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## Health Disparities in Adults with Developmental and Intellectual Disabilities

Tulsi Patel  
*Dominican University of California*

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**Health Disparities in Adults with Developmental and Intellectual Disabilities**

Tulsi Patel

Department of Nursing, Dominican University of California

NURS 4500: Nursing Research and Senior Thesis

Dr. Patricia Harris

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**Abstract**

This paper reviews literature pertaining to the treatment of people with developmental disabilities. It will emphasize the inadequacies of health care in this population. The literature that will be discussed focuses on disparities in care via proxy, sociodemographic and clinical factors associated with disparities, assessing the needs of this population, the prevalence of disabilities in rural and urban settings, and the comparison of health disparities between adults with and without developmental disabilities.

For the purpose of this paper, a few terms will be defined. Developmental disabilities (DD) will be defined as “a group of conditions due to an impairment in physical, learning, language, or behavior areas...[that] begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime” (CDC, 2021). A person is said to have an intellectual disability (ID) when they have “certain limitations in cognitive functioning and skills, including communication, social, and self-care skills” (Special Olympics, 2021). Intellectual disability is a type of developmental disability.

Keywords: developmental disabilities, inadequacies, inequalities, intellectual disabilities

**Acknowledgment**

I dedicate this thesis to everyone at ABLE (A Broader Living Experience). ABLE is an intermediate care facility for adults with developmental disabilities in San Rafael, CA. It is based in the community of Marin and operates out of a house in a neighborhood. Without places like ABLE and the wonderful people who work there, we would have one less safe haven for our friends with disabilities. I am forever grateful for the opportunity to be a part of the family that ABLE has created, and that would not have been made possible without Samuel Yates and Alice Wolfgramm. Thank you for everything that you do, for me, for my coworkers, and for our lovely residents. I hope to inspire my peers to fight for the rights of the disabled population and get involved locally to make a difference.

## Introduction

People with developmental disabilities (DD) and intellectual disabilities (ID) often are at a loss to understand or navigate the American healthcare system. Preventive measures, such as screening, can be neglected. To compound the problem, fundamental elements of better service for this at-risk population are not emphasized in the education of nurses and other healthcare providers, leaving those entrusted to care for DD patients without the tools they need to provide optimal service.

The DD population is too large for there to not be a systematic approach to offering the most beneficial and efficient care for the disabled. “Even as the health needs of individuals with ID/DD are unveiled, few health professionals have direct training and experience with this population. As a result, individuals with ID/DD experience difficulties accessing high-quality health care” (Ward, Nichols, and Freedman, 2010).

Neurodiversity is defined as “individual differences in brain functioning regarded as normal variations within the human population” (Merriam-Webster, 2021). Healthcare professionals, such as nurses, are trained to address cultural differences but are not required to have neurodivergent competence. This makes it difficult for neurodivergent patients to access high-quality healthcare to address their problems and needs. It has even been found that people with developmental and intellectual disabilities have higher rates of conditions like cancer, heart disease, and bowel obstructions when compared to the general population (Krahn, Hammond, & Turner, 2006; Sohler, Lubetkin, Levy, Soghomonian, & Rimmerman, 2009).

In 2017, it was found that about 17.8%, or approximately one out of every six children, was diagnosed with one developmental disability (Zablotsky and Black, 2020). These children typically grow up to become adults. This is a large number of adults who have a disability that

students are not taught to address in nursing school. The likelihood that a healthcare worker interacts with a DD or ID adult in the healthcare setting is very high. To not know how to work with this person in a way that is beneficial to them and effective in care is to be ignorant of their needs.

Therefore, a comprehensive literature review will be performed and a proposal for further research will be presented.

### **Literature Review**

The purpose of this literature review is to dissect the research that has already been completed regarding the topic of this paper and understand the importance of its findings. The goal is to find flaws in the literature and create a study to fill in the gaps to improve the inadequacies presented.

The question that will be discussed throughout this literature review and research proposal is:

What is the likelihood of an adult with developmental disabilities being undertreated or misdiagnosed?

