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DEVELOPMENTAL DISABILITIES NETWORK JOURNAL, VOLUME 1, ISSUE 1

CHRISTOPHER PHILLIPS; ALEXANDRA
BONARDI; BRYCE FIFIELD; DEREK
NORD; DOROTHY HIERSTEINER;
HENAN LI; JOHN M. ANDRESEN; JULIE
J. CHRISTENSEN PHD, MSW; LAURA
VEGAS; MARVIN G. FIFIELD; MATTHEW
WAPPETT; AND VALERIE J. BRADLEY

Utah State University, Institute for Disability
Research, Policy & Practice
Logan, UT



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Managing Editor: M. Bryce Fifield, Ph.D.

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Sonoran Center for Excellence in Disabilities

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Disability and Community

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Disability and Community Inclusion

Kiriko Takahashi, Ph.D., University of Hawaii at Manoa
Center on Disability Studies

Matthew Wangeman, M.C.P., Institute for Human
Development at Northern Arizona University

Journal Subject Area: The *DDNJ* publishes high-quality research and evaluation about the multiple systems that serve individuals with disabilities and their families. Central to these systems is the “Developmental Disabilities Network,” a group of federally designated programs in each U.S. state and territory, that provide advocacy, training, research, and service focused on the unique needs of people with disabilities and their families. This journal specifically highlights programs, practices, and policies that encourage the full inclusion of

people with disabilities in communities and all aspects of public life.

Advertisements: The *DDNJ* accepts digital advertisements. For advertising rates and specifications, contact editor.ddnj@usu.edu.

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Acknowledgments

This journal has been a labor of love for our team here at Utah State University's (USU) Center for Persons with Disabilities (CPD) and it has been a project that I have wanted to pursue for a very long time. The need for a publication that highlights the work done in UCEDD, LEND, DD Councils, and Protection & Advocacy (P&A) organizations has been something that has been on my mind for years. However, the ability and resources to pull it together have been harder to come by. Fortunately, the stars aligned in 2019 when I was attending a training hosted by the National Center for Cultural Competence (NCCC) at Georgetown. This training included participants from UCEDDs, DD Councils, P&As,

and self-advocacy groups. Our conversations got me thinking again about the need for a dedicated publication to share the innovative and collaborative work being done by these organizations. **Tawara Goode**, the director of the NCCC and the Georgetown UCEDD, has always been a remarkable thinker and I was inspired by her ability to bring these different organizations together to work on issues collaboratively. As we worked together during that week, I was convinced that I needed to pursue this project to share the innovative work that is done within the Developmental Disabilities Network.

One evening, during that same training in Georgetown, I was walking back from dinner with **Wendy Parent-Johnson**, the director of the Arizona Sonoran UCEDD, and we were talking about the concept for this journal and the need for more open-access and truly accessible publications in the disability field. Although there are many publications that cover disability issues, the majority are behind exceedingly expensive paywalls and they are often inaccessible, both technically and intellectually. We saw a niche for a publication that democratizes the knowledge that is emerging from the field and that is accessible to everyone. **Jesse Suter**, the director of the Center for Disability and Inclusion at the University of Vermont, was also participating in the training at Georgetown and he also expressed his support in a short conversation on the final day. These pivotal conversations motivated me to begin working on this project in earnest, and in Fall 2019 we found

a supportive publishing partner in the USU Merrill-Cazier Library and Digital Commons/bepress.

Although it has taken us longer than we anticipated, we are excited to finally launch our inaugural issue. This project would not have been possible without the hard work of many people who have supported the vision for this journal. I would like to thank the following individuals for their dedication and commitment to this project.

- The team at the USU Merrill-Cazier Library including **Becky Thoms, Rebecca Nelson, and Shannon Smith.**
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- The Production Team at the USU Center for Persons with Disabilities: **Bryce Fifield, Ph.D., Dave Clark, Mary Ellen Heiner, and Kelly Smith**
- The founding Editorial Board for this new journal:
 - **Tawara Goode, Ph.D.,** Georgetown University Center for Child and Human Development
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 - **Marcia Moriarta, Psy.D.,** University of New Mexico Center for Development and Disability
 - **Derek Nord, Ph.D.,** Indiana University Institute

on Disability and Community

- **Randall Owen, Ph.D.**, University of California San Francisco Institute for Health Policy Studies
- **Christine Pisani, M.S.**, Idaho Council on Developmental Disabilities
- **Jesse Suter, Ph.D.**, University of Vermont Center on Disability and Community Inclusion
- **Kiriko Takahashi, Ph.D.**, University of Hawaii at Manoa Center on Disability Studies
- **Matthew Wageman, M.C.P.**, Institute for Human Development at Northern Arizona University

This team has been integral to the launch of this project and their support and guidance has been invaluable. We hope that you find value and utility in this new journal and we are interested in your thoughts and feedback. If there are ways that we can make this publication more accessible or inclusive we want to hear from you. Please send your comments and feedback to editor.ddnj@usu.edu.

Thank you.

Matthew Wappett PhD

DDNJ Editor-in-Chief

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Matthew Wappett

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[Opening Editorial: The Origin and Aims of the Developmental Disabilities Network Journal PDF File](#)

Plain Language Summary

In this article, I share my experience of going to school and noticing different groups of students. I noticed that students with disabilities were treated differently, but I didn't understand why. Throughout history, people with disabilities have often been treated differently. For hundreds of years, people with disabilities did not live with their families or in their communities. People with disabilities were often forced to live in institutions or workhouses. Institutions were not good places; they were dangerous, unclean, and isolated. People with disabilities were not allowed to live the life they

wanted. In the 1960s, many advocates wanted to change the dangerous and unhealthy conditions in institutions. These advocates knew that people with disabilities could live in the community. Unfortunately, most communities did not know how to support people with disabilities. President Kennedy also worried about the rights of people with disabilities. He had a sister with a disability, and he knew how dangerous institutions were. President Kennedy helped pass many new laws to support people with disabilities. These new laws also created the “Developmental Disabilities Network”. This journal will publish articles about the importance of the Developmental Disabilities Network and the systems that support people with disabilities. This journal will also include articles by people with disabilities. We want to make sure that people with disabilities also have a voice in deciding what we publish. So, we include people with disabilities in the review and editing process. This journal is different because we want to make it as accessible and inclusive as possible.

September of 2008, I attended a formal parent meeting hosted by the school district where my children are enrolled. The purpose of this meeting was to give parents the opportunity to meet the superintendent, but it was also an opportunity for

the district to present the No Child Left Behind standardized testing results from the previous year. As the superintendent showed charts displaying each school's progress towards meeting the Adequate Yearly Progress (AYP) goals for the past 5 years, it was evident that each school had made significant progress; however, some schools, especially those in the more impoverished areas of the district, were still falling short of the government-mandated AYP threshold. As the superintendent began rationalizing the performance of the under-performing schools, she mentioned that "these schools would be meeting their AYP targets too if it wasn't for the high proportion of 'free lunch' and the 'handicapped' kids in these schools." Everyone in the room nodded their heads knowingly...as if they all knew exactly who she was talking about and nothing more needed to be said.

Growing up, I knew the students the superintendent was referring to as the "breakfast bunch" and the "handicapped kids"²...that is what everyone called them, even the teachers. The "breakfast bunch" would arrive at school and head straight to the cafeteria where they got a free hot breakfast every morning. I did not really start to pay attention to them until middle and high school; probably because I had to get up extra early for the 2-hour bus ride to school, so I often missed breakfast in favor of a few more minutes of sleep. I would shuffle, bleary-eyed and hungry, through the front doors of the school and be greeted by the smell of a hot breakfast every morning. Some mornings the smell was sausage and

pancakes—other mornings it was bacon and eggs. My hunger led me to wonder why some kids got a free hot breakfast and specifically, why I did not. Over time, I began to notice the kids who got free breakfast and lunch, and I specifically noticed that none of them were my friends. Most of the kids who were part of the breakfast bunch were Alaska Natives, some were Black, and others Hispanic, and they were mostly from the “rougher” parts of town. I came from the other side. My father was a well-respected physician; we lived in a large house on a hill several miles outside out town, and we associated with the children of the other people who lived on the hill, primarily doctors, lawyers, teachers, and well-to-do businessmen.

I use this term as an authentic expression of the discourse I grew up with, not as an intentionally derogatory term although it is generally considered to be so these days.

Now, the “handicapped kids” were a whole other matter. Although I rode the bus with some of the kids in the breakfast bunch, I never rode the bus or even came close to associating with any of the handicapped kids. They rode a whole different bus – the “short bus.” The short bus usually got to school about the time the bell rang for classes to begin in middle and high school. As we sat in class, we could look out the windows of the classroom and watch the students with disabilities disembarking from the short bus. Some were escorted by aides who held their hands all the way into the school, others were

lowered on the wheelchair lift at the back of the bus, all of them were clearly different and not part of our world. After they entered the school, you could hear some of them talking loudly as they made their way through the empty halls toward the “Special Ed Room” where they would stay until the end of the day.

At the end of the school day, the process began all over again in reverse. Thirty minutes before the rest of us got out of class, the door to the Special Ed Room would open, the empty halls would again be filled with shouting and hollering as aides and teachers herded the handicapped kids back out the front doors and onto the short bus. The short bus would always be gone by the time the rest of us got out of class. Clearly, they were not like us. Nobody knew who they were, or at least they did not admit it if they did know them. They rode a different bus, they started and ended school at different times, they did not attend class, interact or eat lunch with us, and they did not even use the same bathrooms. Although we never talked about them, we all knew who they were and we knew where they belonged—most importantly, we knew they were not us and did not belong where we belonged.

At the time I was in school, I did not realize that I had been socialized into a particular social grouping and, as a result, had been afforded opportunities and privileges that were denied to others. I did not consciously hear or understand the language, both verbal and nonverbal, that was used to reinforce and protect my social status. But it was there, all around me and

my peers. It was in the language used to refer to others; it was in the spaces we occupied in the halls and classrooms; it was in the way teachers and administrators interacted with us; and, in the case of the students with disabilities, it was in the times they were allowed to cross through our physical spaces. In the case of the breakfast bunch, they were a social group defined by a place and an explicit government-subsidized program that clearly demarcated who they were, who belonged, and who did not. When the breakfast bunch was in session, the cafeteria was closed to the rest of us. All of these elements formed a clear and seemingly real discourse about who each group was and *where* each group belonged. The breakfast bunch and the handicapped kids were different from us, and that difference separated them from us both physically and socially.

Schools have become, and in many ways always were, the arbiters of social stratification in America. Schools decide who is in or out, fit or unfit, good citizen or bad citizen, well behaved or behavior disordered, gifted or special. Through testing, grading, sorting, and tracking, we create classes of students. These class distinctions follow students throughout their lives and dictate the opportunities they are qualified for in the present and into the future. Not coincidentally, these class distinctions often coincide with other social markers like race, culture, and ability. These distinctions are further reified by the fact that they are often associated with official government programs like the free/reduced lunch, Title I, or special education. This direct association with government

programming and, perhaps more importantly, government money, lends an air of bureaucratic legitimacy to these social divisions.

Through money and programming, governments attempt to discipline the “unruly” classes and “undisciplined” bodies in order to bring them into compliance with an unspoken and culturally mediated standard of normalcy. Yet, by creating programs and streams of money, the government actually subverts its normalizing intentions by calling attention to difference. This issue lies at the heart of the work that is done within most social service programs and creates a paradox for those of us who work in disability-related programs where the main goal is to promote integration and inclusion through separate programs or projects. So, how do we make the best use of these separate systems to further the goals of inclusion and integration? How do we ensure that we maintain a focus on our common humanity as we develop “special” programs that are intended to level the playing field for people with disabilities and their families?

The Origin of Our Ideas About Disability and Disability Services

The lives of people with disabilities and their families are bounded by multiple systems that are intended to support, educate, and rehabilitate; schools and special education represent just one of many programs that are intended to help

people with disabilities and their families. These systems have evolved and changed over time, but historically speaking, governments and communities have been in the business of “supporting” people with disabilities for hundreds of years. As social mores and ethics have evolved, so has the structure of these programs. The federal and state systems that serve people with disabilities are a double-edged sword. On the one hand, they provide invaluable and necessary supports; on the other hand, they also serve to reinforce the differences and maintain the separateness of people with disabilities. However, we are making progress towards greater integration and inclusion through the efforts of the professionals who are working to rehumanize the disability service system.

Institutions, asylums, special schools, and workhouses were the predominant model of “support” for people with all varieties of disabilities beginning in the late Renaissance and continued through the late 20th century in Europe and North America. People with disabilities started to be locked away in prisons, workhouses, institutions, and empty leprosariums in the late 1500s, a period that has been referred to by Michel Foucault as “The Great Confinement” (Foucault, 1988/1965). Prior to the late 1500s, people with disabilities had been largely integrated into their families and communities. This certainly does not mean that there were not abuses, especially against individuals with intellectual disabilities and mental illness; but the difficult hardscrabble life of the medieval era, prior to modern medicine, meant that disability was

exceedingly commonplace. In this era, something as simple as a broken bone, an untreated illness, or an injury from battle or an accident could lead to a lifelong physical or cognitive disability. Some people with disabilities organized themselves into beggars' guilds that would travel from city to city begging for their survival (an outstanding description of these guilds can be found in Victor Hugo's description of the Court of Fools in *The Hunchback of Notre Dame*). Begging was viewed as a legitimate trade and beggars played an important role in largely Catholic Europe—the wealthy needed to give to the poor in order to secure a more favorable station in heaven, and some people with disabilities, especially physical disabilities that precluded them from engaging in manual labor, needed the support of the community for their basic survival. The mutually beneficial relationship between the rich and the poor ensured that the poor and disabled were supported by the community, and the rich were assured of a more favorable place in heaven (Stiker & Sayers, 2000).

Despite the commonality of disability, people with disabilities were also often the targets of superstition and fear. Many in Europe saw congenital and developmental disabilities as divine punishment for a family's past wrongdoing. Intellectual disabilities and mental illnesses were often interpreted as the result of the body being possessed by a demon or an unholy spirit. Many of these individuals ended up institutionalized in asylums or institutions run by religious monastic orders. People who were deaf were seen as being

“senseless and incapable of reason” (Aristotle as cited in Freud, 1956); the infamous *Malleus Maleficarum* describes individuals with seizure disorders or mental illness as witches (Mackay, 2009); and individuals with communication or behavioral issues were often isolated or imprisoned (Stiker & Sayers, 2000).

In the late 1500s, after the last major wave of the Black Plague swept through Europe killing millions of people, there were two seminal events that led to the disappearance of people with disabilities from our families and communities—the passage of Poor Laws, and the paradoxically named “Enlightenment.” As governments tried to manage the spread of the Black Plague, they recognized that the disease was spreading from community to community via transient populations like beggars and other homeless and indigent populations. Given their limited understanding of germ theory, governments made the erroneous assumption that the Plague was being spread by these beggars and other travelers. This assumption was a significant factor in the passage of “Poor Laws,” which made it illegal to beg and be homeless or indigent. The punishment for being caught begging, or for not being gainfully employed, was imprisonment; thus, many people with disabilities started to be rounded up and confined in prisons, workhouses, and other institutions. At the same time, the emergence of the Protestant Reformation and its focus on work/labor as an important mechanism for drawing closer to God made individuals who were unable to be

gainfully employed the target of discrimination and suspicion. The workhouses of Europe and America were seen as a mechanism for reforming the lazy, indigent, and unemployed through hard physical labor that would bring them closer to God.

