Curr Dev Disord Rep (2016) 3:97–103
DOI 10.1007/s40474-016-0082-x

INTELLECTUAL DISABILITY (J WEISS, SECTION EDITOR)

Health and Health Service Use of Youth and Young Adults with Intellectual and Developmental Disabilities

Yani Hamdani [1] · **Yona Lunsky** [1,2]

Abstract In this paper, we explore the health and health service use of youth and young adults with intellectual and developmental disabilities (IDD), with a focus on two specific subgroups: youth and young adults with Down syndrome and autism spectrum disorders. Young people with IDD are more likely to develop health problems (e.g., chronic disease and mental illness) than their peers without IDD as they age and require access to complex, coordinated care. The literature indicates that their patterns of health service use tend to shift from community and outpatient care in childhood toward more hospital-based, emergency, and long-term care in adulthood. We highlight some unique issues with respect to understanding the health and health service use of this population, and discuss the implications for health care practice, policy and planning, and further research.

Keywords Health · Health service utilization · Intellectual and developmental disabilities · Down syndrome · Autism spectrum disorders · Youth · Young adult · Review

Introduction

Youth and young adults with intellectual and developmental disabilities (IDD) are more likely to develop health problems (e.g., co-morbid conditions, chronic diseases, and mental illnesses) than their peers without IDD as they age [1, 2]. Yet, they experience significant challenges accessing health care services as adults compared to adults without IDD [1]. In recent years, increasing attention has been paid to the issue of health care transitions between childhood and adulthood for young people with chronic conditions and disabilities. As a subgroup of this broader population, youth and young adults with IDD are at particular risk of falling through gaps in service provision for two main reasons. First, they are often involved with multiple service systems (e.g., health, education, and social services) mandated for children [3•] and require transitions to adult-oriented services. Second, young people with IDD are not a homogeneous group with respect to their health and health care needs. There is an array of physical and mental health problems that can co-occur with IDD, with some problems more common with particular types of IDD (e.g., thyroid dysfunction and vision and hearing problems in Down syndrome, and anxiety and behaviors in autism spectrum disorders). In addition, intellectual impairments are more strongly associated with some developmental disabilities than others. Thus, the health and health service use patterns of youth and young adults with IDD can vary depending on diagnosis, co-morbid conditions, and access to adequate and appropriate health care in both childhood and adulthood. Little is known about the health and health service utilization patterns of this group from a population perspective. The aim of this paper is to explore the health and health service use of youth and young adults with IDD, the unique challenges for addressing and studying their health and health service use, and the implications for health care practice, policy and planning, and further research.

This article is part of the Topical Collection on *Intellectual Disability*

✉ Yani Hamdani
yani.hamdani@camh.ca

Yona Lunsky
yona.lunsky@camh.ca

[1] Centre for Addiction and Mental Health, 1001 Queen Street West, Toronto, ON, Canada M6J 1H4

[2] Department of Psychiatry, University of Toronto, 1001 Queen Street West, Toronto, ON, Canada M6J 1H4

Approach to This Review

We conducted a search of key databases, including Medline and PsychInfo using subject headings and keywords including: “developmental disabilities,” “intellectual disabilities,” and specific subgroups (e.g., “autistic disorder” and “Down syndrome”); “health care utilization” and “health services;” and, “youth,” “young adult,” and “adolescent.” We were particularly interested in the chronological age range of 15 to 24 years. However, we found several challenges in implementing our search. There were significant variations in how IDD and how age categories were defined and operationalized in research, as well as in what constituted a health service. These challenges exist in part because universal definitions for these keywords do not exist in the literature. For example, some studies focused on children, which included adolescents up to the age of 18 years. Other studies focused on adults, but included adolescents as young as 15 years of age. In addition, there are differences across regions and jurisdictions in how these keywords are understood and defined, and in their use for identifying and indexing age categories for literature search databases. For this reason, we decided to conduct a preliminary scoping review of recent studies on the health status and health service use patterns of the broad population of youth and young adults with IDD, then focus on two subgroups (i.e., Down syndrome and autism spectrum disorders), to gain insights into the current state of the literature on this topic. These insights can provide a better understanding of how to approach a more rigorous review in the future. We selected these subgroups as examples because of some unique issues associated with these conditions, and because there were several studies on health status and health use in the emerging adult period for these individuals. We aimed to understand the unique challenges of this population for research and provision of health services, and to consider the potential implications for research, policy, and practice. While the summary of the literature is not exhaustive, we highlight unique issues related to understanding the health and health service use of this population. We discuss the health profiles and service use patterns of the broader group identified as having IDD and the two subgroups of Down syndrome and autism spectrum disorders (ASD).