### **Search Strategy**

The keywords utilized for the search for articles were ‘developmental disabilities,’ ‘health disparities,’ ‘inequalities,’ ‘health care access,’ and a few others. The articles were found in the NCBI database, Pubmed, DOI.org, and other reputable sources. As suspected, it was difficult to find articles for this population because of the lack of research that exists regarding the subject matter. Six articles were found and chosen based on their pertinence to the topic. The articles that will be discussed in the review can be broken up into three categories: health care access, associated risk factors, and disparities.

**Category one: Health Care Access**

Research completed by Krahn et al. and Haverkamp et al. were grouped under Health Care Access because they discuss disparities in this population. They both identify the inequalities in care for adults with DD or ID. There is a comparison in both articles concerning adults with and without disabilities.

*Article 1: A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities*

This article discusses the prevalence of providers with a lack of knowledge in supporting individuals with ID but also acknowledges that there is a need for greater systemic changes to improve the quality of care for the population. It reviews the literature on this topic from 1999 to 2005 to separate health from disability and allow for better health practices for those with a disability. This article also takes apart recommendations of care from various countries, based on their studies, and compiles them to form “guidelines” for improved care.

It also talks about the inequalities of care for people with DD and ID. It identifies the problems with inattention to needs and a lack of response to the health conditions -- which are comorbid, associated, and secondary -- in this population. It discusses the underreporting, specifically associated with hearing and vision impairments, that occurs with proxy reporting. This is an important factor of this research because the proxy reports come from the people that are providing care for those with disabilities, and should be more accurate. This article further provided that there were “high rates of mental health concerns and gaps in medical care and health promotion involvement” (Krahn, Hammond, and Turner, 2006).

Approximately 2% of the population has an intellectual disability. This number will likely increase over time in survival rates due to improvements to medical care throughout the lifespan of someone with an ID. It is identified that folks with ID may have poor health due to a multitude of factors including genetics, socioeconomic status, vulnerability to abuse, insufficient health care attention, environmental impact on conditions, behavioral health or lifestyle factors that may worsen conditions or cause secondary conditions, inaccess to treatment for behaviors such as substance abuse, sedentary communities (or communities that are not disability-friendly), lack of management for comorbidities, and general conditions that could be managed with better care (Krahn, Hammond, and Turner, 2006, p 71).

A large problem that is discussed is that providers are unsure how to promote autonomy in these patients while also advising the best professional guidance. Studies in Canada showed that female psychiatry residents were more open and inclusive to people with ID than their male counterparts were, but that specialized training for the population did help increase the residents' awareness of care and neutralized their views and stigmas (Ouellette-Kuntz et al., 2003). However, a study in Australia identified that greater than half of the medical and dental school deans, as well as 33% of residency program directors, stated that "their alumni as not sufficiently knowledgeable or capable of providing treatment for persons with ID. Moreover, they did not regard clinical training in ID as a priority given faculty expertise and training time" (Lennox and Diggins, 1999). If there is not adequate training and, further, the desire to learn, there is no way that the issue at hand will be addressed. It is impossible to teach those that do not want to learn, but it is even harder to inspire someone to educate themselves on a topic that they do not deem important enough.

Article 2: *The Quality of Health Care for Adults with Developmental Disabilities*

This article contains analyses of the health conditions of adults with DD. It shows the interpretation of the quality of the medical, preventative, dental, and psychiatric services among this population. There are two main research questions in this study: “(a) What is the health status and what are the health habits of individuals with developmental disabilities who reside in community care facilities or in homes in the community (either in their own home with or without assistance or in the homes of family members or friends)? and (b) What is the quality of care provided to this population, particularly with regard to preventive health and dental services and the use of medications in managing psychiatric and seizure disorders?” (Lewis et al., 2002).

The study was conducted in 1977 with a population of 353 adults aged 18 or older with diagnosed DDs that had received health service from the Lanterman Regional Center in Los Angeles, California. The population either volunteered or was given proxy consent by their guardian to participate in the study. Originally, 390 adults were selected using proportional sampling to ensure the involvement of 50% women, 15% living at home, 45% residing with friends or family members, and 40% that lived in care facilities inside of the community. 37 of the selected individuals did not make it into the study; 35 refused to participate and the medical history was inaccessible for the other 2.

