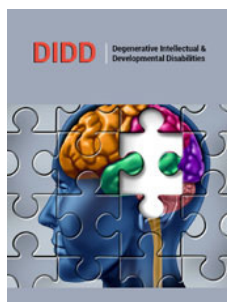# Roles of Academic Librarians in the Provision of Information Services to Intellectually Disabled and Developmentally Disabled College Students

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Abstract

Few articles have provided guidance to United States academic libraries on how to provide information services to college students with intellectual and or developmental disabilities. As more children with various intellectual and or developmental disabilities live into adulthood, there is a need for academic librarians to understand how best to accommodate them to not only combat the stigma associated with intellectual and or developmental disabilities but to generate greater awareness of what the specific types of intellectual and or developmental disabilities are and how to accommodate them in the provision of information services in academic libraries. This is especially important as there is scant to no articles specifically providing an overview of some intellectual and or development disabilities and living into adulthood and the challenges within a higher education environment. Specifically, a general overview of Cerebral Palsy (CP), down's syndrome and other intellectual and development disabilities and secondary or related conditions seeks to inform how the different types of these conditions impact the provision of information services in the academic library and hopefully reduce the social stigma associated with these conditions. Through a metadata analysis or what is plainly stated as a review of websites and journal articles, an overview of intellectual and development disabilities is conducted within the context of United States academic information services or what is colloquially known as reference services. The metadata analysis seeks to inform academic librarians about the different subtypes of intellectual and development disabilities in an attempt to help academic librarians accommodate individuals living with those conditions within the academic library.

Introduction

Academic library users with disabilities oftentimes face challenges "in accessing traditional library services[1]", however understanding the various types of disabilities academic libraries college aged students may present with is key to understanding how to provide reference services to disabled academic library users to help provide information services to those users. In the 2022-2023 school year, the National Center for Education Statistics reported that "15 percent of all public-school students ages 3-21 received special education services[2]" which makes it very likely that the academic library will have to accommodate the needs of academic library users with a variety of disabilities as students in pre-k to high school in the United States using special education services may present with various types of intellectual

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[1]Tharp (2019) Virtual Reality: A New Dimension for Academic Libraries. SSRN. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3601801

[2]National Center for Education Statistics (2025) Students with Disabilities. https://nces.ed.gov/programs/coe/indicator/cgg/students-with-disabilities

and or developmental disabilities. With high school students presenting with various types of intellectual and or developmental disabilities entering college, it is necessary for academic libraries to understand the various types of intellectual and developmental disabilities that college aged students, typically between the ages of 18-24[3], may present with as well as how to address them in the academic library.

Discussion

The first question to answer is: What are developmental disabilities? Developmental disabilities are conditions present at birth which may affect physical, learning, language or behavioral issues[4]. While development disabilities have many etiologies, ranging from antenatal environmental conditions (e.g. substance abuse) to conditions arising during pregnancy (e.g. infections) and are diagnosed in many ways, the purpose of this paper is not to delve into etiologies and or diagnostic tools for each developmental disability or to offer medical or pharmacological advice on how to manage each condition, but rather to provide a general overview of each type of developmental disability may impact the provision of information services to developmentally disabled college students in the academic environment. According to MedlinePlus [1], developmental disabilities include:

A. Learning Disabilities

B. Autism Spectrum Disorder (ASD)

C. Cerebral Palsy (CP)

D. Physical Disabilities

E. Down Syndrome

Cerebral Palsy (CP)

Cerebral Palsy (CP) is defined as a brain disorder that appears in infancy or early childhood and permanently affects body movement and muscle coordination[5]. According to Hallman-Cooper et al. [2] Cerebral Palsy occurs in 1.5 to 2.5per live births and is the most common cause of childhood disability which makes it likely that as more children with CP live into adulthood and graduate high school with the aid of special education services and according to the Cerebral Palsy Guide [3] "more than 80% of people with mild cerebral palsy live beyond age 58 with lifespans similar to the general population", academic librarians are likely to encounter students with CP. However, according to the Cerebral Palsy Guide [3], children with severe cerebral palsy "have about a 40% chance of reaching age 20" depending on the level of care they receive in childhood and makes it unlikely that academic librarians will encounter individuals with severe cerebral palsy.