Health Profiles

Youth and Young Adults with IDD

IDD are disorders that usually begin at birth and follow an atypical trajectory for physical, intellectual, and/or emotional development [4]. Intellectual disability (ID) involves impairments of general mental abilities that impact on adaptive functioning in three domains: the conceptual, social, and practical domains. These domains influence how an individual copes and manages everyday tasks and activities [5]. Developmental disability is a broader term for lifelong disability that may involve both intellectual and physical impairments [4]. As a group, young people with IDD have a higher prevalence of health problems, chronic diseases, and co-morbid conditions compared to the general population [1]. These higher rates are evident at the population level even in adolescence [6, 7]. Common co-morbidities include vision and hearing impairments, epilepsy, psychiatric issues, and cardiovascular and musculoskeletal conditions.

Children and youth with IDD have higher rates of psychiatric, behavioral, and emotional co-morbidities compared to children and youth without IDD [8–11]. For example, in a study of adolescents ($n = 75$) with a broad range of ID (e.g., ID without an identified cause, chromosomal or genetic disorders such as Down syndrome) between 12 and 19 years of age, Hassiotis and Turk [3•] found that 67 % of participants had mental health disorders (e.g., conduct disorders and emotional disorders such as anxiety and depression) as judged by clinical interviews with a qualified psychiatrist. In addition, half of the adolescents and/or their families had sought mental health services and almost half of the adolescents receiving medications were on psychiatric medications.

Youth and Young Adults with Down Syndrome

Down syndrome, also known as Trisomy 21, is a genetic chromosomal disorder that is characterized with distinct facial and physical features and some degree of ID. The prevalence of Down syndrome is estimated to be between 6 and 9.8/100,000 adolescents [12]. There are several physical health problems that commonly occur with Down syndrome, including obesity, obstructive sleep apnea, thyroid dysfunction, celiac disease, seizure disorders, and vision and hearing problems [13]. In addition, many young people with Down syndrome have cardiac, respiratory, musculoskeletal, and mental health problems [14•]. However, research indicates that the medical conditions associated with Down syndrome have changed over time. For example, Thomas et al. [2] found that children with Down syndrome in 2004 were less likely to have a bowel condition, have a problem related to a pre-existing cardiac conditions, or have an episodic illness or infection compared to a cohort in 1997. They also found that the use of general practitioners, combined with medical specialist visits, overnight hospital admissions, and length of hospitalizations was reduced between 1997 and 2004. These findings suggest that the health profiles of youth and young adults with Down syndrome not only change with age but have also changed over time and across generations.

In a study in Western Australia, Pikora et al. [14•] found that nearly one third of their cohort of youth and young adults with Down syndrome between 15 and 30 years of age (*n* = 197) had mental health conditions, which was four times higher than the prevalence in the general population of a similar age. Anxiety and depression were particularly prevalent in their cohort, with rates of approximately 22 and 11 %, respectively. Baumer and Davidson [13] suggested that understanding depression for young people with Down syndrome is important because it can potentially be mistaken for cognitive decline. It is also more common for individuals with Down syndrome to have a diagnosis of ASD, another type of developmental disability, compared to the general population; however, they tend to be diagnosed at an older age than those without Down syndrome [13].

Youth and Young Adults with ASD

ASD are a group of disorders characterized by functional limitations in social communication (e.g., verbal and nonverbal communication) and social interaction and restricted or repetitive stereotyped behaviors, interests, or activities [5]. ASD affects as many as 1 in 68 children and 1 in 48 males [15]. A population surveillance study in the USA found that approximately one third of children aged 8 years with ASD also have ID [15]. Individuals with ASD have increased rates of medical and psychiatric comorbidities including epilepsy, gastrointestinal problems, sleep issues, anxiety, depression, and respiratory, food, and skin allergies [16]. Regarding psychiatric co-morbidities, Narendorf et al. [17] found that 70 % of youth with ASD had at least one mental health condition that might warrant intervention. Behavior issues, particularly aggression to self and others, and episodic psychiatric disorders, most commonly major depression, are more prevalent in adolescents with ASD and ID than in those with ID alone [18].