77 of the individuals filled out the questionnaires by themselves and the remaining 276 participants had history forms filled out by their caregiver. Vaginal exams and Pap smears were completed for women in the study that consented, blood was drawn for laboratory tests from 222 of the individuals, BMIs were measured, a licensed dentist performed examinations and advised for treatment if necessary, and all information was sent to the participant’s primary health care provider if they had one. If they did not, they were assigned a staff physician at the UCLA

Medical Center. There was also a study psychiatrist that went through all of the participants' files to note psychiatric diagnoses and legitimized the diagnoses with the presence of the *Diagnostic and Statistical Manual of Medical Disorders* (DSM) criteria.

Less than 5% of the 353 participants had elevated blood pressures; 10% of the 222 laboratory test participants were diagnosed with hypercholesterolemia, 5% had hemoglobin levels lower than 12 g/ml, about 25% had leukopenia, and 2% had elevated blood sugar levels. More than 25% of the total population of 353 participants had epilepsy, about a tenth had Down syndrome, another tenth had cerebral palsy, and a tenth had autism. Of 352 participants (one medication history was not available to review), 172 were prescribed psychotropic medications, including anticonvulsants. In participants prescribed medications that were exclusively used in treatment for behavioral health (110 participants), only 27/110 individuals had a record of psychiatric consultation, and 40/110 participants received said medications without an identifiable psychiatric diagnosis. It appears in this study that anticonvulsants were properly prescribed to those with seizure disorders, but antipsychotics were often prescribed without justifiable reason. Also, "clients without mental retardation (12/56; 21%) were nearly twice as likely to have psychiatric consultations available in their records as were those with mental retardation (34/296; 11%;  $p < 0.05$ , chi-square test)" (Lewis et al., 2002). Of the 169 women, about 39% had not received a Pap smear in the past three years. About two-thirds of the women that live at home did receive a Pap smear, and so did just a fourth of those that lived with family or friends. Less than half of the women that lived in care facilities received cervical cancer screenings.

**Category two: Associated Conditions**

This category was created to discuss the associated conditions that sometimes occur with developmental and intellectual disabilities. The included articles discuss the incidence of several conditions that affect this population, and also the lack of preventative measures that are taken to aid them.

*Article 1: Factors associated with obesity and coronary heart disease in people with intellectual disabilities*

This article utilized an administrative and chart review from a local medical practice for the population with ID. The population included adults that had an ID, lived within the community (in New York City, NY) by themselves or with family, had a primary care visit during the study, and received all planned care through the chosen medical practice.

The study found that in their population of 274 people, 13 had a diagnosis of diabetes mellitus, 77 had hypercholesterolemia, 58 had hypertension, and 126 were obese. Age, BMI, and gender were the largest risk factors for the diagnosis of hypertension, hypercholesterolemia, and diabetes mellitus in this population. This study emphasized that the presence of an intellectual disability did not affect the prevalence of any of these conditions. The authors of this article hope to inspire an improvement of care for the risk factors of chronic disease in the population with ID.

*Article 2: Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data*

This article focuses particularly on the accessibility of care for the diagnosis of cancer in the population with intellectual disabilities. The purpose is to distinguish the difference between care for cancer patients with and without an intellectual disability. The article utilizes a population-based cohort study that involves Dutch people that had an ID diagnosis between 2012 and 2015, of all ages, that were alive on January 31, 2012, but were cancer-free in 2013. In the population of this study, for every person with an ID, there are two people without an ID. Health insurance claims were used to evaluate the care that was sought and received for the cancer diagnosis.

There were no parameters on age for this study -- any Dutch individual that received care via the Chronic Care Act for their ID was legible. There were a total of 65,183 people included in the intellectual disability cohort and 129,497 people included in the general population cohort for this study. The 1:2 ratio is age- and sex-matched. The study ran from 2013 to 2015 and the included sample remained cancer-free throughout that time. A 95% confidence interval was used to compare the groups.

The study found an association between the population with an ID and a lower usage of cancer-related healthcare services (incidence rate ratio = 0.64, 95% CI 0.62 - 0.66) than the population without an ID. It was also found that cancer care for female breast, cervical, and colon cancer was less in people with an ID. The article states that “while people with ID generally are higher health care users, our analyses do not show this for the utilization of cancer care” (Tobi et al., 2020). However, the research points out that it is unclear whether this population suffers less from cancer diagnosis, or if it is indeed a lack of access and utilization.