Almost simultaneous with the passage of Poor Laws in Europe was the advent of the “Scientific Revolution,” the “Age of Enlightenment,” and the Protestant Reformation. These intellectual movements were driven by a rediscovery of classical philosophy and marked a clear intellectual turn from superstition and religious explanations of the world towards a more rational understanding of the world built upon empiricism and logic. Philosophy and science started to challenge religion and began to focus on concepts of personal liberty, logic, and epistemology that stood in stark contrast to the religious beliefs that were predominate in Europe through the medieval era. Although these overlapping intellectual movements were certainly vital to creating our modern world, they led to increased discrimination and marginalization of people with disabilities and provided a “supposedly” scientific and intellectual rationale for removing people with disabilities from society. The philosophy of this era was driven by rationalist philosophers like René Descartes and Immanuel Kant. Descartes’ proposition *cogito ergo sum* (“I think, therefore I am”) encapsulates the Enlightenment’s preoccupation with logical thought as the basis for being. Unfortunately, Descartes’ notion of logical thought and the

ability to communicate those thoughts meant that individuals with mental illness, cognitive, or communicative disabilities were seen as being not fully human because of their challenges with demonstrating or communicating their thinking. For example, individuals who were deaf were assumed to be living a “purely animal life” because of the deprivation of language (Chottin, 2018) and were, therefore, frequently confined to institutions along with thousands of other people with disabilities whose thinking, communication, and body deviated from accepted norms.

The issue of institutionalization and the wholesale removal of people with disabilities gained further justification and momentum with the advent of Darwinism and the application of evolutionary theories to the human population. Social Darwinism, or eugenics, provided a seemingly scientific rationale for maintaining a clear separation of the disabled from the able-bodied population. The discourse of normalcy promoted by eugenics conflated disability, mental illness, race, gender, social class, or any other deviation from the desired norm as a threat to human flourishing and led to the further growth of institutions and asylums in Europe and the U.S. By the early 20th century, the institutional population numbered in the tens of thousands who were locked away on huge institutional campuses usually located in rural areas where they were literally “out of sight, out of mind.” Families, doctors, and law enforcement continued to commit people to institutions and asylums; many institutions maintained

massive “potter’s fields” where they buried the thousands of individuals who died in their care in unnamed and often unmarked graves.

By the early 1970s, people with disabilities had been absent from community life for hundreds of years—locked away in institutions, sanitariums, asylums, and prisons with the poor, criminals, and other “undesirable” elements of society. The passage of Poor Laws and Ugly Laws (Schweik, 2008) made it difficult for people with disabilities to even be visible in public, let alone fully participating members of the community. By the 19th century, the assumption was that people with disabilities, disfigurements, or mental illness were not fully human and were a source of shame for families and communities. Babies born with disabilities were immediately taken to institutions before a mother could even see them; in the worst cases, doctors would practice “eugenicide” by withholding sustenance and life-saving medical care for children born with severe congenital conditions. Individuals who acquired disabilities through injury or accidents were also forced into institutions where they would not be visible in the community. For example, the U.S. saw a significant increase in institutional populations after the Civil War, World War 1, and World War 2, as veterans who returned home with injuries and post-traumatic stress disorder, or “shell shock”, were locked away from public view. By the mid-20th century, people with disabilities were almost completely absent from public life and

the institutions and asylums had become a dirty secret that were essentially out of sight, out of mind.

Birth of the Modern Disability Service System

Although there were a few attempts at creating community-based disability support programs in the early 20th century, usually for wounded veterans with physical disabilities, there was not a truly systematic effort until John F. Kennedy was elected president. The origins of our modern disability system owe much to the efforts of the Kennedy family and their specific focus on developing programs to support people with disabilities in the community instead of segregated institutions. The Kennedy family was intimately familiar with the conditions in institutions and asylums because their daughter and sister, Rosemary, had occasionally been institutionalized as a result of an unspecified intellectual disability. In fact, Robert Kennedy referred to the conditions at New York's infamous Willowbrook institution as "a situation that borders on a snake pit, [where] the children live in filth" ([WABC-TV Channel 7, 1972](#)).

In 1961, shortly after his election, JFK convened the President's Panel on Mental Retardation and tasked them with developing a groundbreaking set of recommendations for addressing the needs of people with disabilities, especially individuals with intellectual disabilities, who were housed in

institutions across the U.S. This panel submitted a set of 97 recommendations for improving “research, training, income maintenance, and services” that would shape a new comprehensive federal approach to supporting people with intellectual and developmental disabilities ([National Association of State Directors of Developmental Disabilities Services \[NASDDDS\], 2020](#)).

In 1963, President Kennedy delivered his “Special Message to the Congress on Mental Illness and Mental Retardation.” In this message, he outlined a new federal approach to disability services that included “new programs for maternity and prenatal care, initiatives for moving away from ‘custodial institutions’ to community-centered agencies, and plans for the construction of research centers that would include diagnostic, clinical, and treatment services” ([John F. Kennedy Presidential Library and Museum, 2020](#)). Congress acted quickly and passed the Maternal and Child Health and Mental Retardation Planning Amendments of 1963 and the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. These initial pieces of legislation evolved over the years until they eventually became the Developmentally Disabled Assistance and Bill of Rights Act in 1975—or what is now known as the “DD Act”.

The DD Act helped to define developmental disabilities, but it also laid the foundation for the “DD Network,” which includes University Centers for Excellence in Developmental Disabilities (UCEDDs), State Councils on Developmental

Disabilities (DD Councils), and Protection and Advocacy Systems (P&As). The 1970 and 1975 amendments to the DD Act defined the roles and functions of these agencies, which were intended to build capacity, support advocacy, and protect the rights of individuals with disabilities and to help support state efforts to move people with disabilities out of institutions and back into the community. Over the past 50 years, these programs have grown to become an integral part of the disability support system in the states. Today, each state and territory has at least one UCEDD, DD Council, and P&A agency that is focused on advocating for and supporting the needs of people with disabilities and their families.

Federal programs like Medicaid Home- and Community-Based Services, Social Security, Special Education, Vocational Rehabilitation, and many more are administered in partnership with states. However, it is these federal disability systems that provide the foundational support that allows people with disabilities to live, learn, work, and play in our communities, schools, and workplaces. The DD Network is a key partner in these disability-support systems and provides the advocacy, research, service, training, and technical assistance that establishes evidence-based practices and drives innovation and builds capacity in these various programs. The DD Network ensures that the voices and rights of people with disabilities remain at the forefront of the systems that are designed to serve them. These programs form the foundation of a system that is committed to ensuring that people with

disabilities are supported and included in all aspects of community life. These programs are vital to ensuring that our country never returns to the days of segregation and institutionalization.

The Mission of the *Developmental Disabilities Network Journal*

One of the primary missions of this new journal is to provide a forum where we can turn our critical gaze to these disability systems to evaluate their efficacy, to review evidence of their impact, to better understand their long-term outcomes so that we ensure that the organizations and systems that we work within truly meet their intended aim of increasing inclusion and opportunity. Although there are multiple journals that cover disability-related research and policy, there is not a journal specifically dedicated to the “DD Network” and the various other systems that define the lives of people with disabilities in the U.S. The *Developmental Disabilities Network Journal* (DDNJ) provides an open-source, accessible, forum to publish research and scholarship about disability systems and the value and impact of the DD Network. We publish research, evaluation, and editorial perspectives on the work of the core partners in the DD Network: UCEDDs, State DD Councils, and Protection & Advocacy Organizations. However, we recognize that these core partners also work with many other federal and state programs to accomplish their

missions, so we also welcome scholarship from programs with a similar focus on disability rights, community living, and interdisciplinary research including Rehabilitation Research and Training Centers (RRTC), Leadership Education in Neurodevelopmental Disabilities (LEND) programs, Intellectual and Developmental Disabilities Research Centers (IDDRC), Parent Training and Information Centers (PTI), Aging and Disability Resource Centers (ADRC), State Independent Living Councils (SILC), Centers for Independent Living (CIL), State Grant for Assistive Technology Programs, Projects of National Significance, and Family Support Programs (see the following link for more information about these programs and their relation to the DD Act: <https://acl.gov/about-acl/history-dd-act>).

DDNJ provides a peer-reviewed venue to publish research by staff and faculty who work in these various programs. Our mission is to highlight research and evaluation that demonstrates the value and impact of the DD Network and related programs. This first issue of the journal includes a broad range of articles ranging from an in-depth history of the UCEDD program to recent data from the National Core Indicators project, employment outcomes for people with disabilities, and an editorial reflecting on the impact of the COVID-19 pandemic on people with disabilities. Our hope is that this journal can reflect the diversity of the various federal programs that serve people with disabilities, although we will also occasionally publish a focused issue on timely and relevant

topics. For example, our Winter 2020 issue will be focused on the impact of the COVID-19 pandemic on people with disabilities and the programs that serve them.

Perhaps the most important aspect of the *Developmental Disabilities Network Journal* is our focus on accessibility. Most of the leading academic publications focused on disability issues are very expensive and inaccessible to anyone outside of higher education. Furthermore, although these existing journals give lip-service to the importance of inclusion and participatory methodologies, they do not provide meaningful opportunities for people with disabilities to participate in the review and publication process. Finally, the structure, format, and processes used by these publications often do not meet basic digital accessibility guidelines, and the content of these journals are frequently written at a reading level that makes it difficult for people with intellectual disabilities or nonacademics to access and understand. We firmly believe that it is important that information about disability systems should be directly accessible to the people who are served by these systems.

One of our core missions is to ensure that the information published in our journal is accessible to people with disabilities, parents, siblings, caregivers, and direct-support professionals. This is relatively new territory for an academic publication, so we will be figuring things out as we go, but we have taken some preliminary key steps to meet this goal. For example, each article that is submitted for review will be

reviewed by an individual with a disability. We are committed to building a cadre of reviewers who can provide a real-world, live experience perspective on the articles submitted for publication in our journal. We are working with the Georgetown University UCEDD to develop guidelines and a process to support self-advocates with intellectual disabilities who want to participate in the peer-review process and future articles in this journal will share these guidelines and our process so that other journals could adapt it for their purposes. We are also committed to publishing participatory action research and contributions from parents and people with disabilities. As with other articles, these submissions will be peer reviewed in order to ensure that the focus and quality of the journal, but our review criteria privileges disabled voices in the hopes of ensuring that the work published in this journal reflects the perspectives of people with disabilities.

In order to increase accessibility, we have also made a few key changes to the structure of articles in our journal. For example, in place of an abstract we have asked that authors provide a “plain language summary.” This summary is intended to help nonacademic readers understand the focus and content of each article. We are also encouraging authors to provide video abstracts or summaries of their articles. This opening editorial is accompanied by a video summary and our hope is that more and more authors will be willing to take the time to create a video version of their work. As video becomes more and more ubiquitous, it is important that academic publishing adapt

and embrace these new technologies that allow us to share information in a variety of methods. The more options that we provide for accessing information, the more likely we are to meet the needs of a wider audience.

We are privileged to have some committed partners in the publication of this journal, and we are grateful to all the individuals who have agreed to sit on our editorial board, or whom have volunteered to serve as peer reviewers for this journal. Any large undertaking like this is a group effort and I am grateful for the support and collaboration of the Utah State University Merrill Cazier Library, the production team at DigitalCommons/BePress, and our support staff at the USU Center for Persons with Disabilities. Our hope is that this journal will reset expectations around inclusion and accessibility and will help make high-quality information regarding disability programs and services more readily available to individuals in our communities.

We are always seeking more reviewers. If you would like to serve as a reviewer for the journal please send an email to the Managing Editor (editor.ddnj@usu.edu) describing your qualifications and interest. You are welcome to call our office at (435) 797-1981 if you would like to discuss opportunities to participate in our peer-review process.

Finally, our Winter 2020 issue will be focused on the impact of the COVID-19 pandemic on people with disabilities and the disability service system. We are seeking research articles, personal perspectives, and preliminary analyses focused on the

COVID-19 pandemic. Our hope is to publish a wide variety of articles that highlight how the pandemic had impacted people with disabilities on a personal, local, state, and national level. The Winter 2020 issue is being co-sponsored by the Association of University Centers on Disabilities (AUCD) Council on Research and Evaluation (CORE). The CORE group will be helping with reviews and editorial content and we are really excited about this opportunity to partner with this committed group of researchers from across the UCEDD and LEND network.

Thank you so much for your interest in this grand experiment. We hope that you will continue to find our content and process interesting, inclusive, and accessible.

Sincerely,

Matthew T. Wappett, Ph.D.

Editor-in-Chief

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2.

EMPLOYMENT FIRST IN A TIME OF PANDEMIC

Julie J. Christensen PhD, MSW

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[Employment First in a Time of Pandemic PDF File](#)

Plain Language Summary

Employment First ensures that people with disabilities have real jobs for real pay. Changes are being made in laws and Medicaid policies. We were making progress towards competitive, integrated employment for people with disabilities. Unfortunately, the COVID-19 pandemic has halted progress towards employment first. Traditional employment supports are no longer available. Over 55% of employed people with disabilities have lost their jobs. We can make post-COVID-19

employment supports for people with disabilities better.

Employment First is a movement to deliver meaningful employment, fair wages, and career advancement for people with disabilities. Since 1988, the Association of People Supporting Employment First (APSE) has been on the front line of this movement, working to ensure “real jobs for real pay” for people with disabilities. The movement has accomplished much. However, despite growing evidence of the many positive contributions people with disabilities bring to the labor market, multiple societal and systemic barriers have prevented full inclusion and participation in the workforce.

The passage of federal laws that recognize the rights of people with disabilities to live, work, and participate in their communities have propelled and sustained the movement. Yet despite such landmark advances achieved through Title II of the Americans with Disabilities Act (ADA, 1990), as interpreted by the Supreme Court (*Olmstead v. L.C.*, 1998), and the Workforce Innovation and Opportunity Act (WIOA, 2014), the employment rate of people with disabilities has remained stubbornly at or near 35% as compared to 70% for the general population (U.S. Census Bureau, 2008-2018).

At the start of 2020, the Employment First movement was experiencing a new surge of momentum. The passage of WIOA established competitive, integrated employment as the

first and preferred option for people with disabilities and we were beginning to see some tangible results. Progress was being made on compliance with the Medicaid Home and Community-Based Services (HCBS) rule, which requires Medicaid-funded services to shift away from congregate settings and into the community. Efforts to eliminate 14(c) certificates—the provision under the 1938 Fair Labor Standards Act that allows some businesses to pay individuals with disabilities below the minimum wage—had generated sufficient attention to warrant Congressional action by way of the introduction of the Transformation to Competitive Employment Act (HR 873 / S 260). Most importantly, growth in both the labor market participation rate and the employment-to-population participation ratio of people with disabilities was outpacing rates for people without disabilities (Kessler Foundation & University of New Hampshire Institute on Disability, 2020).

Then, suddenly, the world changed.