In recent years, the prevalence of ASD as a diagnosis has increased, which has implications for service use as they approach young adulthood [19]. The coordination of cross-sector services is an important consideration for young people with ASD because they generally have challenges with communication and social interaction, greater reliance on others for assistance and support, and high rates of co-morbid health and mental health problems [19]. It is particularly important to understand their health and health service needs as they transition out of school and health and social services mandated for children.

In this section, we described health profiles of young people with IDD, Down syndrome, and ASD. On the whole, these profiles suggest that many young people with IDD develop additional physical and mental health problems as they age and indicate the need for specialized and coordinated care across the lifespan. In what follows, we review what is known about the health service utilization of these three groups.

Patterns of Health Service Use

IDD

Overall, the literature indicates that young people with IDD use a wide range of health services, including hospital and community-based services. In a study using population data in Taiwan, Yen et al. [6] found that more than half of adolescents between 11 and 17 years of age had used outpatient care in the previous 6 months. A number of adolescents had used emergency care and had been hospitalized, approximately 10 and 5 %, respectively. Nearly one in four of these adolescents were prescribed medications. In a smaller study in the UK, adolescents and young adults, all of whom had challenging behaviors, used a variety of hospital and community-based services, plus informal care provided by families [8]. These research findings suggest that young people with IDD use a wide range of hospital and community services and illuminate the need for coordinated, complex care in young adulthood. Moreover, there is not necessarily a "one-size-fits-all" pattern of service use, but rather an array of services that youth with IDD and their families need to access and coordinate.

With respect to primary care, "health checks" are less common for young people with IDD than those without IDD [6, 7]. Yen et al. [6] found that less than half of the adolescents in their study had received an annual physical exam. Similarly, Nachshen et al. [7] found that children with IDD in Quebec, Canada, had fewer annual checkups than children without disabilities. This pattern continues into adulthood [20], despite international primary care guidelines [21, 22] and evidence on the importance of health checks for this population [23].

Regarding specialty care, young people with IDD use specialty and ambulatory care services at higher rates than those without IDD. In a large population-based study in Taiwan, Chiang et al. [24••] found that children and adolescents with ID had higher use rates of rehabilitative and psychiatric services and significantly higher ambulatory care visits per year than the general population. In contrast, Hassiotis and Turk [3•] found that adolescents with ID (between 12 and 17 years of age) in the UK had limited involvement with rehabilitative services, such as occupational therapy and physiotherapy, but were linked to psychological services for assessments and interventions. The majority of adolescents were receiving both health and social care (e.g., from child development teams, psychological counseling, and community services for people with ID). Hassiotis and Turk [3•] proposed that the high use of psychology-related services is consistent with other research that underscores the prevalence of mental illness in young people with ID. However, they found that young people who were no longer in school and who were not involved in day activities were receiving psychological services infrequently or not at all. These studies suggest that adolescents with ID are frequent users of particular health care services, but the type and range of services accessed may be limited by what is available, rather than based solely on health care needs. Barron et al. [8] suggested that the range of community services available and accessible to young people with ID might be limited by local service configurations and arrangements.

Down Syndrome

As described previously, young adults with Down syndrome have different health profiles and health care needs than their younger peers. Young adults with Down syndrome have fewer acute episodes of illness, especially respiratory infections, and less need for hospitalizations associated with episodic illnesses compared to children with Down syndrome [14•, 25]. However, they appear to develop more life style diseases such as obesity and mental health and musculoskeletal problems, which can lead to needing hospital services for other reasons. Pikora et al. [14•] found that young adults with Down syndrome between 15 and 24 years of age in Western Australia had more hospital visits, similar general practitioner visits, and fewer dental visits than the general population of the same age. Of the young adults with Down syndrome who had at least one hospitalization in their study, the most common reasons were for surgery, dental treatment, and eye treatment. Similarly, Hung et al. [26] found that patients with Down syndrome (under 65 years of age, mean age of 16.8 years) in Taiwan had more hospital admissions and stays than the general population. Thus, it is possible that the use of hospital-based services may not change significantly between childhood and adulthood for people with Down syndrome. However, their reasons for accessing hospital services may change as they age, particularly with increases in chronic disease and mental illness. In addition, Geelhoed et al. [25] found an increased need for family respite as children with Down syndrome aged, which may reflect the increased demands on families to provide ongoing informal and unpaid health and personal care.