### **Category three: Disparities and their effects on mental health**

These articles were grouped to address the prevalence of mental health issues in people with developmental disabilities. The first article discusses children and their incidence rates; however, children do often grow into adults so the research material is still applicable in this context. Both articles discuss the presence of mental health issues and, often, the need for emotional support.

#### *Article 1: Do Children with Developmental Disabilities and Mental Health Conditions have Greater Difficulty Using Health Services than Children with Physical Disorders?*

This article is an analysis of health conditions and the care of a child with a developmental disability, and the family demographics of the child. The authors utilized a data analysis of the National Survey of Children with Special Health Care Needs (NSCSHCN) from 2005. The NSCSHCN is a cross-sectional study review that is conducted over the telephone, using a random-digit-dialed telephone number to ask questions to the caregivers of children with special health care needs. The survey that was analyzed during this study was conducted from 04/2005 - 02/2006.

The responses from the caregivers were utilized to place the children in four different categories. Children with autism spectrum disorders, Down syndrome, developmental delay, and cerebral palsy were placed in the developmental disability (DD) group. Children with ADHD, depression, anxiety, and emotional problem were placed in the mental health conditions (MH) group. Children with asthma, diabetes, blood or heart conditions, muscular dystrophy, CF, seizures, joint problems, headaches, and allergies were placed in the physical disability (PD) group. The fourth group is composed of children that fall into multiple categories: multiple

conditions group. During the phone survey, a question was asked: “Thinking about [your child’s] health needs and all the services that (he/she) needs, have you had any difficulties trying to use these services during the past 12 months?” If a caregiver answered “yes,” they were allocated to having difficulty using services (the dependent variable), while those who answered “no” were not allocated in that group.

This study found that 2.6% of children had DD, 12.9% had MH, 49.9% had PD, 34.6% had multiple health conditions. It was more likely for a child with DD or MH to be male, the ethnic population that made up most of the DD was Hispanic, and the population that made up most of the multiple conditions group was Black. “CSHCN with DD were more likely and those with PD least likely to have difficulty using services. Children in the multiple condition group had the most difficulty in using services” (Nageswaran et al., 2010). Multiple other factors implied a greater chance of having difficulty using services: Hispanic families, low-income households, children with greater functional limitations, children without insurance, single-parent households, and metropolitan residents.

*Article 2: Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina*

This article identifies disparities between populations with and without disabilities in medical care and assesses and compares patterns under these circumstances. The focus is on three groups: adults without disabilities, adults with disabilities, and adults with developmental disabilities.

The data used in this study was gathered from the North Carolina Behavioral Risk Factor Surveillance System and the North Carolina National Core Indicators (NCI) survey. Both of

these methods found that adults with DD were more likely to lead sedentary lifestyles than those without a disability. This population was also found to receive seven times less emotional support from those around them. The population with disabilities was also just generally in poorer health than those that were not afflicted. The women in the disabled population were less likely to have access to cancer screenings -- breast and cervical cancer in particular.

People with developmental disabilities have unequal access to disease prevention, health promotion, early detection, and, generally, access to universal health care. When compared to a population without disabilities, disabled people are at a loss for help.

The article also suggests an adjustment in coverage and financing options for those with a developmental disability. To adequately aid this population, there needs to be a system in place to track and monitor health status and health program usage. Granted, this is difficult to ensure, given that data relies on proxy-reporting and self-reporting -- this can cause underreported or inaccurate data.

This article maintains that there are significant differences in the utilization of medical care for adults with DD. It supports the NCI protocol (National Core Indicators) and the BRFSS (Behavioral Risk Factor Surveillance System) in creating a more accurate measure of health in people with disabilities but argues that there needs to be greater efforts for assisting this population (Havercamp et al., 2004).

## **Discussion of Literature**

Overall, the research available for this population is minimal. Several studies have been conducted, and some results are found, but there is not enough evidence to create a concrete plan to aid those with intellectual and developmental disabilities. However, the six articles included in

this research review did contribute to a greater understanding of the population and their needs. About 2% of the population has an intellectual disability (Krahn, Hammond, and Turner, 2006, p 71), though there is not enough education taught to medical professionals to adequately serve this group (Lennox and Diggins, 1999). The number of cancer screenings performed for adults with developmental disabilities is also much lower than those without a disability (Lewis et al., 2002), and the number of people that do utilize cancer care when diagnosed is also lower in the disabled population (Tobi et al., 2020).