The COVID-19 pandemic has challenged every aspect of our society and economy, and people with disabilities were not spared. In fact, during the early weeks of the crisis in the U.S., it became clear that people with disabilities were going to be disproportionately negatively impacted. For the Employment First movement, several issues quickly emerged. With the broad shut down of the economy and the mass shift to “work from home,” there were immediate implications for the disability employment service system. First and foremost was

figuring out how to continue to provide critical supports to workers with disabilities who remained on the job as “essential employees.” Indeed, the types of businesses that were identified as essential during the pandemic, such as medical/healthcare facilities, retail distribution centers, and grocery stores, represent the very market sectors that have historically been most accommodating to hiring people with disabilities prior to the pandemic.

Many of these essential workers rely on supports from job coaches and employment specialists to navigate changes in business practices and job responsibilities. These supports are generally funded through vocational rehabilitation (VR) and/or Medicaid via payments to disability service providers. When the economy shut down, complicated state and federal regulations that define how services are delivered hampered the ability for VR and Medicaid dollars to flow. Provider agencies needed to quickly learn how to provide supports remotely, utilizing various forms of readily available technology, often without assurances that remote services would be reimbursed. This was just the tip of the proverbial iceberg in terms of barriers faced by people with disabilities who were already in the workforce, much less for job seekers with disabilities who were largely left in limbo. Despite the relatively quick response of VR and Medicaid to ensure that funding could continue, it was not fast enough for some parts of the country where disability services providers had to weigh decisions whether to furlough staff or close their doors entirely.

It will take some time to fully understand the true impact of the COVID-19 pandemic on the disability service system and employment outcomes for people with disabilities, yet early analysis paints a bleak picture. Preliminary data from a sample of five state intellectual and developmental disabilities (IDD) agency members of the State Employment Leadership Network (SELN) suggest that, for people with disabilities who were working on March 1, only 45% remained employed by mid-June. The remaining 55% were either furloughed, laid off, or needed to leave employment because of health and safety concerns (J. Butterworth, personal communication, June 10, 2020). Preliminary results of APSE's national survey of disability employment services providers on the impact of the COVID-19 pandemic indicate that over 40% of provider agencies had to furlough or layoff employment specialists/job coaches, and those same agencies anticipate that only 50% of this displaced workforce will be rehired post-COVID. Additionally, 37% of provider agencies have closed down their supported employment programs entirely (APSE, 2020).

Despite these challenges, there are positives that are emerging from the pandemic as well. Of those provider agencies that continued to deliver employment services and supports during the first 3 months of the pandemic, 53% reported success in assisting people with disabilities to fill essential jobs in their communities, with the largest job gains being reported in retail, the general service industry, and healthcare. Additionally, nearly 30% of facility-based

prevocational training programs and 50% of facility-based day habilitation programs closed. Providers have indicated that many of these congregate setting closures will be permanent, which presents a unique opportunity to shift services and supports toward competitive, integrated employment (APSE, 2020).

This leaves us at a moment of contemplation. The COVID-19 pandemic has changed the way employment support services are provided. It has also changed the narrative about the role of people with disabilities in the workforce—it is no longer about charity or simply doing the right thing, but instead it is about doing what needs to be done. Approximately 1 out of every 4 adults in the U.S. is living with some type of disability (Centers for Disease Control and Prevention [CDC], 2018), and this number is likely to grow as a result of COVID-19. What we have learned during this time of crisis is that our economy simply cannot work if people with disabilities are not part of the workforce.

However, this particular moment is also about more than reacting and adjusting amidst a global healthcare crisis. The reinvigoration of the #BlackLivesMatter movement has forced some hard and overdue conversations to take place within the disability rights movement, where intersectionality has not been prioritized historically. Employment First can no longer be a movement to simply advance the civil rights of all people with disabilities to work and to be compensated equally. We cannot think about the future of disability employment

services without also recognizing the other pandemic that we face—that of systemic racial and ethnic discrimination, which has led to significant disparities in the workforce for people of color. The employment rate of Black/African Americans is 70%, compared with the national average of 75% for all races combined. For Black/African Americans with disabilities, the disparity is even greater. Where the national employment rate for people with disabilities (all races) was 33%, it was a mere 25% for Black/African Americans with disabilities (National Disability Institute, 2019).

There is no doubt that the months and years ahead will be challenging. The disability services system will be forced to do more with even less, as “across-the-board” budget cuts are inevitable. We have a unique opportunity to lead the way in charting the pathway forward. It is imperative that we continue to be a force for change through proactive planning to ensure that services and supports are prioritized to meet the needs of those who need them most. We are, after all, a community that embraces the concept of universal design. When those with the most significant barriers are afforded opportunity and supported appropriately, everyone benefits.

We must ask ourselves, what is the system we **want** when we emerge on the other side and into the “new normal”? Let us name and build it together, because the “normal” we had before was not working equitably for everyone.

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3.

THE ORIGINS OF UNIVERSITY CENTERS ON DEVELOPMENTAL DISABILITIES: EARLY EXPECTATIONS AND LEGISLATION

Bryce Fifield and Marvin G. Fifield

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[The Origins of University Centers on Developmental Disabilities: Early Expectations and Legislation PDF File](#)

Plain Language Summary

This article describes the origins of disability-related programs at U.S. universities. The idea for these

programs came from a committee set up by President John F. Kennedy in 1962. This committee included stakeholders who wanted to improve the lives of people with disabilities. This article includes an overview of the recommendations by this expert committee. The committee suggested developing disability-related programs at universities. These programs would help people with disabilities through research, service, and training. This article describes key decisions that shaped the identity of these programs. These university programs were originally known as University-Affiliated Programs (UAP). They were later renamed University Centers for Excellence on Developmental Disabilities (UCEDD).

Current Context to Understand the Past

This article is the first of a two-part publication describing the origins, evolution, and programmatic expectations of University Centers on Developmental Disabilities (UCEDDs). Originally conceived as University-Affiliated Facilities (UAF), these programs were to bring the expertise of the academic community to focus on the needs of people with disabilities and address recommendations made in the original Report of the President's Panel on Mental Retardation (1962).

There are currently 67 UCEDDs and 52 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs in the U.S. and its Territories. These programs are made up of a variety of academic institutions, organized in a wide range of administrative structures, and entertaining a broad spectrum of disciplines. UCEDDs engage in many different service, teaching, research, technical assistance, advocacy, and policy activities. They are part of an evolving, but loosely connected, web of public, private, and government agencies serving the disability community. The UCEDD network has evolved over its 55-year history along with this web of disability stakeholders; sometimes by design, sometimes by neglect, sometimes out of necessity, and sometimes in desperation.

Capturing this diversity and describing the key junctures that have influenced the evolution of UCEDDs is challenging. It is difficult to present a linear historical discussion of events that are intertwined, often parallel, and frequently cyclical. Furthermore, because of the historical complexity and constant changing relationships between those who have big stakes in the UCEDD network, it is often difficult to attribute key decisions to particular individuals or events.

UCEDDs evolve. Part of that evolution is reflected in the various names of these programs. Originally described as University-Affiliated Facilities (UAFs), they became University-Affiliated Programs (UAPs), later to become University Centers of Excellence in Developmental

Disabilities Education, Research and Services (UCEDDERS), and, most recently, University Centers of Excellence in Developmental Disabilities (UCEDDs). Their organizational structure morphs in response to academic and instructional pressures. The focus of their work changes with the availability of funding and the expertise of faculty and staff. The language they use to describe their work and impact on the disability community drifts with the language used in legislation and resulting regulations. At their core, UCEDDs are unique members of the disability community. Located at universities, teaching hospitals, or institutions of higher learning, they are frequently misunderstood by siblings in the disability community. Having a foot in the community for service and technical assistance, they are often viewed askance by their academic siblings in the academe.

UAFs for individuals with developmental disabilities were first authorized in Title I, Part B of Public Law 88-164. This Act was signed into law October 31, 1963, by President John F. Kennedy, just 22 days before he was assassinated. The signing of Public Law 88-164, along with Public Law 88-156 seven days earlier, represented the initial legislation intended to implement the recommendations of the President's Panel on Mental Retardation.²

The term "Mental Retardation" is used in this article because that was the historical term used in the official legislation, correspondence, professional, and advocacy literature of the

time. Over time, this term took on derogatory connotations, fell out of favor with the consumer community, and has been replaced with the more generic term of “developmental disability.”

Mental retardation had been recognized as a public health issue 7 years earlier when the Department of Health, Education, and Welfare (HEW) established the Department Committee on Mental Retardation —later known as the Secretary’s Committee on Mental Retardation. This committee was given the authority to expand Maternal and Child Health services authorized by Title V of the Social Security Act to address the needs of persons with mental retardation and their families (Office of Mental Retardation Coordination, 1972).

The findings, recommendations, and resulting implementation legislation attributed to the President’s Panel on Mental Retardation built upon the work of the Secretary’s Committee on Mental Retardation, programs promoted by the Children’s Bureau through Title V of the Social Security Act, as well as the Technical Advisory Committee established in 1959 (Hormuth, 1981). It was against this background of committee assignments and expanded national and local programming that the Panel’s Report to the President was prepared and submitted.³

Between 1960 and 1994, many changes occurred in the organizational structure and the names of federal agencies administering disability programs. Often, the same unit had several different names within the span of a few years. In addition, the names of disability interest groups changed to reflect more current service philosophies.

A Call to Action

President Kennedy's Panel on Mental Retardation was appointed in October of 1961 and consisted of 27 distinguished physicians, scientists, educators, lawyers, and family members. The Panel was organized into six task forces: (1) prevention (clinical and institutional), (2) education and habilitation, (3) law and public awareness, (4) biological research, (5) behavioral and social research, and (6) coordination. Following a year of work, the Panel published its findings and recommendations in the *Report to the President: A Proposed Program for National Action to Combat Mental Retardation* (President's Panel on Mental Retardation, 1962). The report identified the status ("State of the Nation Data") and need for expanded services to individuals with mental retardation. More than 95 recommendations for action were made in various sections of the report. Major system-wide needs included the following.

- *Training.* The critical shortage of trained personnel was identified repeatedly, and more than 21 recommendations focused on action needed to address such shortages.
- *Research and Statistical Data.* The report emphasized the need for additional research and statistical information on the incidence, causes, and related data concerning mental retardation. It called for institutions of higher education to undertake research linked with clinical service programs.
- *Role of Government Organizations.* Several recommendations addressed the role and responsibility of federal government agencies in supporting basic research, providing scholarships for training, and encouraging clinical research.
- *Facilities.* The shortage of buildings and other facilities in which to conduct research and provide service and training programs for individuals with mental retardation was addressed by recommendations in several sections of the Report.
- *Coordination Between Governmental Agencies.* The Report documented the independence and lack of cooperation between governmental agencies and called for increased cooperation between and among agencies at both the state and federal level.

When published, the Panel's Report was among the most

comprehensive, multi-faceted, and well-researched documents in the disability field. It called for a comprehensive approach on many fronts including: federal, state, local, interagency, and interdisciplinary. Each section provided both specific and general recommendations followed by a statement of where the responsibility for action lies (President's Panel on Mental Retardation, 1962).

President Kennedy had a personal commitment to improving the lives of people with mental retardation and was not reluctant to ask Congress for the funding necessary to implement the vision of the Report. Even before the Report was made public, efforts to implement the recommendations had begun (R. L. Cooke, personal communication, June 22, 1994). By the time the Panel's Report was published in 1962, President Kennedy was pressing Congress and his administration for legislative action.

Dr. Robert L. Cooke, a member of the President's Panel and advisor to the Kennedy family, reported that by the spring of 1963 a series of draft bills had been prepared by HEW to be used as the basis for President Kennedy's forthcoming message to Congress. During the preparation of these bills, decisions that would impact the disability field in various ways were made. It was determined that the President's message to Congress would combine legislation on mental health and mental retardation into a single package. However, in combining these two programs, mental health interests seemed to overshadow the concerns for mental retardation. To balance

this, a fresh angle or idea was needed for mental retardation. At the request of Eunice Kennedy Shriver, President Kennedy's sister, Dr. Cooke described the need for facilities at medical centers, similar to mental health facilities, combining interdisciplinary training, service, and clinical research. The few paragraphs drafted by Dr. Cooke that developed this concept into a proposal was later included in the President's message on mental retardation, and subsequently, into the Mental Retardation Facilities Construction Bill (R. L. Cooke, personal communication, June 22, 1994).

The UAF provision "...called for the establishment of University-Affiliated Facilities to be constructed on a somewhat regional basis in association with major medical centers so that practical, clinical training in comprehensive diagnosis, care, and treatment of individuals with mental retardation would be available to all graduates of schools of medicine, nursing, social work, and the like. These facilities were to make possible an interdisciplinary approach to the training of physicians, nurses, therapists, and many types of educators and psychologists with opportunities for clinical exposure comparable to that existing in many major medical centers in the field of mental health" (R. L. Cooke, personal communication, June 22, 1994).

The proposal combined several recommendations from the Panel's Report to the President into a single initiative: "The construction of academic facilities for higher education..., the critical shortage of trained personnel..., research and training

in service settings..., interdisciplinary training, interagency support and comprehensive diagnostic and evaluation services” (President’s Panel on Mental Retardation, 1962, pp. 70, 82).

The proposed UAFs could also address other initiatives outlined in the Panel’s Report, such as: continuum of care, community-centered services, employment, parent training, strengthening of families, prevention, etc. The ability to respond to these new initiatives was especially important because it addressed the needs expressed by parents of children with mental retardation. As secondary consumers of disability services, they had expressed a need for practical solutions that focused on immediate needs and would result in immediate changes.

The support of higher education was stimulated by the possibility of federal funds for campus facilities to conduct research, provide training, and clinical services. By linking training and service programs in higher education institutions with service-delivery systems, many of the needs of state service agencies could also be addressed.

As the UAF concept was further developed, much discussion was generated around the most appropriate setting and program structure for UAFs. Dr. Elizabeth Boggs, also a member of the President’s Panel, stressed the need for a strong community-based program with linkage to universities. Dr. Tarjan, who was the Vice Chairman of the President’s Panel, emphasized the need for a university-based unit that reached

out to the community and linked the resources of the university with the disability community (V. Keeran, personal communication, July, 1994). The name selected for the program reflected both of these concepts, and UAFs emerged as a program to provide interdisciplinary training, service, and clinical research centers to implement many of the major recommendations of the Panel's Report. Many of these provisions were included in the Developmental Disabilities Act (DD Act) of 1970, The Rehabilitation Act of 1973, the Education for All Handicapped Children Act of 1974, and the Technology-related Assistance Act (1988). Further, the core concepts outlined in the Panel's Report also influenced the language used in Americans with Disabilities Act (ADA), and subsequent reauthorizations of disability programs (M. B. Fifield & Fifield, 1994).

Enthusiasm for the proposed UAF program was not universal. Some administrators in HEW recognized that their limited resources would be needed if this new initiative was to be implemented. This would place other priorities on hold. The funding for construction of UAFs came from monies budgeted to community centers rather than research centers. The Division of Hospital and Medical Facilities of the Public Health Service was given the construction authority, and the legislative authority was patterned after the Hill Burton Act (Secretary's Committee on Mental Retardation, 1966).

On several occasions, provisions to earmark funds for the staffing and operation of UAFs were proposed to the

Secretary's Committee on Mental Retardation similar to those provided to mental retardation research centers. Such proposals were not accepted. Some said the authority already existed and, thus, was not needed. Others felt that additional time was needed to develop a "sound and well-thought-out proposal for initial staffing grants" (R. L. Cooke, personal communication, June 22, 1994).