ASD

Research on health service utilization indicates that young people with ASD increasingly use high-cost services (e.g., hospitals and long-term care) as they age. A study by Cidav et al. [27••] found that aging was associated with higher use of long-term care, psychiatric medications, case management, medication management, day treatment/partial hospitalization, and respite services by young people with ASD. In contrast, the use of occupational, physical and speech therapy, mental health services, diagnostic/assessment services, and family therapy decreased with age. In another study, Nayfack et al. [28] found that hospitalizations for young people with ASD up to age 18 years had increased threefold over 10 years, particularly for the oldest age group (15 to 18 years of age), compared to young people with other conditions (e.g., cerebral palsy, Down syndrome, other ID). The leading cause of hospitalizations for young people with ASD in the older groups was mental health concerns, whereas neurologic issues were the leading cause for the younger groups and second leading cause for the older groups [28]. Related to hospitalizations, Iannuzzi [16] found that emergency department use by adults with ASD was considerably higher than that of children with ASD. Thus, the health service use patterns of children with ASD appear to shift from outpatient and community health services toward high cost hospital-based services in adulthood.

Regarding mental health services, the literature indicates that youth with ASD often use mental health services provided by schools [17, 19]. For example, Narendorf et al. [17] found that almost half of the youth with ASD in their study had used a mental health service in the past year and of those that received a service, almost half had received it at school. In general, they found that students with ASD used mental health services more than other students in special education. In addition, over half of the youth and their families had sought help for mental health needs outside of school and almost half of those receiving medication were on psychiatric medications. Sixty-eight percent of the parents reported visiting their general practitioner more than three times in the past year, citing their children's problem behaviors as the reason for these visits. Shattuck et al. [19] found that young adults with ASD (age range of 19 to 23 years, mean age 21.5 years) used mental health services the most, followed by medical evaluation and assessment, speech-language pathology, and case management services. These studies indicate that many youth with ASD have access to mental health services while they are enrolled in school and suggest a need to consider what happens when these young people finish school and have to access mental health services in the community.

Implications for Health Care Practice, Policy and Planning, and Research

The literature indicates that youth and young adults with IDD, as a group, develop chronic diseases and mental illnesses that require access to complex and coordinated health care as they age. In addition, it appears that they increasingly use high-cost health care services once they "age out" of childhood services in the health and education service systems, which suggests that they may face challenges accessing other forms of health care as young adults. There are several implications of these findings for practice, policy and planning, and further research.

From the perspective of practice, clinicians working with youth and young adults with IDD can improve the uptake of regular health checks across the lifespan and incorporate care aimed at preventing the onset of chronic diseases and mental illness that tend to be common with particular subgroups and with the broader population with IDD. In addition, clinicians can ensure that referral pathways to specialty care, such as mental health care, are in place, particularly when youth are no longer eligible for services from schools or children's health care providers and must transfer to services for adults. They can also educate parents and caregivers, who are usually very involved in the health management of youth with IDD into adult life, about preventing chronic diseases and mental illnesses, but also about recognizing symptoms of these conditions so they can intervene or seek primary or community health care consultations before symptoms escalate to the point that emergency care or hospitalization are the only options. Primary and community-based care providers may require additional training on how to address the health and health care needs of youth and young adults with IDD in order to prevent the need for high cost health care services.

This review did not address the informal, unpaid care and coordination provided by family members and caregivers, particularly once youth with IDD leave school. Family members face numerous difficulties arranging and providing personal care and health care for young people with IDD, which can affect their health and well-being [20]. Furthermore, family members spend significant time and effort arranging daily and weekly programs and activities for young adults with IDD once eligibility for school ends. Public school provides youth with IDD with special education programs, services and supports, including personal care assistance and transportation, throughout the school-age years, which then ends and leaves families seeking community and social service programs to fill the gaps in daily activities and personal care. Thus, efforts to improve services and supports for family members and caregivers, and their access to coordinated health care, including community, social and respite services, is important for maintaining the health and well-being of young people with IDD, but also the health and well-being of family members and caregivers themselves.

Young people with IDD increasingly use high cost health care services as they age, which has implications for health care policy and planning. Changes to health care policy might focus on reallocating resources and services to more effectively meet the complex health care needs of this population across the lifespan. This might require a focus on community-based services that incorporate coordinated care processes and proactive planning to prevent gaps in accessing appropriate and timely care, particularly between childhood and adulthood. A life course view of the health needs of this population can assist in planning for the types of health services that are required to prevent and address co-morbidities. Developing health care systems based on this view can potentially shift health care costs away from the most expensive services and foster better access to appropriate and timely care.