But what is meant by mild cerebral palsy vs. severe cerebral palsy? According to Kumor et al. [4], types of CP can be classified according to the GMFCS or Gross Motor Function Classification System which have five categories:

a. **GMFCS I:** the person is ambulant and can walk indoors and outdoors, run, or jump with small limitations in gross motor function.

b. **GMFCS II:** the person is ambulant but requires a railing, handheld mobility device, or assistance while climbing stairs, walking long distances, or walking on uneven surfaces.

c. **GMFCS III:** the person requires a wheeled mobility device for daily activities or needs a manual wheelchair for long distances.

d. **GMFCS IV:** the person typically uses wheeled mobility in most environments and may use body support walkers to mobilize in some environments.

e. **GMFCS V:** the person is completely dependent on assistance in daily activities. Some might achieve self-mobility using a powered wheelchair with extensive adaptations.

Adding to the complexity of accommodating college students with cerebral palsy in the academic library is that there are many types of cerebral palsy. According to the NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development, the types of cerebral palsy include:

A. Spastic cerebral palsy is the most common form and falls into a few subcategories:

a. Spastic hemiplegia affects the arm, the hand, and sometimes the leg on only side of the body with normal intelligence and sometimes delays in learning to talk in childhood.

b. Spastic dipelgia have normal intelligence and language skills are usually normal and have muscle stiffness in the legs while the arms and face are less severely affected.

c. Spastic quadriplegia may involve serve IDD as well as trouble speaking and unable to walk. Spastic quadripelgia is the most severe form of CP and also involves severe stiffness of the arms and legs and a floppy or weak neck.

B. Dyskinetic cerebral palsy usually does not result in intellectual problems, however people with dyskinetic cerebral palsy have trouble sitting straight or walking and involve slow and uncontrollable jerky movements of the hands, feet, arms, or legs. The face muscles and tongue may be overactive and cause some children to drool or make faces.

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[3]PNPI (2025) Post-Traditional Students in Higher Education. https://pnpi.org/factsheets/post-traditional-students/

[4]MedlinePlus. (2025) Developmental Disabilities. https://medlineplus.gov/developmentaldisabilities.html

[5]National Institutes of Neurological Disorders and Stroke (2025) Cerebral Palsy. https://www.ninds.nih.gov/health-information/disorders/cerebral-https://www.ninds.nih.gov/health-information/disorders/cerebral-%20

C. Ataxic cerebral palsy affects balance and depth perception. People with ataxic cerebral palsy walk in an unsteady manner and have a hard time with quick or precise movements such as writing, buttoning a shirt, or reaching for a book.

D. Mixed types include symptoms including a mix of other types of cerebral palsy.

Also, according to the Cerebral Palsy Research Network [5], there are co-conditions occurring with cerebral palsy which may include:

i. Autism Spectrum Disorder

ii. Hearing Impairments

iii. Speech Impairment

iv. Visual Processing Disorders, CVI

v. Intellectual Disability

vi. ADHD (Attention Hyperactive Disorder)

vii. Contractures

viii. Ocular Impairments

As more people with CP live into adulthood, it is incumbent upon academic librarians to understand how best to accommodate their information service's needs. Also, Kumar et al. [3] does state that increased focus on comprehensive mental health as well as addressing individual, environmental and health care barriers is key to ensuring successful aging with cp. The focus on mental health as well as a drive to address societal and environmental barriers also needs to be taken into account in the provision of academic library services to college students with cp. Also, there is a dearth of literature which specifically addresses library services for college students with cp, however Nord [6] does state that "there is a twofold benefit for people with disabilities being in the library: (1) we can provide quality programs for them free of charge and (2) their presence can be a good influence" which also rings true for people with cp.