Because the President's Panel had recommended cooperation from a variety of government agencies in supporting UAFs, it seemed that providing operational funds for UAF staffing was to be a shared responsibility and, thus, did not need to be provided explicitly. However, what seemed to be overlooked was that HEW offices, bureaus, and programs were already short on resources and were in the habit of competing for new resources, not cooperating. Funding to staff to operate UAFs would have to be taken from existing priorities in a variety of different agencies.

Mental Retardation: An Early Program Priority

The 1960 Amendments to Title V of the Social Security Act pertaining to Maternal and Child Health and Crippled Children's Programs included special project grants that went directly to public and nonprofit institutions of higher learning for regional and national projects. The Children's Bureau in HEW administered these special projects and had established

a number of comprehensive diagnostic centers (Hormuth, 1981). In its assessment of resources, the President's Panel reported 77 special child development clinics supported by Title V funding, serving more than 20,000 children and families. Some of these clinics were in university settings. Still others provided limited training and multidiscipline service programs (R. L. Cooke, personal communication, June 22, 1994; Hormuth, 1964). These Children's Bureau clinical training and demonstration projects provided ongoing program support, but they did not provide for critically needed space, particularly in universities. Because the UAF application was to construct facilities, less attention in the application was given to the program to be housed in such facilities. Initially, it was assumed that the program (Children's Bureau Projects) would exist before the construction was completed. After 1968, UAF construction applications were approved for universities that presented acceptable plans to develop and organize training and service programs.

Although the need for on-campus facilities was common to all UAF applicants, the programs these facilities were to house differed depending upon the Children's Bureau support already obtained and other program support planned. Each university application incorporated different projects under the proposed structure of the UAF. The first UAF applications came from universities receiving Children's Bureau support. However, at the time, it was unusual for any university to have a training or service program emphasizing

mental retardation. It was the Mental Retardation Research Centers (MRRC) and UAF Program that made such research and training respectable academic activities. Thus, it was not until a UAF program became operational that a significant number of universities across the nation became active in mental retardation and developmental disabilities research.

The application used to request UAF construction funding was an adaptation of the hospital construction application used in the Hill-Burton program. The application emphasized documentation of the need for services, compliance with building codes, and relationships between other health services (Utah State University, 1966). The criteria for approval included, among other things, the amount of matching money and projections of financial self-sufficiency (Mayeda, 1970). However, there was little effort on the part of the agency reviewing construction applications to monitor these plans or to determine how realistic they were because the application was viewed as more an application for construction than a program.

Dr. Cooke reported that the minutes of the meetings of the committee reviewing UAF applications suggested sharp differences in the opinions of members regarding the expectations of UAFs. Medical representatives emphasized the health orientation of the legislation; whereas, the behaviorists and educational specialists felt that to be interdisciplinary, UAFs must include behavior and education specialties (R. L. Cooke, personal communication, June 22, 1994).

Consequently, some facilities were approved to provide programs with strong clinical and medical orientations, while others focused on behavior and learning (Boggs, 1971) Efforts to bring participating organizations together to agree on a common mission and to address the need for core support and staffing were of limited success.

University-Affiliated Facilities Program Support

To find operational and training funds for UAFs, the Secretary of HEW established an ad hoc liaison committee with representation from the Office of Education, National Institutes of Health, Children's Bureau, Vocational Rehabilitation, and National Institute of Mental Health, as well as representation from the mental retardation field. R. L. Cooke (personal communication, June 22, 1994) pointed out that it was the committee's purpose to obtain program and staffing funds from each agency on a voluntary basis.

Unfortunately, the only agency that responded with operational and training support for UAFs was the Division of Health Services in the Children's Bureau under Dr. Arthur Lesser. The 1965 Amendments to the Social Security Act authorized the Children's Bureau to support training first under Section 519 of Title V of the Social Security Act. A year later, Section 511 of Title V extended the provision to provide

interdisciplinary training in multi-agency settings (Division of Developmental Disabilities [DDD], 1972).

Public Law 88-164 provided not only construction authorization, but Title III of the Act authorized the Bureau of Education of the Handicapped (BEH) to provide funding to train special education teachers. Because this training authority and the UAF Construction Authority were in the same legislation, it would be expected that training funds from the BEH would have been made readily available. However, this was not the case. The BEH determined that the only eligible recipients for special education training funds were colleges of education. Because the first UAFs were established as components of medical schools, the BEH considered them medical rather than university units; thus, they were not eligible for such training support. In response to inquiries about BEH resistance to support UAFs, Dr. Gallagher, Director of the BEH, contrasted the medical orientation of UAFs to that of education and argued that UAFs were not appropriate settings in which to train special education teachers. In 1968 BEH submitted plans to provide funding for five selected UAFs to establish a program which would support a coordinator as a member of the interdisciplinary teams (Baxter, 1969, Memorandum to Kendrick Lee, Jr., Budget Examiner, Bureau of the Budget, Department of Health, Education, and Welfare). By 1970, BEH had funded six of the UAFs and offered to extend it to all 19 if additional funding was provided. In fact, the BEH provided funding

(\$390,747) for a special education coordinator in 16 of the first UAFs. The special education coordinator's role was not to train special education teachers; rather, it was to acquaint the trainees of other disciplines with the field of special education. By 1972, the BEH was providing \$493,000 for special education coordinators in 18 programs (Braddock, 1972, p. 22). After 1976, and the passage of the Education for All Handicapped Children Act (94-142), special education funding to UAFs was discontinued.

Diverging Expectations

In 1966 several mental retardation authorities, including the Hospital Improvement Program (HIP), were consolidated into the newly elevated Division of Mental Retardation (DMR) under the direction of Dr. Robert Jazlow. It was staff from the DMR who established the guidelines for UAF construction (DMR, 1964). However, the Children's Bureau published its own guidelines for staffing and training programs (Children's Bureau, 1965). The eligibility criteria and expectations for UAFs proposed by DMR and the Children's Bureau were quite different.

The Children's Bureau, which included both Crippled Children's Services (CCS) and Maternal and Child Health (MCH), was transferred to Social and Rehabilitation Services (SRS) in 1967. Two years later, MCH and CCS were moved into the Health Services and Mental Health Administration

(HSMHA) of the Public Health Service (PHS). The MCH expectations for UAFs reflected its health mission (i.e., nursing, nutrition, occupational and physical therapy, speech pathology, social work, as well as audiology, health administration, psychology, pediatric dentistry, and where BEH support was lacking, special education). In contrast, the criteria established by the DMR reflected the social and vocational priorities of the Rehabilitation Service Administration (RSA).

Furthermore, construction applications submitted to DMR were derived from several different planning programs that had different expectations. Between 1963 and 1969, the Joseph P. Kennedy, Jr., Foundation, along with the Mental Retardation Branch of the Public Health Service, provided planning grants to assist in developing interdisciplinary programs. Mayeda (1970) reports that approximately 30 universities received such grants and used them to plan and prepare their applications for UAF construction funds. During this same period, other universities received special planning grants from the public health service and/or clinical service grants from the Children's Bureau. These grants were also used as the basis to plan and apply for UAF construction funds. Other universities applied directly for construction funds without any federal or foundation planning money.

The construction application was different than the MCH program support application (Federal Register, 1964). Consequently, some universities applied for only UAF

construction funds, others applied only for MCH program training monies, and others applied for both construction and training funds. All of the above were happening simultaneously and amounted to diverse channels by which UAF applications were submitted. Different components were included in the applications, and components being approved as UAFs independent of decisions on other components (Mayeda, 1970).

The federal designation of UAF was based on the construction authority from the DMR. However, programs that did not receive construction funds but did receive Children's Bureau training grants were also considered UAFs. As a consequence, some UAFs were facilities without programs, others were programs without facilities, and still others had both construction and program support (Mayeda, 1970).

The multi-dimensional approach to establishing UAFs continued even after the construction funding was discontinued in 1970. UAF centers were established by the DDD, while other programs approved by MCH, which administered UAF Section 511 training funds after it had been moved from the Children's Bureau, also considered themselves UAFs. Furthermore, there was limited communication between the DDD and MCH. Programs often considered themselves UAFs and became members of the Association of University-Affiliated Facilities when they were conducting UAF-like programs funded by special MCH training projects

or DDD projects of national significance. Such programs were frequently used as a basis for pursuing UAF, MCH, and/or DDD funding.

The first-generation UAFs (1963-1974) emphasized clinical services, diagnosis and treatment programs, interdisciplinary leadership training of personnel, and the concentration of expertise in a single location. The second generation UAFs (1975-86) emphasized community-based services and developmental concepts. Serving the full life span of persons with developmental disabilities was to be considered along with environmental concerns. Third-generation UAF expectations (1987-1994) focused on consumer empowerment, independence, and inclusion.

Accumulating Expectations

It should be noted that the expectations of first-generation UAFs were not superseded by second-generation expectations. Second-generation expectations were generally added to previous expectations. Thus, as expectations changed, they were not replaced but became cumulative. For example, first-generation UAFs, were expected to provide diagnosis, treatment, and clinical services (Federal Register, 1964). However, once such programs were established, it was difficult to shift resources to respond to other expectations. Facilities were designed and built, programs were created, and staff were recruited and selected (often with tenure) in response to the

initial expectations. Further, once such commitments were made on the part of a UAF, other university, community, and state expectations of the UAF began to take shape. As a consequence, first- and second-generation UAFs seldom dropped or discarded ongoing training or service programs. Rather, they added new services and program elements in response to the emerging national expectations of later generations.

This process of accumulating expectations has increased the diversity within the UAF network. As a consequence, many UAFs have evolved as umbrella-type organizations under which different programs reflected different models, techniques, and philosophies of service depending on their funding source (M. G. Fifield, 1991). For example, many first-generation UAFs started by providing clinical diagnosis and treatment services required by MCH training grants, which have been continued. Later, they added demonstration classrooms, specialized services, treatment, education, training and care, as well as, preschool, early intervention, and aging programs (Federal Register, 1964). To this, they then initiated programs that focused on community-based services and home programs. Technical assistance and outreach training were then added to keep pace with later expectations and state-of-the-art practices.

First Generation University-Affiliated Facilities

In February of 1965, the John F. Kennedy Institute at Johns Hopkins University became the first institution to be awarded a construction grant—5 months after the first announcement of the program in the Federal Register. By January 1967, the DMR had approved and funded 14 additional UAFs to be constructed in 18 locations, obligating \$30.3 million. By 1967, there were 43 applications for planning programs, and more than 100 universities had expressed an interest. By late 1967, two UAFs were operational: Boston Children's Hospital directed by Dr. Alan Crocker and Johns Hopkins, The Kennedy Institute, directed by Dr. Robert Cooke. Three additional projects had been approved but not funded. The administration proposed a 5-year extension, projecting \$10 million in fiscal year 1968 and \$20 million in each of the successive 4 years, for an accumulation of 23 additional new facilities. However, by December of 1967, the fiscal climate had changed and the total increase was \$9.1 million. These were the last dollars actually appropriated for construction of new UAFs.

By 1969, the Federal Government had spent \$41,836,000 for the construction of 19 UAFs. Approximately 49% of the costs of the facilities had come from federal sources. The remaining construction costs came from the universities in which the UAFs were located, from state agencies, and from

local contributors. In fiscal year 1969, the investment of the Federal Government in training and core support was \$9,105,000. Ninety percent of this came from Children's Bureau/MCH and totaled slightly less than half of the amount estimated to be required to maintain the facilities at full training capacity (Mayeda, 1970).

First-Generation Expectations

The 1965 decision of the Children's Bureau to provide training support to UAFs was pivotal in establishing initial expectations. Because no other federal agency provided staffing, training, or other program support until 1969, it was the policies and priorities of the Children's Bureau, (later MCH in HSMHA) that controlled the activities of most UAFs. Consequently, UAF training was focused on children. Health services were emphasized, and only those UAFs located in medical schools were eligible for MCH Section 511 funds. Non-MCH funded UAFs found what support they could from their host universities or from small training grants. In addition, non-MCH funded UAFs pursued direct service and research contracts, piggybacking the training they provided from such activities.

Early Oversight Review of the University-Affiliated Facility

Program

The absence of coordination between federal agencies in promoting UAFs and the variation in the amount and type of support received had not gone unnoticed. Concerns about coordination and the types of support received from federal programs stimulated efforts to describe and evaluate the network and to generate recommendations for its improvement (Babington, 1969). One of the first investigations of this nature was requested in July of 1969 by Wallace Babington, Executive Director of the Secretary's Committee on Mental Retardation. In response, W. F. Baxter, Staff Assistant to the Secretary's Committee on Mental Retardation, prepared a report and summarized the inconsistencies:

The Division of Mental Retardation administers the UAF Construction Program, but has practically no funds available to support those programs after the construction phase. Although there is multiple funding within the department for operating expenses, most of the available monies come from the Children's Bureau. Funds from the Children's Bureau are limited to services and training in the health field and, therefore, are not available to University-Affiliated Facilities with a behavioral orientation. Additionally, these funds are limited and do not meet the needs of eligible universities.

The report (Baxter, 1969, Interdepartmental Assessment of

the UAF Program, memorandum to the Budget Examiner, Bureau of the Budget, Department of Health, Education, and Welfare) further pointed out that UAFs had not been able to establish special education and vocational rehabilitation components as originally recommended because they were not able to obtain support from the relevant federal agencies. Perhaps the most significant recommendation of Baxter's report was to earmark funds so that support for UAFs would not have to be taken from an agency's existing priorities.

While Mr. Baxter's report was being prepared, a contract was issued by the Social and Rehabilitation Services of HEW to EDUCOM to visit each of the UAFs in the network and provide a complete report on "all phases of the...program" (Baruch, 1969). During the next few months, Mr. Tadashi Mayeda, as project director, visited 19 sites and collected and analyzed an extensive amount of data. Mayeda identified the 16 original objectives for UAFs from P.L. 88 164. He catalogued the emerging requirements of UAFs and related these to the President's Panel and the various groups implementing the recommendations of the Panel. He described the diversity of the UAFs, noting that each started from a unique position and then moved on to other activities as opportunities were available. While noting that MCH support was addressing the need for mental retardation specialists in the health field, he pointed out that the comprehensive training mission of UAFs was virtually neglected.

No UAF had seriously addressed the task of upgrading the professionals, currently or about to be employed, in mental retardation residential institutions, foster homes, day care centers, community diagnostic and evaluation clinics, sheltered workshops, or any other institution or program specializing in mental retardation problems. (Mayeda, 1970, p. 9)

Mayeda was asked to gather data to determine the role of the facility in responding to the UAF objectives in P.L.88 164. In particular, he was asked to respond to two questions: “Is a facility required to implement the concept of the program?”; and “If required, are more facilities needed?” He answered the first question with a resounding **yes!**

The facilities produce a capstone effect on separate and isolated programs beneficially bringing them together into one setting for their benefit and, most importantly, for the benefits of the individual seeking services. (Mayeda, 1970, p. 30)

In answer to the second question, Mayeda pointed out that by 1969, the first generation UAFs had progressed beyond the first phase of development, and that new and expanded plans should be formulated for Phase II. He also pointed out that new construction should be part of the second phase (Mayeda, 1970).