Several gaps in knowledge about health and health service use for this age group and life stage were found in this review that can inform further research. First, there are limited studies that examine the health and health service use of youth and young adults with IDD from a population perspective. In general, existing studies compare youth and young adults with IDD to the general population and suggest that subgroups have unique health and health service needs, but do not compare health service use patterns between these subgroups. Further research can draw on the lessons learned from particular subgroups to examine similarities and differences in health and health service utilization across subgroups, rather than in comparison to the general population for whom we know fewer health services are required. In order to conduct this research, further work is needed to define or conceptualize what is meant my "youth" and "young adult" so that appropriate age or life stage comparisons can be made.

Second, there is a gap in knowledge about the nuances of what services are used and when they are used over the life course. In order to investigate the nuances of health service use patterns, some preemptive work is required to define what constitutes a health service. For example, does a health service include services beyond medical services, such as psychological counseling or respite?

Third, our review provided valuable insights into the health status and health service use of this population, which can inform policy, planning and practice, however, the lived experiences of young people with IDD and their families when accessing and using health care are equally important to understand. Further research might explore health care needs and access from the perspective of youth and young adults with IDD and their family members. Finally, there is a growing body of research on transitions between child and adult health care services for young people with a variety of disabilities and chronic conditions. This research can be better linked to the research on health service utilization to create a fuller picture of the factors that influence health care use and access of young people with IDD and their families. In addition, research that investigates the transitions in social roles, activities and settings between childhood and adulthood experienced by young people with IDD can potentially generate knowledge about the effects of achieving or not achieving traditional indicators of adulthood (e.g., employment, further education, independent living) on their health and well-being.

Conclusion

Our paper explored the health and health service use of the broader group of youth and young adults with IDD, and two specific subgroups: youth with Down syndrome and youth with ASD. As a group, youth and young adults with IDD have an array of physical and mental health problems that can benefit from complex, coordinated care. As they age, young people with IDD have higher rates of chronic diseases and mental illnesses compared to young people without IDD. In addition, their patterns of health service use tend to shift from community and outpatient care toward more hospital-based, emergency, and long-term care as they transition from childhood to adulthood. We highlighted some unique issues with respect to understanding the health and health service use of this population, which can shed light on potential opportunities for health care practice, policy and planning, and further research.

Acknowledgments This work was done as part of the Health Care Access Research and Developmental Disabilities Program. We gratefully acknowledge the Province of Ontario for their support of this paper through their research grants program. The opinions, results and conclusions in this paper are those of the authors and do not reflect that of the Province.

Yani Hamdani was supported by a CAMH Fellowship.

Compliance with Ethical Standards

Conflict of Interest Yani Hamdani and Yona Lunsky declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

References

Papers of particular interest, published recently, have been highlighted as:

- • Of importance
- •• Of major importance

1. Ali A, Scior K, Ratti V, Strydom A, King M, Hassiotis A. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. PLoS ONE [Electronic Resource]. 2013;8(8):e70855.
2. Thomas K, Bourke J, Girdler S, Bebbington A, Jacoby P, Leonard H. Variation over time in medical conditions and health service utilization of children with down syndrome. J Pediatr. 2011;158(2):194–U38.
3. • Hassiotis A, Turk J. Mental health needs in adolescents with intellectual disabilities: cross-sectional survey of a service sample. J Appl Res Intellect Disabil. 2012;25(3):252–61. **This study is based on a small service sample, but highlights the mental health needs of adolescents with ID that may go untreated.**
4. National Institute on Child Health and Human Development. In: Intellectual and Developmental Disabilities (IDDs): Condition Information. 2016. https://www-nichd-nih-gov.myaccess.library.utoronto.ca/health/topics/idds/conditioninfo/Pages/default.aspx. Accessed 11Mar 2016.
5. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Washington: Author; 2013.
6. Yen C, Lin J, Loh C, Shi L, Hsu S. Determinants of prescription drug use by adolescents with intellectual disabilities in Taiwan. Res Dev Disabil. 2009;30(6):1354–66.
7. Nachshen JS, Martin-Storey A, Campisi L, Stack D, Schwartzman A, Serbin L. Health and psychiatric disparities in children with cognitive and developmental delays: implications for health policy in Quebec. J Appl Res Intellect Disabil. 2009;22(3):248–55.
8. Barron DA, Molosankwe I, Romeo R, Hassiotis A. Urban adolescents with intellectual disability and challenging behaviour: costs and characteristics during transition to adult services. Health Soc Care Community. 2013;21(3):283–92.
9. Dykens EM. Psychiatric and behavioral disorders in persons with Down syndrome. Ment Retard Dev Disabil Res Rev. 2007;13(3):272–8.
10. Kolaitis G. Young people with intellectual disabilities and mental health needs. Curr Opin Psychiatry. 2008;21(5):469–73.
11. Mantry D, Cooper S, Smiley E, Morrison J, Allan L, Williamson A, et al. The prevalence and incidence of mental ill-health in adults with Down syndrome. J Intellect Disabil Res. 2008;52(2):141–55.
12. Presson AP, Partyka G, Jensen KM, Devine OJ, Rasmussen SA, McCabe LL, et al. Current estimate of down syndrome population prevalence in the United States. J Pediatr. 2013;163(4):1163–8.
13. Baumer N, Davidson EJ. Supporting a happy, healthy adolescence for young people with Down syndrome and other intellectual disabilities: recommendations for clinicians. Curr Opin Pediatr. 2014;26(4):428–34.
14. • Pikora TJ, Bourke J, Bathgate K, Foley K, Lennox N, Leonard H. Health conditions and their impact among adolescents and young adults with Down syndrome. PLoS ONE. 2014;9(5):e96868. **Using questionnaire data, this study identifies that young people with Down syndrome are at risk of lifestyle diseases as they age.**
15. Centers for Disease Control and Prevention, US Department of Health and Human Services. Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. Morb Mortal Wkly Rep. 2014;63(SS-2):1–21.
16. Iannuzzi DA, Cheng ER, Broder-Fingert S, Bauman ML. Brief report: emergency department utilization by individuals with autism. J Autism Dev Disord. 2015;45(4):1096–102.
17. Narendorf SC, Shattuck PT, Sterzing PR. Mental health service use among adolescents with an autism spectrum disorder. Psychiatr Serv. 2011;62(8):975–8.
18. Bradley E, Bolton P. Episodic psychiatric disorders in teenagers with learning disabilities with and without autism. Br J Psychiatry. 2006;189:361–6.
19. Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post-high school service use among young adults with an autism spectrum disorder. Arch Pediatr Adolesc Med. 2011;165(2):141–6.
20. Lunsky Y, Tint A, Robinson S, Gordeyko M, Ouellette-Kuntz H. System-wide information about family carers of adults with intellectual/developmental disabilities-a scoping review of the literature. J Policy Practice Intellect Disabil. 2014;11(1):8–18.
21. Sullivan W, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. Can Fam Phys. 2011;57(5):541,553 + e154-e168.
22. Sullivan WF, Heng J, Cameron D, Lunsky Y, Cheetham T, Hennen B, et al. Consensus guidelines for primary health care of adults with developmental disabilities. Can Fam Physician. 2006;52(11):1410–8.
23. Lennox N, Van Driel ML, van Dooren K. Supporting primary healthcare professionals to care for people with intellectual disability: a research agenda. J Appl Res Intellect Disabil. 2015;28(1):33–42.

24.•• Chiang P, Chang Y, Lin J, Tung H, Lin L, Hsu S. Healthcare utilization and expenditure analysis between individuals with intellectual disabilities and the general population in Taiwan: a population-based nationwide child and adolescent study. Res Dev Disabil. 2013;34(9):2485–92. **This is a population-based study that created a profile of ambulatory care service utilization for subgroups based on age ranges of children and youth with ID. These children and youth were found to use rehabilitative and psychiatric services more than the general population.**

25. Geelhoed EA, Bebbington A, Bower C, Deshpande A, Leonard H. Direct health care costs of children and adolescents with Down syndrome. J Pediatr. 2011;159(4):541–5.

26. Hung W, Lin L, Wu C, Lin J. Cost of hospitalization and length of stay in people with Down syndrome: evidence from a national hospital discharge claims database. Res Dev Disabil. 2011;32(5): 1709–13.

27.•• Cidav Z, Lawer L, Marcus SC, Mandell DS. Age-related variation in health service use and associated expenditures among children with autism. J Autism Dev Disord. 2013;43(4):924–31. **This is a large-scale population-based study examining health service utilization associated with ASD using Medicaid data across 50 U.S. states, which compares subgroups of children aged 3 to 20 years old. It found that aging was associated with use of higher cost institution-based care and lower use of community-based therapeutic services.**

28. Nayfack AM, Huffman LC, Feldman HM, Chan J, Saynina O, Wise PH. Hospitalizations of children with autism increased from 1999 to 2009. J Autism Dev Disord. 2014;44(5):1087–94.