To provide quality programs for college students with CP, accommodations for each of the subtypes of CP in the academic library are discussed.

GMFCS I & II Spastic CP

Academic library reference services for GMFCS I & II Spastic CP are similar to the general undergraduate population as such college students can walk and have normal intelligence. However, co-morbidities associated with GFMCS I & II Spastisic CP may necessitate academic reference librarians going the extra mile to help college students with GFMCB I & II Spastic CP. For instance, with students who have a speech impairment, Forro [7] suggests using a word board, where words relevant to the library are on the board, using a laminated map of campus buildings as well alphabet and numbers. Having academic reference librarians point to the location or words on the word board until the student indicates the proper selection or have the college student gesture

to the appropriate location or word on the word board is further suggested by Forro [7], however not sure if it is commonly used as it is labor intensive and requires patience on the part of the academic reference librarian and it may also be applicable to GMFCS III, IV and V Spastic CP with speech co-morbidity.

GMFCS III, IV, and V Spastic CP

Academic library reference services for GMFCS III, IV, and V Spastic CP are similar to the general undergraduate population except that academic reference libraries should be sensitive of the socio-economic experiences of those who are wheelchair bound and may use assistive communication devices but otherwise have normal intelligence. A study by Rasoulivalalajoozi et al. [8] revealed social stigma & discrimination, self-identity & body image, social integration & support, independence & autonomy, emotional well-being, perception of control & agency are all components of the socio-emotional experience of wheelchair users. Academic librarians need to be sensitive to those using assisted communicative devices as well as direct their responses to the person, not to the helper or aide with them. Being calm and spending time listening to the library patron as the American Psychological Association [9] suggests may also help academic librarians provide reference services to those in the GMFCS III, IV, V Spatistic CP. Additionally, fostering what Sakakibra et al. [10] calls self-efficacy encourages those with GMFCS III, IV, V Spatistic CP and other wheelchair bound academic library users to use the academic library by making the building, reference materials wheelchair accessible, as well as having a robust virtual or digital reference platform.

GMFCS I, II, III, IV, and V spatistic hemiplegia, diplegia and dyskinetic, ataxic and mixed types of CP

To accommodate college students with other forms of CP, just follow similar guidance offered for GMFCS I, II, III, IV and V Spastic CP with the understanding that some college students may require assistance getting a physical item (e.g. book) in the academic library. Simply offer to help them and understand that they may not always ask for help and may have similar co-conditions to Spastic CP.

Hearing Impairments and Other Co-Morbid Conditions

The section on the Intellectual Disability Spectrum is a reference point for dealing with academic library patrons who may have Intellectual Disabilities and CP, regardless of the type and the section on Autism & ADHD is helpful for dealing with library patrons who may have Autism, ADHD and CP, regardless of the type of CP. Hearing impairments are another co-morbid condition with CP and the National Deaf Center [11] suggests that captioned media, speech to text services and interpreters be offered as accommodations and again similar to CVI, the type of accommodation that individuals need from the academic reference librarian is individualized. Visual Processing Disorders and Cerebral Visual Impairment (CVI) is a co-morbid condition with CP and Chokron et al. [12] notes that CVI has wide ranging manifestations ranging from visual defects to visual recognition defects. Academic librarians may have to help college

students locate materials, locate materials with larger print to help deal with CVI however the help is individualized and the college student often articulates a need for such help to the reference librarian. According to Chokron et al. [12], CVI also contributes to learning disabilities, such as reading, which also requires the academic librarian to obtain materials in alternative formats or help the college student in another way that they ask for to get whatever reference material(s) that they want.

Spastistic Quadripelgia CP

To accommodate those with Spastic Quadripelgia, the usage of assisted communication devices, such as virtual reality may be helpful as according to Tharp [13], virtual reality allows triage reference, bibliographic instruction and virtual realities to access archives. Also, virtual reality reference may be helpful for providing reference services for GMFCS III, IV and V of other types of CP as some of those with Spastic Quadripelgia CP do not survive to college age depending on the severity of their disabilities and level of care that they receive. Additionally, those with Spasticistic Quadriplegia CP and significant intellectual disability are unlikely to interact with academic librarians.