The Mayeda report, aside from bringing together important descriptive information about the development of UAFs, is particularly interesting because of the issues addressed and the

methodology used. He analyzed cost of tenancy estimates, tenant capacity, and descriptive information on resident and training populations. These ratios were selected to reflect the prevailing expectations of UAFs as health-related programs and cost-effectiveness indices appropriate to teaching hospitals (i.e., bed counts, residence-to-staff ratios, percent of maximum utilization of facilities, etc.).

Mayeda estimated that in 1969, UAFs were operating at approximately 20% of their training capacity due to the unavailability of training support. He reported that all UAFs were experimenting with new methods of care, focusing on the total environment and bringing in the resources of the community. He calculated ratios between construction costs, floor space, and both client and trainee residence. In addition, he calculated ratios between client waiting periods, caseload data, and the distribution of staff and labor costs.

Mayeda concluded that the full training capacity of the UAFs could be reached by fiscal year 1974. However, to reach full training capacity, he recommended an investment of at least \$6.7 million per annum over a 5-year period awarded at the rate of \$300,000 per institution on a cost-sharing basis. He recommended an extra \$100,000 be awarded for each satellite unit (Eugene, Oregon; Bloomington, Indiana; Lawrence and Parsons, Kansas). He further recommended that new construction be based on regional requirements and provided a rationale for changing the staffing and training grants. In the appendix of his report, he provided examples of management

plans, instruments for the evaluation of UAFs, and annual report requirements.

Of particular importance to the future development of UAFs was Mayeda's assessment of UAFs not located in medical centers, specifically the multi-location UAFs, which were considered satellites affiliated with colleges of education. These units, he reported, were excluded from training and operating monies and seemed to be "...awkward appendages to the central unit not capable of providing a complete range of interdisciplinary training...but in a unique position as stations for traveling clinics or service clinics away from the central unit" (Mayeda, 1970).

This evaluation clearly reflected the health and medical emphasis of the first generation UAFs. Programs that were designed around an educational or behavioral model that provided inservice training and technical assistance were noted as "gross departures from operating norms" (Mayeda, 1970).

However, despite its sophistication and comprehensive methodology, Mayeda's report had little impact, and his recommendations received little attention from the UAF network or the funding agencies (i.e., MCH and DDD). Mayeda described UAFs as they were in 1969, and his recommendations were based on early expectations of UAFs. Even before his study was started, professionals and constituency organizations were at work on new legislative provisions for future amendments of P.L. 88-164 that would

significantly change the expectations of UAFs in the years to come (Boggs, 1971).

Between 1966 and 1969, many of the recommendations of the President's Panel on Mental Retardation were being implemented. However, despite efforts of the National Association of Retarded Children, other constituency and professional organizations' progress on improving services to individuals with mental retardation was minimal. Some of the key congressional supporters were no longer in positions to direct the needed legislation, and by 1969 the Johnson Era, along with the Great Society, was replaced by a much more conservative Nixon White House. This, along with several reorganizations within HEW, resulted in many new players and decision makers.

In early 1969, a coalition of various mental retardation constituencies formed to promote legislation and expansion of the programs and services introduced during the Kennedy era. This coalition included the American Association of Mental Deficiency (AAMD), National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR), Council for Exceptional Children (CEC), National Association of Retarded Citizens (NARC), and United Cerebral Palsy Association (UCPA). Dr. Boggs reported that the coalition initially had misgivings about including the UAFs. The UAFs were seen as political liabilities because the new administration had not sought any further funding for them and because some state mental retardation coordinators

saw the UAFs as unwilling to reflect state needs in their goals. It was later decided to include support for UAFs in legislation, but to separate it into a different title (Boggs, 1976, personal communication).

Early in 1969, the Senate Committee on Labor and Public Health, chaired by Senator Yarborough, introduced amendments to P.L. 88-164. Senator Edward Kennedy asked to be the prime sponsor of the legislation, citing the family history of association with the cause of mental retardation and with P.L. 88-164 in particular. On August 13, 1969, Senators Kennedy and Yarborough introduced S.2846, referred to as the Disability Services Act. Dr. Robert E. Cooke's input into the UAF title of the bill was solicited by Senator Kennedy. Dr. Cooke used videotapes of two children seen at the John F. Kennedy Institute, the first UAF to become operational. The two children, whose progress was shown, were present at the hearing with their families and provided an impressive demonstration of the benefits of services they had received (Boggs, 1971).

Both House and Senate bills included provisions to continue the UAF construction authority at \$20 million per year. In addition, the Senate bill authorized \$5 million and the House bill \$8.5 million for UAF operational support. In conference, it was the language of the House Bill that was accepted, after which it was submitted to the President for signature.

There were presidential advisors urging President Nixon to

veto the bill, but with the support and urging of Dr. Edward Newman, Director of the Rehabilitation Service Administration, and H.E.W. Secretary Elliot Richardson, the President signed the bill on October 30, 1970, and P.L. 91-517, the Developmental Disabilities Service and Facilities Construction Act of 1970, became law (Boggs, 1971). However, the appropriation of federal funding to implement the new provisions was a separate struggle that required an additional year and resulted in far lower funding than had been originally authorized.

Early in January 1971, Assistant Secretary Hitt of HEW established a special interagency committee to review the regulations and guidelines for P.L. 91-517, the DD Act. This committee was to serve as a coordinating broker and to provide input to other agencies on the implementation of the DD Act. Five months later, Assistant Secretary Egeberg, HEW Assistant Secretary for Scientific Affairs, established an ad hoc committee on funding of University-Affiliated Facilities. This committee included membership from all of the relevant agencies. The minutes of committee meetings, planning papers, and interoffice memos suggest a lack of agreement and the inability to provide meaningful coordination of the DD Act on funding of UAFs. Of particular concern was a limited involvement of special education in DD Act planning for UAFs.

President Nixon signed the appropriation bill on August 12, 1971, which provided \$4.25 million for the operation of

UAFs, just half of the amount authorized, and no money was appropriated for new construction. The same appropriation bill included a significant increase in Section 511 for training in MCH-funded UAFs.

Developmental Disabilities Act Support and Expectations

1. Of the \$4.25 million appropriated for UAFs, approximately \$600,000 was distributed to nine additional UAFs at about \$75,000 each. These funds were used as planning and startup costs. However, no additional funding was provided to the new UAFs for the next 4 years.
2. Less than \$3 million was distributed to UAFs approved earlier with ongoing programs, including those with construction facilities.
3. Funds provided by the DD Act were to be used for administrative and operating costs only (DDD, 1972).
4. In an effort to decentralize the administration, the DDD passed much of the grant approval authority on to the 10 HEW regional offices.
5. The DD Act funding focused on a large number of social and organizational expectations, which changed with each administration and reauthorization.

Maternal and Child Health Support

and Expectations

1. MCH fiscal support for UAF training was significantly greater than support provided through the DD Act.
2. During this same period, MCH also made the decision to allow UAFs to retain clinical income rather than returning it as an offset to their grant. As a result, revenues available for MCH funding for UAF program support increased significantly (R. L. Cooke, personal communication, June 22, 1994).
3. MCH support was provided to only 19 UAFs for clearly stated, stable program objectives, which were administered at the Washington level.

The differences between MCH support and expectations with those of DDD had a significant impact on how UAFs would evolve, eventually leading to two diverging emphasis areas: policy/ systems change, and professional training.

University-Affiliated Facilities for the Developmentally Disabled

The impact of the DD Act (P.L. 91 517) was, however, much more than fiscal resources or how the program was administered. The coalition building that preceded its final approval and the statement of philosophy and purpose were to have major impact in the years to come. Each section from the

stated congressional findings and purposes to the definitions and provisions themselves, later had an important impact on future expectations of and activities in UAFs.

The DD Act instigated many important changes that were adopted and later included in other legislation (M. B. Fifield & Fifield, 1994). The term “mental retardation” was dropped in favor of developmental disabilities. This change in language was insisted on by UAF directors who pointed out that mental retardation was too narrow and could not be diagnostically differentiated from other similar disabilities (Boggs, 1971). Representative Rogers modified the definition to include sensory disorders and chronic disease, and Senator Kennedy accepted—tying it to neurological handicapping conditions related to mental retardation.

The term “developmental disabilities” not only broadened the service population, but it also implied a different service philosophy. Rather than approaching a developmental disability as a disease to be cured or cared for, it was viewed more as a delay in development—a delay that could be ameliorated by educational intervention, instruction, stimulation, and expanded opportunities for inclusion (M. B. Fifield & Fifield, 1994).

The 1970 legislation provided a federal/state formula grant to assist states in developing and implementing a comprehensive state plan. The law also provided for the comingling of funds from other federal programs to facilitate

the development of comprehensive services for people with disabilities.

The DD Act identified the purpose of UAFs and changed the term “clinical training” to “interdisciplinary training” to emphasize the cross-disciplinary nature of UAFs. It changed the name of the administering agency from the Division of Mental Retardation to the Division of Developmental Disabilities (DDD) and placed it under the Rehabilitation Service Administration.

In the fall of 1972, the DDD provided its first description of the mission, purpose, and objectives of UAFs (DDD, 1972).

The mission of the University-Affiliated Centers is to lead the field of service to the developmentally disabled of all ages by (1) training administrative, professional, technical, direct care and other personnel needed to provide the whole range of services for the developmentally disabled; (2) demonstrating exemplary services; (3) carrying out research incidental to those activities; and (4) assisting communities, states, and regions to reach their objectives. (p. 2)

UAFs should

...exemplify the principles and practices which will lead to increasing effective programs for prevention, treatment, and habilitation including active participation in planning activities. The usual resources of the college or university provides the basic elements required by this multi-faceted program, but the center should not limit its activities and concerns to the academic setting only. It must involve itself

in all appropriate ways with the special needs and resources of the community and region within which it operates. (DDD, 1972, p. 2)

This document further defined a UAF as a center housed in an identifiable building or suitable portion thereof, which encompasses the following program elements:

- The responsibility for overall administration resides within the university;
- The university demonstrates a significant long-term commitment to interdisciplinary training and developmental disabilities;
- An organizational entity within the administrative structure that has as its primary function the responsibility for interdisciplinary training;
- Individuals responsible for the program have regular faculty appointments;
- Training programs are interdisciplinary and encompass a broad and comprehensive range of disciplines;
- The program is designed to be relevant to the manpower needs of the geographic area served;
- The program is integrally related to exemplary service functions; and
- The program demonstrates a capacity to utilize the resources of the university to develop new approaches (DDD, 1972).

Notwithstanding the UAF language in the DD Act, and the mission and purpose of UAFs as stated by DDD, the importance of the expectations listed above was not implemented until after 1975 following the first amendments. Several reasons can be identified for this delay. First, the core funding authorized by the new DD Act was used to help provide administrative support to assist in the administration and supervision of other services which the UAF provided (DDD, 1972). Because approximately 90% of all fiscal support provided to UAFs came from MCH training (Mayeda, 1970), DD core support was viewed as administrative support for MCH training.

Second, the decisions of the Director of Social and Rehabilitation Services (SRS; the agency to which DDD reported) to use much of the \$4.25 million appropriated to plan and start new UAFs rather than provide UAF program support, established a precedent that continues in the new millennium. Politically appointed commissioners, directors, and sometimes associate secretaries made decisions about the allocation of congressionally appropriated funds that had significant impact on the evolution and expectations for UAFs. Beginning in 1972, most additional funding provided for UAFs would be used to start new programs rather than to expand and improve the support for those currently in the network. Furthermore, new initiatives and expectations would accompany each legislative reauthorization, and there would be many changes in administrative personnel.

In 1972, DDD awarded grants to 30 UAF programs. Planning and start-up grants were awarded to nine universities ranging between \$35,000 and \$75,000 each. Core grants were awarded to 20 UAFs, ranging between \$79,293 and \$417,696 (Braddock, 1972). All of the UAFs that had constructed facilities participated in this allocation. New UAFs receiving DD core support included some that originally applied in the late 1960s for construction and/or pending MCH training support. Although UAF construction funding was authorized in the new DD Act, funding for construction of new UAFs was not appropriated, and the UAF construction program was phased out. In later reauthorizations, construction was dropped from the legislation. Other federal support provided in fiscal year 1972 included \$12,988,000 through MCH, Section 511 Training Support, for 18 programs ranging between \$112,000 and \$1,612,000 per UAF. That same year, BEH provided \$493,000 to 18 programs with grants ranging between \$25,000 and \$30,000 (Braddock, 1972).

Core funding provided by the DD Act changed the relationships between UAFs that had two or more facilities in the same state. MCH training support was not shared with their satellite facility except as an outreach site. Thus, the facilities on other campuses were on their own to find funding and other program support. Consequently, some satellite facilities negotiated separately for DD core support. Oregon established two separate UAFs, as did Indiana. Tuscaloosa was dropped from the network, as recommended by Mayeda. The

Georgia and Kansas UAFs elected to stay together as a single administrative unit and make their case for additional DD core funding. Between 1972 and 1975, when the first reauthorization of the DD Act was passed, the DDD added an additional nine programs to the UAF network—only two of which received MCH support.

When the DD Act was first authorized in 1970, it was for 3 years. Thus, it was to expire or be reauthorized in 1973. Congress, facing the need to reauthorize 13 major federal programs, which included the DD program, elected to give all of these programs a 1-year extension under an amendment to the Public Health Service Act, without any changes in language or appropriation.

Summary

The decade between 1960 and 1970 saw the genesis of what would eventually become a nationwide network of University Centers on Developmental Disabilities (UCEDDs). These evolved rapidly from what were essentially UAFs for mental retardation to two distinct program foci—one on hospital-like clinical programs and the second focused on umbrella organizations focusing on a panoply of treatment, service, education, and intervention programs. Legislation and funding authorizations rapidly moved from construction of brick-and-mortar buildings to funding operational programs, but struggled to craft language broad enough to describe

everything that these programs should be doing. Originally conceived as an academic/community combination that could address recommendations made in the President's Report, these programs immediately faced the challenge of finding funding for such innovations. Thus, these University-Affiliated Facilities (UAFs) became University-Affiliated Programs (UAPs) and their combined work scope was covered with a host of federal grants, a few state contracts, and local services. The range of activities was largely dependent on the salesmanship and success of individual program faculty and staff at finding a market for the things they could do with (and for) the disability community.

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4.

COGNITIVE DISABILITY AND POSTSECONDARY EDUCATION: A NATIONAL STUDY ON EARNINGS STUDY ON EARNINGS

John M. Andresen and Derek Nord

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[Cognitive Disability and Postsecondary Education PDF File](#)

Plain Language Summary

Higher education helps people learn new skills. It increases their chances of getting a job after graduation. Opportunities for individuals with

disabilities to take part in higher education are increasing. More and more people with disabilities are enrolling in colleges and universities. They are earning degrees in a wide variety of areas. A college or university degree helps students with disabilities be more competitive when looking for a job. Students who graduate from college earn more money than those who begin to work right after high school. This study shows that a student with an intellectual disability who earns a bachelors' degree may earn 68% more than a student who did not go to college. This means that a college degree may help students with disabilities get better jobs. This article may help students with disabilities or their family members to make decisions about going to college. The authors suggest that colleges and universities should provide more opportunities for students with intellectual disabilities in the future.

Postsecondary education presents an opportunity for increasing the economic potential of individuals in the labor force. Employers' expectations of postsecondary education and training continue to expand with a 10% increase in average number of schooling years in the first 15 years of the 21st century globally (Psacharopoulos & Patrinos, 2018). Additionally, research has estimated that in 2020, 65% of all

jobs will require postsecondary education or training, an increase from 28% of jobs in 1973 (Carnevale et al., 2013).