The article by Krahn et al., has the limitation of being a proxy-completed survey. Proxy reporting often leads to the underrecognition of health problems in people with intellectual disabilities. The aspect of health that is the most affected by proxy reporting is vision and hearing screening. This is a part of a person that can only be answered to by themselves. The study completed by Nageswaran et al. is a cross-sectional study, which disallows them to fully determine a connection between a person's condition and their difficulty in utilizing services. The Dutch research by Cuypers et al. is a cohort study that follows the population for two years. One of the problems with this study was that the researchers did not have access to some medical records and the participants were able to decline access to some data, which complicated the compounding of numbers.

Overall, most of the articles displayed great information. They all had large population sizes and followed from reputable sources. They were all able to follow through with their designs with the resources at hand.

### **Proposal for Further Study**

After completing the literature review, a lasting question still stands: What is the likelihood of an adult with developmental disabilities being undertreated or misdiagnosed? The reviewed literature showed that there were larger numbers of the disabled population affected by specified diseases than the non-disabled population, though the reasoning was unclear. Are disabled people more susceptible to these diseases? Or is it the inaccess to care and utilization of care for this population that has skewed these numbers?

### **Theoretical Framework**

The theoretical framework that best compliments this research topic is that of Hildegard Peplau: Interpersonal Relations Theory. This theory is composed of four parts: person, environment, health, and nursing. The model also identifies four phases of the interpersonal relationship: orientation, identification, exploitation, and resolution. Hildegard Peplau used this theory to define nursing as “An interpersonal process of therapeutic interactions between an individual who is sick or in need of health services and a nurse especially educated to recognize, respond to the need for help” (Peplau, 1952, as cited in Oliphant, 2021, p. 3). This theory can be applied to this thesis because the population with developmental and intellectual disabilities needs that interpersonal relationship with their nurse or any other healthcare provider. It is important to establish this relationship to understand the patient and the needs that they need to be met. As was mentioned before, there is a lack of education surrounding the needs of the disabled population (Lennox and Diggins, 1999). It is the role of the nurse to care for their patient to the best of their ability, and educating themselves on how to care for a patient with a disability is a part of that role.

## **Primary Research Aim**

This research aims to establish a figure of the likelihood of an adult with a developmental disability being undertreated or misdiagnosed. This study is important in finding a better way to assist this population and improve general health.

## **Ethical Considerations**

There are a few considerations to be noted to legitimize this research study. First of all, participation in the study should be completely voluntary, with the ability to leave the study whenever necessary. Allowing for absence in the presence of medical complications is actively understanding the severity of the condition. Also, the patient identification will remain confidential and will only be used to identify the patient in provided medical records. Anonymity is important in allowing the patient to feel comfortable in disclosing all information that may be required throughout the study.

## **Research Methodology**

### **Design**

This design of this research will be a closed cohort study to measure the factors that affect the likelihood of undertreatment and misdiagnosis within the population.

### **Population**

This population will be gathered from Marin County, CA, USA. The sample will include 200 adults with developmental and intellectual disabilities that reside in Marin County and have or continue to attend programs for adults with disabilities. Participants will be recruited through Marin Ventures, a day program that is conducted for adults with developmental disabilities in

Marin County. Participants of the program and/or their caregivers will be asked to participate in the study when they check-in for the day, and are more than welcome to decline participation.

### **Procedure**

This study will utilize a mixed approach. It will be quantitative in that it will note how often particular instances have occurred for the entire population. It will be qualitative in that it will ask participants to answer questions that are specific to their situation and condition(s).

The quantitative portion of the study will ask closed-ended, yes/no questions, such as:

- Have you received your flu shot this year?
- Have you received cancer screening as applicable to your gender on routine (breast, cervical, prostate)?
- Have you received any mental health care this year?
- Do you feel safe in your current place of residency?
- Do you feel that your caregiver (if applicable) is accurately able to speak on your behalf regarding any and all health conditions?