Down syndrome

Down Syndrome or what MedlinePlus [14] calls Trisomy 21 is a condition where a "person has an extra chromosome or piece of a chromosome (MedlinePlus)." As the symptoms of Trisomy 21 vary from person to person, Trisomy 21 may also be characterized as an intellectual disability. Some Trisomy 21 college students may be no different from other undergraduates in terms of their reference needs while others may require assistance described in the Intellectual Disability Spectrum section. Also, according to the NIH National Institute on Aging, by age 40 most people with Down Syndrome have tau tangles which result in 50% or more people with Down Syndrome developing dementia due to Alzheimer's which combined with communication difficulty in others with Down Syndrome may result in the academic reference librarian having to simplify their communication to such individuals in response to reference questions.

Intellectual Disability

The second question is: What is an Intellectual Disability? According to the American Psychiatric Association [9], an intellectual disability is a neurodevelopmental condition affecting both cognitive functioning and adaptive functioning. As there are many etiologies associated with intellectual disabilities, it is not within the scope of this article to discuss the diagnostic and or evaluation of intellectual disabilities or to offer medical or pharmacological advice on how to manage intellectual disabilities but rather to educate academic librarians, colleges and universities and others on intellectual disabilities and common co-morbid conditions which may overlap with co-morbid conditions for developmental disabilities. According to the American Psychiatric Association [9], co-morbid or related conditions associated with intellectual disabilities include:

    a.   Autism spectrum disorder

    b.   Attention-deficit hyperactivity disorder

    c.   Impulse control disorder

    d.   Anxiety disorders

According to aruma [15], types of intellectual disabilities include:

    a.   Fragile X Syndrome

    b.   Down Syndrome

    c.   Developmental Delay

    d.   Prader-Willi Syndrome (PWS)

    e.   Fetal alcohol spectrum disorder (FASD)

Each of these types of intellectual disabilities as well as the intellectual disabilities spectrum will be briefly overviewed in order to inform academic librarians on how to provide reference services to these individuals.

Fragile X Syndrome

According to the National Fragile X Foundation [16], Fragile X Syndrome occurs in "1 in 7,000 males" and "1 in 11,000 females" and is from a change in the FMR1 gene on the X chromosome and is incurable. Academic librarians have a greater likelihood of encountering females with Fragile X Syndrome in the library because "a small percentage of females[6]" may exhibit no intellectual disability and would use the reference desk as any other college student would do so. Also, among females with Fragile X Syndrome "one third have none to very mild learning disabilities[7]" and another "one third have mild learning disabilities[8]" which may make it likely that academic librarians may encounter Fragile X Syndrome college students who require a little more assistance with locating items, academic coursework, etc. and may engage in self-advocacy to ensure that their reference needs are met. Academic librarians may also encounter females with Fragile X Syndrome who are the "one third having moderate to significant intellectual disabilities[9]", however it depends upon where on the intellectual disability spectrum they fall on. For some guidance on how to manage them in

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[6]National Fragile X Syndrome (2025) Fragile X Syndrome. https://fragilex.org/fxs/about/

[7]National Fragile X Syndrome (2025) Fragile X Syndrome. https://fragilex.org/fxs/about/

[8]National Fragile X Syndrome (2025) Fragile X Syndrome. https://fragilex.org/fxs/about/

[9]National Fragile X Syndrome (2025) Fragile X Syndrome. https://fragilex.org/fxs/about/

an academic reference environment, please refer to the Intellectual Disability Spectrum section. Males with Fragile X may or may not be encountered by academic librarians, however according to the Fragile X Foundation [14], males may present with more "severe intellectual disabilities[10]" which would not be encountered by academic librarians while others may have "moderate learning disabilities, sensory-based hyperarousal, aggression, ADHD, autism and autistic behaviors, social anxiety[11]" which may make those with social anxiety and sensory issues more apt to use virtual or distance reference services to interact with academic librarians while others without social anxiety use the academic reference desk like any other college student.