Research in economics traditionally invokes a rational-behavioral model to describe the process of postsecondary attendance, suggesting that individuals utilize a form of cost-benefit analysis to determine whether the economic and time costs of education outweigh the education, skills, experience, and economic returns expected after graduation (Brand & Xie, 2010). With economic returns 10 times over for women and even greater for men (Hout, 2012), the number of individuals accessing higher education continues to increase (McFarland et al., 2018). For example, an individual with a bachelor's degree will earn \$24,600 more annually than their peers without a postsecondary degree (Ma et al., 2016).

However, it remains important to disaggregate the impacts of postsecondary education while accounting for the demographic make-up of the society. For example, when accounting for gender, increases in annual earnings are different for male and female postsecondary attendees; a \$23,200 increase for women and \$26,200 for men (Ma et al., 2016). Postsecondary education additionally provides noticeable earnings improvements in the early career years as well, specifically for individuals between the ages of 25-34. For these young adults, median annual salary for an individual who earned a bachelor's degree was 57% higher than a high school completer. Even those individuals who earned an associate's degree had work earnings 19% higher than

individuals who only completed high school (McFarland et al., 2018). Research on the impacts of postsecondary education disaggregated by race provides similar findings, with roughly a \$6,000 increase in yearly income for Black and Hispanic bachelor's degree recipients (Perna, 2005). Positive impacts of postsecondary attendance for individuals of low socioeconomic status (SES) has highlighted close to a \$5,000 increase for individuals in the lowest quartile of SES (Perna, 2005). While research has identified a variety of demographic subpopulations in the literature, disability is often overlooked.

Disability in Postsecondary Education

Research has indicated that postsecondary education can provide the opportunity to increase individuals' earnings potential, but research in postsecondary education does not often identify individuals with disabilities. For a period of time, the limited research base could be attributed to the lack of individuals with disabilities on campuses, as faculty often believed that educating students with disabilities would not be worth the effort (Nugent, 1978). While opinions have changed and more individuals with disabilities are included on campuses today, there is still limited research into this minority group on college campuses. In a recent study that examined 906 articles in higher education journals, Leake and Stodden (2014) found that only 11 of the articles (1.2%) focused on students with disabilities.

While it is recognized that individuals with disabilities could benefit from postsecondary education, determining how many individuals with disabilities are pursuing postsecondary education can be challenging (Evans et al., 2017). The shortage of research can be attributed to the difficulties in defining this minority group. Disabilities can differ by severity, they can present at any point in life, and the prevalence of disability can vary according to the diagnostic measures used, or the concepts, methods and system of reporting on the student population (Fujiura & Rutkowski-Kmitta, 2001; Stroman, 2003). Researchers and practitioners have found it difficult to determine exactly what constitutes the vast category of individuals with disabilities, and these students in postsecondary education provide another difficult-to-define population (Evans et al., 2017; Madaus, 2000).

This phenomenon is aggravated by the complexity with which disability data are collected, with definitions often being too broad or not broad enough to encapsulate the variability within the population of individuals with disabilities (Stroman, 2003). By defining disability with strict diagnostic criteria, the medical model of disability utilizes a fixed conceptualization of disability. The social model of disability is generally more suited to provide disability definitions in postsecondary education. For example, the American with Disabilities Act (ADA) defines disability not simply as an impairment that substantially limits the activities of an individual, but also recognizes disability as “a record of such an

impairment; or being regarded as having such an impairment” (ADA , 1990). For the purposes of studying the economic impacts of postsecondary education on earnings potential, the social model of disability provides the opportunity for the analysis of individuals and their interactions with possible barriers created by the surrounding environments (Stroman, 2003). In the current research, the social model of disability allows for the recognition of a range of disabilities that could impact the ability of a student to interact in a postsecondary environment and their earning potential in the future.

Intersections of Cognitive Disability, Postsecondary Education, and Earnings

Cognitive disabilities constitute a subsection of the broad population of individuals with disabilities in higher education. Individuals with cognitive disabilities may have difficulty interacting with the academic environment of postsecondary education. The American Community Survey (ACS) defines a cognitive disability as a “physical, mental, or emotional condition lasting six months or more that results in difficulty learning, remembering, or concentrating” (U.S. Census Bureau, 2010). This definition includes a variety of disabilities that are commonly identified in secondary settings, such as mental illness, traumatic brain injuries, intellectual and developmental disabilities, and other neurological

impairments. Research on this large category of postsecondary attendees may prove vital as employment struggles are common in this population.

Unemployment figures of individuals with disabilities confirm the extent of the issue. Utilizing data from the ACS, it is estimated that 35.4% of individuals with a disability are employed, in comparison with 74.3% of those without a disability (Winsor et al., 2017). When accounting for specific disability groups, research depicts significantly poorer outcomes for individuals with cognitive disabilities. Only 25.7% of those with cognitive disabilities are employed (Winsor et al., 2017). Additionally, those with cognitive disabilities are more likely to be unemployed than those without disabilities and even those with physical disabilities, leading to more opportunity for reliance on social support systems throughout the U.S. Likewise, even those individuals who are employed are unlikely to keep their employment throughout the year, with only 52.7% of individuals with cognitive disabilities indicating that they have been employed throughout the entirety of the last year (Winsor et al., 2017). Variable unemployment has impacts on an individuals' financial security. Individuals with cognitive disabilities are more likely to live under the poverty line than those without disabilities; 16% of individuals with cognitive disabilities live under the federal poverty line (Winsor et al., 2017).

Initial research has indicated that postsecondary education could be impactful for the employment prospects of

individuals whose cognitive functioning is impaired. For example, individuals with disabilities who attend postsecondary school of any kind are more likely to be competitively employed in the workforce. In a study utilizing the National Longitudinal Transition Survey – 2 (NLTS-2), researchers found that individuals with disabilities who attended some form of postsecondary education were significantly more likely to be employed in a competitive work setting (Wehman et al., 2015).

Postsecondary education can also impact earnings potential. Multiple studies have identified that people with cognitive disabilities who received postsecondary education in the Vocational Rehabilitation (VR) services system tended to have higher earnings (Gilmore et al., 2001; Miller et al., 2019). As far back as 2001, Gilmore et al. found that people with cognitive disabilities who received funding from the VR system for postsecondary supports earned \$16,900 per year, annually, compared to \$12,376 for those without support (Gilmore et al., 2001).

More recently, Miller et al. (2019) found that individuals with IDD who advanced into postsecondary certificate or degree completion earned \$17,839.12 each year in comparison with \$10,245.56 of those who did not. While the findings from Miller et al. are beneficial for the field, there remains a need to disaggregate the various levels of postsecondary education and their effects on the earnings potential of individuals with cognitive disabilities. For example, is there a

considerable difference in earnings potential increase for an individual who pursues an associate's degree instead of a bachelor's? Current research has not identified the benefits of the various postsecondary options for students, including those students who attend postsecondary education but do not receive a degree. In addition to disaggregating degree types, research is needed that is not reliant on specific disability service providers. For example, Miller et al. utilized only data found from the VR system in California. Research is needed on whether these impacts are found throughout the U.S., regardless of affiliations with service providers.

Purpose

Improving occupational outcomes for individuals with cognitive disabilities has long been difficult because of poor funding, low expectations from faculty members and parents, prerequisite tests, procedural issues, and many other barriers (Baker et al., 2012; Bruder & Mogro-Wilson, 2010; Hart et al., 2004). With the expansion of postsecondary education options for individuals with cognitive disabilities, colleges and universities present another option for ameliorating the poor occupational outcomes faced by this population. Thus far, there is a lack of a national perspective that uses population level data to determine how postsecondary education can improve the economic lives of individuals with cognitive disabilities. Therefore, the purpose of this study is to

determine the extent to which postsecondary education can improve the earnings potential of individuals with cognitive disabilities across the U.S. The research questions are as follows.

1. What percent of the population of working Americans with cognitive limitations completed various levels of postsecondary education?
2. What proportion of the variability in work earnings is attributable to postsecondary education for working Americans with cognitive limitations?
3. What are the comparative financial benefits of different levels of postsecondary education for working Americans with cognitive limitations?

Method

This study utilized extant data analysis on U.S. population-level data to provide a national picture of postsecondary and employment experiences of working Americans with cognitive limitations. Data utilized were from the 2017 ACS program, a project by the U.S. Census Bureau. The ACS is an ongoing survey that provides yearly updates about the citizens of the U.S. The U.S. government utilizes ACS data to determine how federal and state funds are distributed. Respondents answer questions covering a variety of topics, including ancestry, disability status, home heating, number of occupants per

household, educational attainment, rent, fertility rates, among many others. The Integrated Public Use Microdata Series (IPUMS) data were utilized to locate and refine the data set for this research (Ruggles et al., 2019).

Sample and Inclusion Criteria

This study seeks to build knowledge about employment outcomes among people with cognitive limitations, a broad term that is intended to include various disability categories under a single classification based on an individuals' measure of their intellectual ability (Cohen, 2014). The selection of the participants in this study is focused on a functional limitation that impacts access to postsecondary education. In the ACS, cognitive disabilities are defined as a “physical, mental, or emotional condition lasting six months or more that results in difficulty learning, remembering, or concentrating” (U.S. Census Bureau, 2010). The ACS definition can include disabilities related to mental illness, traumatic brain injuries, intellectual and developmental disabilities, and other neurological impairments. The ACS Subcommittee on Disability Measurement created this measure to identify certain aspects of disability in order to investigate how identified populations experience restrictions in community participation because of institutional barriers (Brault, 2009).

Participants for this study were chosen who were of working age (18-65) and who had identified themselves as experiencing

a cognitive limitation. Additionally, since the study's focus was to understand the relationship between postsecondary education and earnings, participants were selected who indicated active employment for the year 2017. The IPUMS system was able to isolate and retrieve the maximum number of participants who satisfied both categories. This sample returned 26,095 participants. Of the participants selected for inclusion in the study, 1,529 individuals received no yearly income or wages—indicating that their work hours were unpaid time. These individuals were excluded from the study, as they do not qualify as individuals with cognitive limitations who are employed for the economic benefits. Data cleaning and assessing assumptions further limited the sample to 21,544 participants. In order to calculate a sufficient sample size, the formula proposed by (Green, 1991; $N \geq 50 + 8m$; m = number of independent variables) was used to determine a sufficient sample size for estimation. After analysis, 21,544 participants constituted a sufficiently large sample size for use in the analysis.

Variables for Analysis

Work Earnings

The dependent variable for analysis was annual work earnings, a continuous measure of one's pre-tax wages and salary. Upon assessing the distribution, it was found that work earnings did

not meet normality assumption because of a positive skew. As such, logarithmic transformation was applied to the outcome variable to reach normality. The logarithmical transformation of work earnings ($\bar{M} = 4.18$, skew = -0.58, kurtosis = 0.11) proved the assumptions tenable, unlike the work earnings untransformed ($\bar{M} = 28,289.34$, skew = 6.05, kurtosis = 61.93).

Demographic

Age was identified in the data set as a continuous variable and was measured in years. Sex was a dichotomous variable and was coded 1 to indicate female and 0 to indicate male. Race was dummy-coded to indicate 1 as being a member of the race and 0 as being not a member of the race; the categories included were White, Black, and other. Ethnicity was coded to indicate Hispanic as 1 and non-Hispanic as 0. These four variables were included to identify the impacts of multiple social identities on individuals with cognitive limitations, which is often absent from the literature in higher education and disability (Evans et al., 2017).

Income Supports

Income support was constructed to indicate whether an individual receives any income supports including supplemental security income, social security income, or welfare. In the original data set, there were dollar amounts

indicated for each of the three categories of income supports. In this study, the three categories were collapsed into one to determine whether an individual received any income supports in the previous year. To ensure that assumptions were met, the categories of Supplemental Security Income, Social Security, and welfare were combined into one variable by adding all three values together to create a new variable of income supports. The variable was then coded as 0 for no supports and 1 to indicate the receipt of money from any of the three programs.

Employment

Employment variables were the participant's report of the usual number of hours worked each week over the previous year and the number of weeks worked over the previous year. The construction of the weekly hours worked variable was continuous and measured in whole hours. The number of weeks worked in the previous year was constructed to be an ordinal variable with the following coding scheme: 1-13 weeks was coded as 1, 14-26 weeks was coded as 2, 27-39 weeks was coded as 3, 40-47 weeks was coded as 4, 48-49 weeks was coded as 5, and 50-52 weeks was coded as 6.

Postsecondary Attainment

The ACS provides number of years of schooling, high school diploma, associate's degree, etc. For the purposes of this study,

these variables were recoded into five categories. The five categories were high school (HS) degree (which included HS equivalent degrees or less), some college with no degree, associate's degree, bachelor's degree, and advanced degrees. The advanced degree category consisted of both masters and doctoral degrees, and was collapsed because of low sample sizes in both categories separately. The categories were dummy coded and "High School" served as the reference category.

Analysis

Multiple regression analysis was performed on the dependent variable of logarithmic-transformed yearly work earnings (Y), entering variables in four blocks. The sequencing of the blocks was utilized to partition the variance to determine the amount of variability that is accounted for by each category of variables. The initial block assessed the effects of demographic characteristics, block two accounted for the variance attributed to income support programs, and block three accounted for the variance attributed to employment-related variables. The final block incorporates postsecondary education in addition to all preceding blocks (see Table 1). The analysis was performed using IBM SPSS 26. The null hypothesis being tested was $H_0: R = 0$, which denotes that there is no relationship between the reported yearly work earnings and the six explanatory variables.

Table 1
Four Linear Regression Blocks for Analysis

Block	Y'	X_1	X_2	X_2	X_4	X_5	X_6
Demographics	Earnings	Age	Sex	Race	Ethnicity		
Income supports	Earnings	Age	Sex	Race	Ethnicity	Income supports	
Workplace	Earnings	Age	Sex	Race	Ethnicity	Income supports	Hours worked
Degree	Earnings	Age	Sex	Race	Ethnicity	Income supports	Hours worked

Results

Table 2 presents the weighted and unweighted sample characteristics of working Americans with cognitive limitations aged 18 to 65 in the 2017 ACS. Utilizing the weighted sample characteristics, the majority of the individuals in the study were male (53.2%), White (76.8%) and non-Hispanic (86.5%). Of the sample, a majority of individuals did not receive an income support in the previous year (83.1%) and the majority of individuals were employed between 50-52 weeks in the previous year (70.0%).