The qualitative portion of the study will ask open-ended questions, such as:

- How many times have you been to the dentist this year?
- How many times have you been to your eye doctor this year?
- How many times have you seen your primary care provider this year? For what?
- How many times have you seen your mental health specialist this year (if applicable)?
- Do you feel that you have adequate emotional support for your situation?

- Do you feel that you have adequate resources to improve your quality of life and promote health?

### **Data Analysis**

Since this study will use a mixed approach, there will be both qualitative and quantitative analysis. The qualitative questions in the study will be analyzed using content analysis. This will allow the answers to the open-ended questions to be examined and properly identified. The quantitative questions in the study will be analyzed using inferential statistics. Analysis of variance will be performed between groups that answer yes and no to the questions presented on the survey. Descriptive statistics will be utilized to analyze the numbers and responses that are provided to the questions and create percentages of the whole population to see the number of visitations and amount of support that is available for the population.

### **Conclusion**

After completing the literature review, it is clear that there is a need for further research to answer the research question: What is the likelihood of an adult with developmental disabilities being undertreated or misdiagnosed? This question was not answered through this literature review but hope has not been lost. There is continued research regarding this topic and there will be plenty more articles to review and further research to be completed.

However, the findings of this thesis can still be applied to clinical practice. The incidence rates of comorbidities in the disabled population are much higher than those without disabilities. With this information in mind, there is an opportunity to show an increased amount of care and support when working with the disabled population. All patients should receive the best care that

their nurse has to offer, and it is important to ensure that stigma does not interfere with that capability. Nurses are meant to heal and to offer comfort and support in every way possible, and this disabled population needs that more than ever.

The proposed research mentioned in this thesis will allow for further development and understanding of care for people with intellectual and developmental disabilities. This research can help to create lasting guidelines and frameworks for screening processes, general visitations, and support resources that can help to improve the health and quality of life of this population. There is still much to be learned and much research to be completed, but this is a step in the right direction. Analyzing existing literature and compiling data is a key point in the process of conducting further research that is well-informed and well-intentioned.

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## APPENDIX

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Health Disparities in Adults with Developmental Disabilities Literature Review Table

Purpose	Investigators	Sample Population	Design Type	Major Findings
<p><b>A cascade of disparities: Health and health care access for people with intellectual disabilities. <i>Mental Retardation and Developmental Disabilities Research Reviews</i>, 12(1), 70–82. <a href="https://doi.org/10.1002/MRDD.20098">https://doi.org/10.1002/MRDD.20098</a></b></p>				
<p>This article discusses the prevalence of providers with a lack of knowledge in supporting individuals with ID but also acknowledges that there is a need for greater systemic changes to improve the quality of care for the population.</p>	<p>Krahn, G. L., Hammond, L., &amp; Turner, A. (2006).</p>	<p>Taiwan/New Zealand US/Israel</p>	<p>Proxy-completed surveys: parents and caregivers of children and adults with severe or profound ID in daycare institutions</p>	<p>Proxy reporting leads to underrecognition of health problems in persons with ID</p>
<p><b>Factors associated with obesity and coronary heart disease in people with intellectual disabilities. <i>Social Work in Health Care</i>, 48(1), 76–89. <a href="https://doi.org/10.1080/00981380802451160">https://doi.org/10.1080/00981380802451160</a></b></p>				
<p>Sociodemographic and clinical factors associated with</p>	<p>Sohler, N., Lubetkin, E., Levy, J.,</p>	<p>Adult subjects with an ID in NYC that live</p>	<p>Administrative and chart review</p>	<p>126 people (43%): obese 58 people (19.9%): HTN 77 people (26.5%):</p>

<p>obesity, hypertension, hypercholesterolemia, and diabetes mellitus in an ethnically/racially diverse sample of people with ID in NYC</p>	<p>Soghomonian, C., &amp; Rimmerman, A. (2009).</p>	<p>in the community with relatives or independently; who received all of their planned outpatient care services during the study, and had a primary care visit during the study period</p>		<p>hypercholesterolemia 13 people (4.5%): DM</p> <p>Age, gender, and BMI for HTN, hypercholesterolemia, and DM were the most common risk factors</p>
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**Do Children with Developmental Disabilities and Mental Health Conditions have Greater Difficulty Using Health Services than Children with Physical Disorders?**  
<https://link.springer.com/article/10.1007/s10995-010-0597-4>