ADHD, Autism, Impulse Control Disorder and Anxiety Disorders

Co-morbid conditions associated with Fragile X Syndrome, ADHD and Autism, may require some accommodations by academic librarians. A study by Collard-Stayte [17], states "someone with ADHD is likely to forget that they have a library book due for return[12]" While electronic reminders may be effective in helping college students with ADHD remember to visit the reference desk if they have a question. As ADHD and autism spectrum disorder operate on a spectrum, college students with those conditions may or may not need other types of assistance from reference librarians and it is incumbent upon the college student to advocate for him or herself. Regarding institutional and or library support for autistic college students, Everhart et al. [18] did suggest that online training be utilized with or without on-site coaching sessions to determine effective

accommodations for autistic college students, Connor et al. [19] conducted a nation-wide survey which found that academic libraries have "a golden opportunity to make up for a professional history of neglect [19]" which suggests that with the appropriate resources which suggests that perhaps different training modalities and ways to access library resources, such as using virtual or chat reference, to encourage autistic students to access the appropriate library resources if social interaction(s), interacting with reference staff, etc. prove to be too burdensome for those on the autistic spectrum. However, usage of virtual or chat reference is not restricted to autistic students as many colleges and universities currently use

distance or virtual learning with Oladokun et al. [20] reporting that academic libraries' usage of "the metaverse enables real-time access to digital information, it allows the creation of virtual library tours, immersive exhibitions, interactive reading and AI-guided reference service." These technologies allow autistic college students and college students without autism to not only interact with the reference staff virtually but also to access other forms of digital information via the academic library. Other co-morbid or co-existing conditions associated with intellectual disabilities include anxiety disorders which according to MedlinePlus [21] is a feeling of fear, dread and uneasiness which may have physical manifestations (e.g. sweating) and include Generalized Anxiety Disorder or GAD, Panic Disorder and Phobias. As anxiety disorders and their manifestations vary by person to person, college students with anxiety disorder (e.g. GAD) ought to advocate for themselves in the academic library and academic librarians' interactions with those college students resemble reference interactions with the general undergraduate population.

Prader-Willi Syndrome, Impulse Control Disorder and FASD

Prader-Willi Syndrome (PWS) according to the Prader-Willi Syndrome Association [22] is "caused by an abnormality on the 15th chromosome resulting in a defect in the hypothalamus." Correspondingly college students with PWS may lack impulse control and display inappropriate emotions. Also, people with Fetal Alcohol Spectrum Disorder (FASD)[13] lack impulse control[14]. In addition, people with Developmental Delay regardless of the etiology as well as with Impulse Control Disorder[15] lack impulse control. Regardless of the specific cause, an academic librarian is apt to encounter college students who may be emotional and or lack impulse control which presents challenges not only in terms of communication but how they process rejection, e.g. a book they want is on hold. Additionally, the academic librarian is required to exhibit a high degree of professionalism and emotional intelligence when dealing with emotional undergraduate library patrons, especially during stressful times (e.g. final exams).

Intellectual Disability Spectrum

The Consumer Version of the Merck Manual [23] has a chart showing intellectual disabilities are on a spectrum, ranging from

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[10]National Fragile X Syndrome (2025) Fragile X Syndrome. https://fragilex.org/fxs/about/

[11]National Fragile X Syndrome (2025) Fragile X Syndrome. https://fragilex.org/fxs/about/

[12]Collard-Satyte, R (2024) Increasing accessibility of library services for adults with ADHD and autism" https://works.hcommons.org/records/w9xn3-7kw54 p. 16

[13]National Library of Medicine National Center for Biotechnology Education (2025) Developmental Delay. https://www.ncbi.nlm.nih.gov/books/NBK562231/

