering adulthood deserving high quality care. The body of literature describing HCT pilot interventions to address HCT core elements continues to grow but without agreement on how outcomes should be measured. Policies promoting access to structured HCT and adult care for those with IDD and reimbursement for such services also rely on measurements to evaluate HCT quality. Priority Quadruple Aim outcomes identified in this scoping review can be used by HCT experts and advocates to develop HCT outcome measures relevant to medical, behavioral, and adaptive needs of the IDD population transitioning to adult care as well as needs of their caregivers and healthcare providers.

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Ethical statement

As this article is a scoping review, no institutional review was required.

CRediT authorship contribution statement

Kathleen Irby: Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Ellen Fremion:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Formal analysis, Conceptualization. **Uluer Ahmet:** Writing – review & editing, Validation, Methodology, Formal analysis, Conceptualization. **Dava Szalda:** Writing – review & editing, Validation, Methodology, Formal analysis, Conceptualization. **Susan Shanke:** Writing – original draft, Validation, Methodology, Funding acquisition, Conceptualization. **Carlie Stein Somerville:** Validation, Methodology, Formal analysis, Conceptualization. **Parag Shah:** Writing – original draft, Validation, Methodology, Formal analysis, Conceptualization. **Sophia Jan:** Validation, Methodology, Formal analysis, 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.

Appendix A. Search strategy

A search was conducted by a medical librarian on August 6, 2021 in Medline Ovid, Embase, Web of Science, PsycINFO, and Cochrane. The strategy was initially created in Medline Ovid using MeSH terms as well as keywords and phrases. Results were limited to articles published in English during or after the year 2000. The Medline Ovid strategy was subsequently translated to the other databases. A repeated search was performed April 24, 2023 to retrieve additional articles published.

Medline Ovid Search Strategy.

1. Young Adult/
2. ("young adult*" or "new adult*" or "emerging adult*" or "emerging adult*").ti,ab,kw.
3. or/1-2
4. exp Intellectual Disability/
5. Developmental Disabilities/
6. Cognitive Dysfunction/
7. ((intellectual* or mental* or development* or cognitiv* or adaptiv*) adj3 (disabilit* or disabl* or impair* or deficien* or dysfunc* or defect* or disorder* or "dis-order*")).ti,ab,kw.
8. ("intellectual* disabilit*" or "intellectual* disabl*" or "intellectual* impair*" or "intellectual* deficien*" or "intellectual* dysfunc*" or "intellectual* defect*" or "intellectual* disorder*" or "intellectual* dis-order*" or "mental* disabilit*" or "mental* disabl*" or "mental* impair*" or "mental* deficien*" or "mental* dysfunc*" or "mental* defect*" or "mental* disorder*" or "mental* dis-order*" or "development* disabil*" or "development* disabl*" or "development* impair*" or "development* deficien*" or "development* dysfunc*" or "development* defect*" or "development* disorder*" or "development* dis-order*" or "cognitiv*

- disabilit*" or "cognitiv* disabl*" or "cognitiv* impair*" or "cognitiv* deficien*" or "cognitiv* dysfunc*" or "cognitiv* defect*" or "cognitiv* disorder*" or "cognitiv* dis-order*" or "adaptiv* disabilit*" or "adaptiv* disabl*" or "adaptiv* impair*" or "adaptiv* deficien*" or "adaptiv* dysfunc*" or "adaptiv* defect*" or "adaptiv* disorder*" or "adaptiv* dis-order*").kw.
9. ("mental* retard*" or adrenoleukodystrophy or "adreno-leukodystrophy" or "adrenoleuko-dystrophy" or "adreno-leuko-dystrophy").ti,ab,kw.
 10. ("Cri-du-Chat" or "De Lange" or "DeLange" or "Down* Syndrome*" or "Prader-Willi" or "Rubinstein-Taybi" or "Trisomy 13" or "Trisomy Thirteen" or "Trisomy 21" or "Trisomy Twenty-One" or WAGR or Williams or "Coffin-Lowry" or "Fragile X" or "Lesch-Nyhan" or "Menkes Kinky Hair" or Rett*).ti,ab,kw.
 11. (Alpers* or mannosidosis* or COFS or "Cerebro-oculo-facio-skeletal*" or Danon* or Dubowitz* or "Ellis van Creveld*" or "Ellis van Creveld*" or "Hunter* syndrome*" or "Hurler* syndrome*" or "Kabuki makeup*" or "Kabuki make-up*" or Leigh* or leprechaunism* or "maple syrup urin*" or Sjogren* or "Maroteaux Lamy" or "prolidase deficien*" or Sandhoff* or Sanfilippo* or "San-Filippo*" or "Weismann Netter*).ti,ab,kw.
 12. ("Mucopolysaccharidosis II" or "Mucopolysaccharidosis 2" or "Mucopolysaccharidosis Two").ti,ab,kw.
 13. ("Pyruvate Dehydrogenase Complex Deficiency" or PDCD*).ti,ab,kw.
 14. exp Autism Spectrum Disorder/
 15. (autism* or autistic* or asperger*).ti,ab,kw.
 16. Cerebral Palsy/
 17. "cerebral pals* ".ti,ab,kw.
 18. exp Spinal Dysraphism/
 19. ("spin* dysraph*" or "spin* bif*").ti,ab,kw.
 20. (diastematomyel* or "diastemato-myel*" or lipomeningocele* or "lipo-meningocele*" or lipomyelomeningocele* or "lipo-myelomeningocele*" or "lipomyelo-meningocele*" or meningo-myelocele* or "meningo-myelocele*").ti,ab,kw.
 21. or/4-20
 22. Transition to Adult Care/
 23. (transition* and adult*).ti,ab,kw.
 24. "transition* age* ".ti,ab,kw.
 25. ("age out" or "aging out" or "ageing out").ti,ab,kw.
 26. or/22-25
 27. 3 and 21 and 26
 28. limit 27 to (english language and yr="2000 -Current")

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