<p>Analysis of health condition and health care of a child with a developmental disability, and the family demographics</p>	<p>Savithri Nageswaran, Susan L. Parish, Roderick A. Rose, Melissa D. Grady</p>	<p>Data analysis of the National Survey of Children with Special Health Care Needs (NSCSHCN) 2005</p>	<p>Cross-sectional study review</p> <p>NSCSHCN: random-digit-dialed phone survey conducted from 04/2005 - 02/2006</p> <p>The sample is weighted to counterbalance nonresponse and</p>	<p>2.6% of children had DD, 12.9% had MH, 49.9% had PD, 34.6% had multiple health conditions</p> <p>More likely for a child with DD or MH to be male</p> <p>The population that made up most of the DD was Hispanic</p> <p>The population that made</p>
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			undercoverage	up most of the multiple conditions group was Black
<b>The Quality of Health Care for Adults with Developmental Disabilities</b> <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497422/pdf/12357002.pdf">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497422/pdf/12357002.pdf</a>				
Analyses of the health conditions of adults with DD. Interpretation of medical, preventative, dental, and psychiatric services among this population.	Mary Ann Lewis, Charles E. Lewis, Barbara Leake, Bryan H. King, Robert Lindemann	353 adults in LA, CA in 1997	Data obtained from the 353 adults, or their caregivers  Physical and dental examinations performed  Blood draws for analysis  Psychiatric medical records were reviewed by a psychiatrist	Preventative services were lacking for this population  < 50% of the 353 adults received a flu shot  1/3 were on psychotropic medications, but only 24% underwent a psychiatric consultation [that was visible in their medical record]  36% were medicated without an identifiable diagnosis -- and the prescription of multiple antipsychotic medications was common
<b>Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. Public Health Reports, 119(4), 418–426.</b> <a href="https://doi.org/10.1016/j.phr.2004.05.006">https://doi.org/10.1016/j.phr.2004.05.006</a>				
Identifies disparities between populations with and without	Havercamp, S. M., Scandlin, D., &	Data sources: 2001 North Carolina	Compared data on health status, health risk behaviors,	People with developmental disabilities have unequal access to disease

<p>disabilities in medical care and assesses and compares patterns under these circumstances.</p>	<p>Roth, M. (2004).</p>	<p>Behavioral Risk Factor Surveillance System  North Carolina National Core Indicators survey</p>	<p>chronic health conditions, and utilization of medical care (no disability vs disability vs developmental disability)</p>	<p>prevention, health promotion, early detection, and, generally, access to universal health care. When compared to a population without disabilities, disabled people are at a loss for help.</p> <p>The article also suggests an adjustment in coverage and financing options for those with a developmental disability. To adequately aid this population, there needs to be a system in place to track and monitor health status and health program usage. Granted, this is difficult to ensure, given that data relies on proxy-reporting and self-reporting -- this can cause underreported or inaccurate data.</p> <p>This article supports the NCI protocol (National Core Indicators) and the BRFSS (Behavioral Risk Factor Surveillance System) in creating a more accurate measure of health in people with disabilities.</p>
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<b>Disparities in cancer-related healthcare among people with intellectual disabilities: A population-based cohort study with health insurance claims data; DOI: 10.1002/cam4.3333</b>				
To distinguish the differences between care for cancer patients with and without ID.	Maarten Cuypers, Hilde Tobi, Cornelis A. A. Huijsmans, Lieke van Gerwen, Michiel ten Hove, Chris van Weel, Lambertus A. L. M. Kiemeney, Jenneken Naaldenberg, and Geraline L. Leusink	Dutch population  Cancer-free in 2013 (studied through 2015)  Health insurance claims utilized  Registered ID diagnosis in the Chronic Care Database between 2012 - 2015	Population-based cohort study; health insurance claims were evaluated  Random 1:2 ratio comparison (1 individual from ID cohort and 2 individuals without ID diagnosis)	The population with ID received less cancer-related care when compared to the population without ID.  This article acknowledges that it is possible that the population with ID has a lower occurrence of cancer, but suggests that it truly is a case of underdiagnosis and undertreatment.