Table 2
Sample Characteristics, Working Americans with Cognitive Limitations, Age 18-65, 2017 American Community Survey

Variables	Weighted (%) (<i>N</i> = 2,237,27)	Unweighted (%) (<i>N</i> = 21,544)
Gender		
Male	53.2	52.1
Female	46.8	47.9
Race		
White	76.8	79.3
Black	11.9	10.1
Other	11.3	10.6
Ethnicity		
Hispanic	13.5	11.6
Not Hispanic	86.5	88.4
Income supports		
Support	16.9	18.5
No support	83.1	81.5
Weeks worked last year		
1-13 Weeks	5.8	5.8
14-26 Weeks	6.2	6.1
27-39 Weeks	7.8	7.7
40-47 Weeks	7.5	7.6

Variables	Weighted (%) (N = 2,237,27)	Unweighted (%) (N = 21,544)
48-49 Weeks	2.8	2.7
50-52 Weeks	70.0	70.2
Postsecondary education		
HS or GED	47.6	47.1
Some college, no degree	27.9	27.8
Associates	8.3	8.5
Bachelors	12.7	12.8
Advanced	3.5	3.8

According to the weighted characteristics, in 2017 there were 2,237,207 working Americans with cognitive disabilities in the workforce. Of the weighted sample, 47.6% of the population were in the category of high school degree, GED, or less, which indicated that over half of the population had attended some form of postsecondary education. The most common postsecondary degree was a bachelor’s degree (12.3%), and over half of the individuals who attended postsecondary education did not receive a degree (27.9%). Advanced degrees (masters and doctoral) and an associate’s degree were the least common forms of postsecondary education, with 8.3% of the sample receiving an associate’s degree and 3.5% of the sample receiving advanced degrees. However, these figures could potentially be

impacted by the number of individuals who were actively attending college while employed.

Table 3 depicts the means and frequency distributions of dependent and independent variables as well as the Pearson correlation coefficients for all variables included in the final block of analysis. Across the sample, the mean age of individuals in the study was 39.16 years of age. Additionally, the mean number of hours worked by those individuals was 33.67 hours, and the mean work earnings were \$28,289.34. In terms of income support programs, 2,134 individuals received social security income, 1,779 individuals received supplementary security income, and 633 individuals received welfare income in the prior year. The mean amount received through each income support program varied, where individuals receiving social security income, supplemental security income, and welfare income received \$9,504.48, \$7,643.78, and \$2,074.11, respectively.

Table 3
Means, Standard Deviations, and Pearson Correlation Coefficients for Correlations

Variable	N	M	SD	1	2	3
Earnings	21,544	28,289.34	37,608.39	–	–	–
Log-transformed earnings	21,544	4.18	0.54	.240**	-.184**	-.235**
Predictor variable						
1. Age	21,544	39.16	13.63	–	.177**	.020*
2. Social security	2,134	9,504.48	5,752.72		–	.019*
3. Supplementary security	1,779	7,643.78	3,913.64			–
4. Welfare	633	2,074.11	2,992.411			
5. Usual hours worked	21,544	33.67	13.43			

Note. ($N = 21,544$).

* $p < .05$.

** $p < .01$.

Regression Analysis

Analysis of the residuals plots to assess assumptions of homogeneity of variance and independence determined that all assumptions were met. Assumptions of normality were met after the logarithmic transformation of salary and deletion of outliers at both the high and low ends of the distribution of the salary variable. Issues of collinearity were not evident in the regression, and variance inflation factor values for each variable can be found in Table 4.

Table 4
Linear Regression Blocks' R² and Predictors of Logarithmic Transformation of Work Earnings

	Logarithmic transformation of work earnings							
	Block 1	Block 2	Block 3	Block 4				
Variable	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>VR</i>
Constant	3.860*	3.901*	2.776*	2.754*	.011	–	258.954	
Age	0.010*	0.011*	0.005*	0.005*	.000	0.132	30.854	1.0
Sex	-0.107*	-0.112*	-0.029*	-0.046*	.004	-0.043	-10.243	1.0
Black	-0.061*	-0.060*	-0.041*	-0.012	.007	-0.007	-1.664	1.0
Other	0.004	-0.024	0.000	0.009	.007	0.005	1.160	1.0
Hispanic	0.029	-0.011	-0.023	0.007	.007	0.004	.912	1.0
Income supports		-0.536*	-0.221*	-0.185*	.006	-0.133	-26.845	1.2
Hours worked			0.020*	0.019*	.000	0.474	98.944	1.3
Weeks worked			0.115*	0.113*	.001	0.336	76.959	1.1
Some college, no degree				0.060*	.005	0.050	11.140	1.2
Associates				0.133*	.008	0.069	15.894	1.1
Bachelors				0.226*	.007	0.141	31.769	1.1
Advanced				0.314*	.012	0.112	26.036	1.0

	Logarithmic transformation of work earnings							
	Block 1	Block 2	Block 3	Block 4				
Variable	<i>B</i>	<i>B</i>	<i>B</i>	<i>B</i>	<i>SE</i> <i>B</i>	β	<i>t</i>	<i>VI</i>
R^2	.069	.216	.614	.639				

* $p < .001$.

Explained Variance

The first regression block was calculated to predict the logarithmically transformed work earnings based on age, sex, race, and ethnicity. A significant equation was found ($F[5, 21538] = 321.289, p < .000$) with an R^2 of .069, which indicates that roughly 6.9% of the variance in earnings is attributable to demographic factors. Block two added income supports to the model and was found to explain a significant amount of variance ($F[6, 21537] = 988.120, p < .000$) with an R^2 of .216 ($\Delta R^2 = .147$). Block three accounted for employment variables, which were hours worked weekly, and weeks worked. A significant equation was found ($F[8, 21535] = 4281.157, p < .000$) with an R^2 of .614 ($\Delta R^2 = .398$). Finally, block four included postsecondary education. After holding all else equal, postsecondary explained a significant amount of model variance ($F[12, 21531] = 3179.620, p < .000$) with an R^2 of .639 ($\Delta R^2 = .025$).

Covariate Effects

Table 4 includes each block's R^2 , and the unstandardized coefficient and statistical significance, along with standardized regression coefficients, and the standard error of the estimate. Because the outcome variable is log-transformed, strict interpretation of the regression coefficients is inappropriate. Therefore, the formula $(10B - 1) \times 100$ is utilized to determine the percentage change in Y that can be expected with an increase in one unit of the predictor variable.

Demographic, income support, and employment variables were included as control variables for the final model. However, the regression coefficients provide an opportunity for analysis. After holding all else constant, the model predicts a 1.158% increase in salary for each year of age. Additionally, the model predicts that a female can anticipate 10.050% less yearly earnings than a male individual with all other variables held constant. Race and ethnicity variables were not statistically significant and, therefore, interpretation is inappropriate.

For an individual who receives income supports, consisting of one or more of social security income, supplemental security income, and welfare, the model predicts a 34.687% decrease in expected salary in comparison with an individual with all other constants held similar except for income supports. Similarly, for each hour worked, the model anticipates a 4.472% increase in annual earnings; for each

category of weeks worked, the model predicts a 29.718% increase in earnings throughout the year.

Effects of Postsecondary Education

After holding all else constant, an individual who attended postsecondary education but did not graduate averaged 14.815% higher earnings than the reference group—individuals who received a high school degree or less. Even greater earnings increases were experienced by those with higher levels of postsecondary education. Compared to the reference group, average annual earnings increased 35.831% for those with associate's degrees, 68.267% for those with bachelor's degrees, and 106.063% for those with advanced degrees.

Based on the regression coefficients for a 25-year-old White male with a cognitive disability, without income supports, working 40 hours a week year-round, the predicted annual earnings by educational attainment was: \$20,749.14 – HS diploma or less, \$23,823.19 – some college, no degree, \$28,183.83 – associate's degree, \$34,914.03 – bachelor's degree, and \$42,756.29 – advanced degree.

Discussion

The purpose of this study was to determine whether individuals with cognitive disabilities are entering into

postsecondary education and receiving degrees, and whether or not there is a relationship between postsecondary attendance and student's earnings after attendance. As this study demonstrates, there is a significant proportion of individuals with cognitive disabilities who are electing to attend some form of postsecondary education. Additionally, there is a positive financial impact for those individuals who elect to attend, regardless of whether individuals receive a degree or not.

As evidenced in the analysis, individuals with cognitive disabilities are attending postsecondary education and receiving a variety of different degree types. A majority of individuals with cognitive disabilities are attending some form of postsecondary education, with 52.4% of individuals indicating they have attended some form of postsecondary program. Additionally, 12.7% of individuals earned a bachelor's degree or more while attending postsecondary education, indicating that many public and private 4-year institutions need to account for how they are identifying and accommodating individuals with cognitive disabilities in their classrooms. This additional training is critically important for individuals with cognitive disabilities employment prospects, considering that 65% of jobs in the modern economy require some form of postsecondary training (Carnevale et al., 2013). Continuing to increase postsecondary educational access for individuals with cognitive disabilities will prove valuable. Continued research on supports and services that the

education system can provide to increase attendance would prove beneficial for the field. For example, Test et al. (2009) completed a systematic review that identified predictors of positive post-school employment outcomes. These predictors included access to occupational courses, community experiences, and parental involvement in the program, among many others (Test et al., 2009). Universities would be well suited to pursue these activities to ensure greater employment outcomes for individuals with cognitive disabilities.

Postsecondary education accounted for a limited amount of the total variability (2.5%) in yearly earnings based on the predictor variables. For example, individuals' employment hours and weeks (39.8%), and whether or not individuals received public supports (14.7%), had significantly more impact on predictive validity. Additionally, demographic variables accounted for more than double the proportion of variance (6.9%). While previous research has indicated that a significant proportion of the increase in wage inequality can be attributed to the disparity between those who can attend postsecondary education and those who cannot (Lemieux, 2006), it is unsurprising that the other factors included in the analysis accounted for greater variability. For example, the number of hours worked each week and weeks worked each year directly impacts earnings potential; whereas, the training received in postsecondary education is an indirect relation and, therefore, may not provide for as clear of a relationship with earnings. While the proportion of variance may be lower than

other blocks, the finding does provide evidence that postsecondary education shares a relationship with earnings and can have positive effects on employment outcomes. Findings from regression coefficients strengthen this case.

This study provides evidence that postsecondary education can be economically advantageous for a broader range of individuals than were currently represented by the literature. Regression coefficients from block 4 indicate an increase in earnings for attending postsecondary education without a credential (14.815% increase), an associate's degree (35.831% increase), a bachelor's degree (68.267% increase), and advanced degrees (106.063% increase) all indicate substantial financial benefits of postsecondary education for individuals with cognitive disabilities. It has been established that individuals' earnings can be positively impacted by postsecondary education (Hout, 2012; Ma et al., 2016; McFarland et al., 2018; Perna, 2005); however, this is the first study to definitively show that the relationship is similar for individuals with cognitive disabilities.

Related to work, it is known that public perceptions of disability continue to broadly impact the employment prospects of individuals with disabilities. Service providers and teachers sometimes underestimate the ability of an individual with a disability and restrict access to well-paying jobs in the community (Cimera et al., 2014; Pickens & Dymond, 2015). However, postsecondary education may provide an opportunity to increase access to a variety of occupations

through the demonstration of a variety of competencies. There remains a need for more education professionals and service providers to provide postsecondary education as an option upon graduation from secondary school.

Additionally, for individuals with cognitive disabilities who attended postsecondary education without attaining a degree, there was a statistically significant, though modest, increase in income for this population. This finding may be related to research which indicates that more jobs today require some form of postsecondary education (Carnevale et al., 2013), and the inclusion of postsecondary education results in higher earnings (Hout, 2012; Ma et al., 2016; McFarland et al., 2018; Perna, 2005). The research indicates that oftentimes individuals with disabilities lack access to well-paying jobs or have a difficult time finding a job at all (Winsor et al., 2017), so additional access to postsecondary education may provide broader access to higher paying jobs for individual with cognitive disabilities.

In comparison to the general population, the predicted increase in work earnings for a bachelor's degree earner with a cognitive limitation (68.267% increase) is higher than individuals without disabilities (57% increase; McFarland et al., 2018). This finding provides evidence that individuals with cognitive limitations may receive larger personal financial gains from postsecondary education when compared to the general population. This finding suggests that the income inequality experienced by people with cognitive limitations may be

tempered by way of greater access and inclusion in higher education opportunities that can lead to quality employment.

Additionally, this finding provides further indications of the results of Ashenfelter and Rouse (1999), who suggested that further schooling is an opportunity to increase the financial health of individuals and decrease inequalities. Increasing educational access has the potential to decrease the income inequality that is felt by individuals with cognitive limitations in contrast with the general population. Policymakers and practitioners can consider increasing access and supports that individuals with cognitive limitations need to succeed at postsecondary institutions, potentially increasing personal economic gains, decreasing reliance on income supports, and increasing the number of taxpayers throughout the U.S.

Future Research

In considering future research, practice, and policy reform, several areas are worth reflection. This study can provide individuals with cognitive limitations and their families with evidence of the potential economic implications of attending postsecondary education. These results could be considered in contrast with the personal and financial costs of attending postsecondary school. Additionally, further research identifying the causal factors that underlie the correlation between postsecondary attendance and increased earnings would be beneficial for the field. Potential research includes

identification of the skills learned in postsecondary education as well as considering whether personal privilege has impacts on postsecondary enrollment, and whether this explains some of the correlation between postsecondary education and increased work earnings. Furthermore, policymakers should consider legislation that removes barriers to postsecondary education for individuals with cognitive limitations, such as mandatory prerequisite courses and the impacts that low expectations can have on admissions (Hart et al., 2004). This study provides evidence of the value that postsecondary education has for working Americans with cognitive limitations, which could provide society wide benefits such as increasing the taxpayer base and decreasing the reliance on income support systems. Further research is necessary.

Limitations

This research presents a variety of limitations. The ACS data set defines the category of cognitive difficulty as a very broad term that does not provide an easily identifiable group of students within the higher education landscape. Likewise, the ACS does not provide information about disability severity or standardized assessments of intellectual ability, which would have provided a useful variable to control for portions of the variance. Similarly, the variable that codified the weeks worked by the individual was not continuous, which makes

interpretation difficult outside of full-time employment versus variable unemployment.

The research is also limited because the data were extracted after decisions were made about occupations and postsecondary attendance. The study would be strengthened by use of longitudinal data that includes aspects of the decision-making process for working Americans with cognitive limitations. Also, because the ACS provides data for one specific year, causal inference is not possible. This study provides correlational findings.

Conclusion

As this study establishes, postsecondary education plays an influential role in the determinants of earnings for individuals with cognitive limitations. Across degree types, financial gains were found for postsecondary attendees and degree earners over their high school graduate peers. While the academic threshold of many postsecondary institutions is high, providing a variety of options of technical schools, community colleges, and state schools provides greater economic mobility for individuals with cognitive limitations. While further research is needed to determine the causal mechanisms of this correlation, determining the extent of the increase in work earnings that postsecondary education can provide is an important first step. Individuals involved in postsecondary education will continue to work on advancing the inclusion of

individuals with cognitive limitations on their campuses, and now the economic value of these programs for these students is apparent. To continue to decrease the economic inequity felt by individuals with cognitive limitations, policymakers, institutions of higher education, and researchers must continue to pursue promising avenues of economic advancement for this population.

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5.

WHAT DO NCI DATA TELL US ABOUT THE CHARACTERISTICS AND OUTCOMES OF OLDER ADULTS WITH IDD?