[14]NIH National Institutes on Alcohol Abuse and Alcoholism (2025) Understanding Fetal Alcohol Spectrum Disorders. https://www.niaaa.nih.gov/publications/brochures-and-fact-sheets/understanding-fetal-alcohol-spectrum-disorders

[15]National Library of Medicine National Center for Biotechnology Information (2025) Impulse Control Disorders: Updated Review of Clinical Characterists and Pharmacological Management. https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsyt.2011.00001/full

mild to severe as delineated by IQ. College students with Mild Intellectual Disability, that the Merck Manual defines as an IQ between 52-69, may need guidance from academic librarians during times of "unusual or economic stress[16]" in complex academic tasks, such as writing term papers or completing assignments [24]. As students with Mild Intellectual Disability have enough "social skills for self-support[17]", such students may be able to ask academic librarians for help in the form of reference questions just like a college student without an intellectual disability may do so [25]. College students with Moderate Intellectual Disability, that the Merck Manual defines as an IQ between 36-51, may be accompanied by an aide or other support person as they need "supervision and guidance with all but the simplest tasks[18]." Students with Moderate Intellectual Disability may be able to ask academic library reference staff simple questions, such as where to locate a book, however may be accompanied by an aide or support person who may also interact with academic library reference staff [26]. College students with Mild to Moderate Intellectual Disability may also benefit from institutional and or library support, Connor et al. [19] conducted a nation-wide survey which found that academic libraries have "a golden opportunity to make up for a professional history of neglect [19]" which suggests that with the appropriate resources which suggests that perhaps different training modalities and ways to access library resources, such as using virtual or chat reference, to encourage college students with IDD to access the appropriate library resources if social interaction(s), interacting with reference staff, etc. prove to be too burdensome for those on the IDD spectrum [27]. However, usage of virtual or chat reference is not restricted to IDD college students as many colleges and universities currently use distance or virtual learning with Oladokun et al. [20] reporting that academic libraries' usage of "the metaverse enables real-time access to digital information, it allows the creation of virtual library tours, immersive exhibitions, interactive reading and AI-guided reference service [28]." These technologies allow IDD college students and college students without IDD to not only interact with the reference staff virtually but also to access other forms of digital information via the academic library [29]. It is highly unlikely that academic librarians will encounter college students with Severe, that the Merck Manual defines as an IQ between 20-35, to Profound, that the Merck Manual defines as an IQ 19 or below, in that people with Severe Intellectual Disability as according to the Merck Manual they are often in controlled environments requiring assistance with daily tasks and people with Profound Intellectual Disability often require nursing support and may not be able to participate in self-care according to the Merck Manual [30]. In providing reference services to individuals with developmental and or intellectual disabilities [31], academic librarians understand that intellectual disabilities, developmental disabilities (e.g. CP) and some co-morbid conditions present in college students on a spectrum necessitate a tailored individual approach to the provision of academic library reference services [32].

Conclusion

To aid developmentally disabled and intellectually disabled children be successful in college as adults, academic librarians and others ought to understand what the different types of development and intellect disabilities exist as well as how best to help college students' various types of development and intellectual disabilities and co-morbid conditions navigate the academic library. Through a brief overview of the various types of intellectual and developmental disabilities from a metadata analysis briefly skimming current literature and websites, it is identified what intellectual and development disabilities are in order to educate academic libraries on the neurodiversity of the undergraduate population that they may encounter in the academic library and understand how academic librarians may help such individuals at the academic library reference desk. Bear in mind that how academic librarians help developmentally and or intellectually disabled library patrons is individualized as no individual college student is the same and some disabilities, such as intellectual disabilities, operate on a spectrum with correspondingly different levels of support required from academic librarians.

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[17]MSD Manual Consumer Version (2025) Levels of Intellectual Disability. https://www.msdmanuals.com/home/multimedia/table/levels-of-intellectual-disability

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