Valerie J. Bradley; Dorothy Hiersteiner;
Henan Li; Alexandra Bonardi; and Laura
Vegas

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[What Do NCI Data Tell Us About the Characteristics and Outcomes of Older Adults with IDD? PDF File](#)

Plain Language Summary

We did a study of the needs of older people with intellectual and developmental disabilities (IDD) that helped us to understand ways to help them. Every year we survey adults with IDD to find out about their lives. The survey includes people from around the country. The survey gives us information about peoples' ages and where they live. We also ask them if they have health problems. People tell us whether they have friends and if they go out and do things they like. They tell us whether they make choices and if they have a job. We ask them what they do during the day. We used what people told us in 2018 and 2019 for this study. We focused on people in the survey who were over 55 years old so we could get a picture of their particular needs. Do older people with IDD have more health issues than other older adults? Our study showed that the answer is yes. They have more trouble seeing and hearing. They have more trouble walking and getting around. They get more anxious and depressed than people without learning problems. They also show signs of old age—like forgetting things—sooner than other older people. They have fewer friends than younger people with IDD. They are less likely to have a job. They do not spend as much time doing things in

their community. That may be because sometimes they cannot get a ride to get where they want to go.

How can we help older people with IDD? Here are some suggestions. There should be better planning. We should find better ways to find out about their health. We should find houses for them where they do not have to climb stairs. They should have iPads and phones so they can stay in touch with friends. Other devices can remind them to take medication. Cameras in their houses can tell us whether they are okay. Their staff should know how to help older people to stay healthy and happy. They should get rides when they want to go places.

For people with intellectual and developmental disabilities (IDD), transitions from one stage of life to another require thoughtful planning and support in order to ensure that people with IDD can continue to live a quality life according to their own preferences and needs. Whereas some of these critical life junctures have received increased attention in recent years, such as the shift from school to work, the transition when people enter their later years has received comparatively less attention. Yet, as more and more people receiving public support begin to age, it is important for policymakers, providers, and advocates to understand their unique support needs so that the transition is a success and people are able to enjoy their later years.

Using National Core Indicators (NCI)[®] data, this article describes the characteristics of older adults with IDD and what is known about their outcomes. We also provide suggestions for public managers, providers, and other stakeholders regarding how they might use this information to plan for and support older adults with IDD.

As discussed in this article, some older adults with IDD have health challenges in addition to those experienced by the general population. As we write this article, the global community is grappling with COVID-19, a virus that appears to affect older adults more severely than other age groups. Older adults with IDD are now facing additional challenges, both related to the virus and to the steps needed to avoid the illness (social distancing and quarantine). Though this article was written before the COVID outbreak, it offers information about the characteristics, outcomes, and health status of older adults with IDD that will prove helpful to those working to support them during difficult times.

Background

The generation born between 1946 and 1964 makes up a substantial portion of the world's population—and nearly 20% of the American public. In the U.S., we often refer to this generation as the “Baby Boom generation,” since birth rates across the world spiked following the end of World War II. The population with IDD born during those years—5 to 7 decades

ago—has lived through significant social and cultural change. In 1946, for instance, the first year of the baby boom, there were few publicly funded family and community services, and large institutions housed thousands of people with IDD. In subsequent decades, policy shifts have supported greater access to community supports, legal protections, and greater choice and control over services. In their own lives, Baby Boomers with IDD have experienced many life transitions—from early years into school through adolescence and into the many phases of adulthood. Now, as with Boomers in the general population, they are at another stage of life transition—moving into their older years.

The number of older adults in the U.S. continues to grow. Over the past 10 years, the population age 65 and over increased 38.8% from 2008 to 2018, growing from 38.8 million to 52.4 million, and it is projected to almost double to 98 million in 2060 (Administration on Community Living [ACL] and Administration on Aging [AOA], 2019). Currently, one in every seven individuals in the U.S. is over 65, and approximately one in five is over age 55.

Likewise, the numbers of people with IDD over 55 are also growing. This increase is in part the result of a growth in the average lifespan of people with IDD, which is now similar to the general population (Bittles et al., 2002; Janicki et al., 1999, as cited in Heller, 2010), with the mean age at death ranging from the mid-50s for those with more severe disabilities or Down syndrome, to the early 70s for adults with mild to

moderate IDD (Minino as cited in Heller, 2010). The increase in life expectancy may be attributed to better medical care and health surveillance as well as improved living conditions. The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030—when all the Baby Boom generation will be over 65 (Keller, 2019).

As people with IDD age, some will have health challenges in addition to those experienced by the general population. For instance, people with cerebral palsy may experience additional functional limitations, people with Down syndrome are more likely to experience the onset of Alzheimer's disease at an earlier age, and people on the autism spectrum are more likely to have gastrointestinal complications. People with gait and ambulation issues may be more susceptible to falling, and osteoporosis (fragile bones) associated with aging increases the risk of serious injury from a fall (Heller, 2017).

Moreover, given the shifts in models of support and care that have occurred in their lifetimes, many older adults with IDD have previously lived in an institution. Thoughtful planning for these individuals can support aging in place as a feasible option and avoid re-institutionalization in a nursing home as a person's needs increase. As in the general population, older adults with IDD will need support for end-of-life planning and advance care directives. Like people in the general population, people with IDD need assistance to ensure they can secure adequate housing, get access to specialized

health and wellness services, participate in their communities, and ensure that they are safe and secure. However, adults with IDD are at greater risk of abuse, neglect, and other violence against them than the general population. As they age and develop more functional and cognitive limitations, they may be even more vulnerable to abuse, neglect, and exploitation (Baladerian, 2010; NYC Elder Abuse Center, 2017).

According to the American Association on Intellectual and Developmental Disabilities and The Arc (ACL and AOA), agencies that are organized to serve people with IDD are not necessarily equipped to provide such assistance and “have historically not planned for the challenges faced by older people with intellectual and/or developmental disabilities” (ACL & AOA, n.d.) and are not prepared to address these unique needs, including providing education and training on mitigating the risk of elder abuse and neglect for a potentially more vulnerable population of older people.

Understanding how to provide services and supports to older adults with IDD requires further research and exploration. The intention of this article is to provide some insights, using NCI data from 2017-18, into the characteristics and outcomes of older adults with IDD with the hope that it will add to a growing body of knowledge.

To explore the characteristics and outcomes of older adults with IDD, we analyzed NCI[®] In-Person Survey data that was collected in 2017-18 by 35 states and the District of Columbia. Of the 25,671 survey respondents, 25.1% were over age 55

(“older adults” for the purposes of this analysis). To determine whether the needs of older NCI respondents with IDD varies from the needs of the aging general population, we compared NCI data with results from the 2018 National Health Interview Survey (NHIS; U.S. Census Bureau, n.d.).

Methodology

National Core Indicators

NCI is a voluntary effort by public developmental disability agencies across the U.S. to track their own performance by examining the outcomes experienced by individuals with IDD receiving long-term services and supports (LTSS). Each year, states that participate in NCI have the option of conducting the NCI In Person Survey (IPS) with a random sample of adults with IDD receiving LTSS to gain insights into key areas of concern—including employment, rights, service planning, community inclusion, choice, health, and safety. For the purposes of reporting, the data are aggregated to produce every state’s averages and a national average. The IPS also captures information on the demographic and personal characteristics of the individuals in the sample. The NCI dataset offers a unique opportunity to examine the outcomes and personal characteristics of the population of people who receive supports from public agencies.

The data for this analysis comes from states that participated

in the 2017-2018 IPS data cycle. The total sample for 2017-2018 was 25,671 individuals from 35 states and the District of Columbia. All participating states selected random samples from the population of adults (18 and over) with IDD who receive at least one publicly funded service (such as institutional, community, or home-based services) in addition to case management. There are no *a priori* pre-screening or exclusion procedures. States are required to interview a sample large enough so that it meets power requirements of 95% confidence level and 5% margin of error.

The NCI IPS is composed of three parts. The first part is the Background Information Section, which is used to collect demographic and personal characteristics of the individual being surveyed; this information is usually drawn from individual, agency, or case management records. In this section, the respondents' ages are collected. Historically, the second and third parts of the Survey have been collected via an in-person interview only. (NCI states are now piloting remote surveying techniques in light of the COVID-19 pandemic.) The second part of the survey contains questions on the individual's personal subjective opinions; it can only be answered by the individual personally receiving services. The third part of the survey contains questions that pertain to more directly observable, measurable occurrences, such as how often the person participates in specific community events; consequently, proxy responses (e.g., from family members, staff, etc.) are permitted for this portion.

The NCI IPS includes domains aligned with quality-of-life outcomes like those described by Schalock et al. (2002). This framework allows state public managers to assess the performance of public IDD LTSS systems in terms of the life outcomes of those served. This exploratory analysis uses NCI data to assess the characteristics, needs, and outcomes of older adults in the national sample. Of the 25,671 survey respondents, 25.1% were over age 55 (“older adults” for the purposes of this analysis).

Data included in the ensuing discussion are limited to those items that demonstrated significant differences between the different age cohorts. We include only those data that show a significance level of $p \leq .000$. Also included are elements for which the lack of significance was unexpected and were, in the authors’ judgement, relevant to policy and practice concerns.

For this analysis, we divided the survey sample into four cohorts (as shown in Table 1).

Table 1
NCI Survey Respondent Cohorts and Distribution

Age	Frequency	Percent of sample
Under 55	19,149	74.9
55-64	4,065	15.9
65-74	1,826	7.1
75+	522	2.0
Total	25,562	100.0

National Health Interview Survey

The National Health Interview Survey (NHIS)—which dates to 1957—is an annual, in-person survey administered by the U.S. Census Bureau. The NHIS is the largest in-person household health survey and is the primary source of information on the health of the civilian non-institutionalized population. Questions on NHIS include the presence of chronic conditions, such as hypertension and diabetes; sensory impairments; dental health; use of prescription medication; mental health and cognitive issues; immunization history; and availability of health insurance. The survey also includes demographic data including household size, income, race, and ethnicity.

During the 2019 survey, the sample size was approximately 35,000 households containing about 87,500 persons (National Center for Health Statistics, 2019). The NHIS is a cross-sectional household interview survey. Sampling and interviewing are continuous throughout each year. The sampling plan follows an area probability design that permits the representative sampling of households and noninstitutional group quarters (e.g., college dormitories). Clusters of addresses are defined within each state. Each cluster is located entirely within a county, a small group of contiguous counties, or a metropolitan statistical area. The current sampling plan is a sample of these clusters of addresses. Survey

participation is voluntary and confidential. The annual response rate is approximately 70%.

The total NHIS sample is subdivided into four separate panels, or sub designs. The result is that each panel is a representative sample of the U.S. population. This design feature has several advantages, including flexibility for the total sample size. Data are collected by interviewers employed and trained by the U.S. Census Bureau. For the Family Care component, all adult members in the household over 17 are invited to respond. For children and adults not at home, information can be provided by a responsible adult.

Comparisons

For all NHIS data, we have included the **confidence interval (CI)** in parentheses next to the relevant percentage. If the NCI data falls outside of this interval, it means the NCI data are **statistically significantly** different from the NHIS data. In this analysis, most of the NCI data are statistically significantly different from the NHIS data.

However, when NCI data show a statistically significant over- or underrepresentation when compared to the general public, differences in NCI sampling versus NHIS sampling should be considered. For example, NCI data are collected from adults receiving at least one service in addition to case management from the state system of developmental disabilities (DD) supports. Some states limit their samples to

certain programs or waivers, while some states include the entire population of adults receiving DD services (for more see [2017-18 In-Person Survey PART II: History, Methodology, Appendices](#)).

Trends

As shown in Figures 1 and 2, the population of older adults in the NCI sample grew during the last 10 years of NCI data collection.

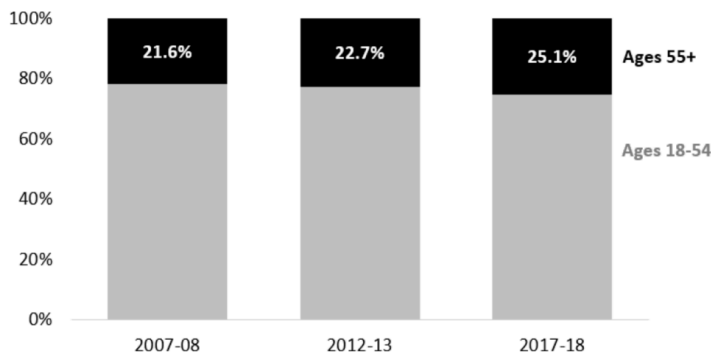


Figure 1
Graphic Depicting Proportion of People Over Age 55 in the NCI Sample

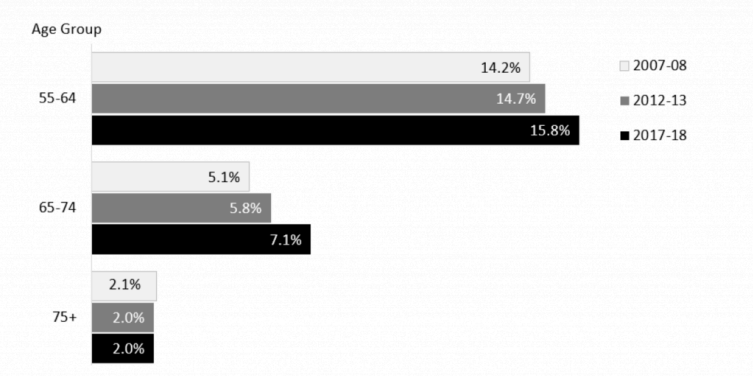


Figure 2

Graphic Depicting Proportion of NCI Sample in Different Age Groups, By Year

Caregivers are also aging—64% of caregivers who responded to the 2018-19 NCI Adult Family Survey were between the ages of 55 and 74, and 11% were 75 years and over. In two states, 13% of the respondents were caregivers over 75.

Given the shifts in models of support and care that have occurred in their lifetimes, many older adults with IDD have previously lived in an institution. As shown in Figure 3, based on NCI In-Person Survey data from the 2017-2018 data cycle, 38% of people over age 75 who were living in the community had previously lived in an institution, as had 25% of those who were between the ages of 55 and 75.

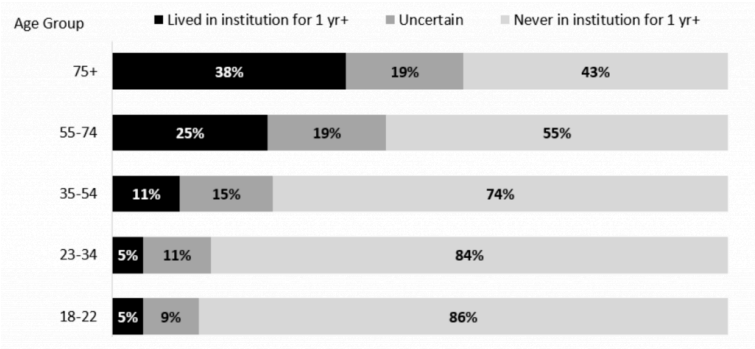


Figure 3
Graphic Depicting Proportion of People in Different Age Groups Reported to Have Lived in an Institution for One Year or More

Demographics

Age

Older adults with IDD (those over 55) represent only 25% of the NCI population. The national portion of the general population over age 55 is 37.4%. In Table 2, you can see that the NCI data points fall outside the NHIS 95% CI. This means the NCI data are statistically significantly different from the NHIS data. Those over age 55 may be underrepresented in the NCI dataset when compared with the general population.

Table 2
Age Group

Age	NHIS (%)	NHIS 95% CI (%)	NCI (%)
Under 55	62.6	61.9-63.3	74.9
55-64	16.9	16.5-17.3	15.9
65-74	12.2	16.5-17.3	7.1
75+	8.3	8.0-8.6	2.0

Note. Weighted percentage denominator: 249,448,868 (adults 18+ in the U.S.). NHIS 2018 Sample Universe (U.S. population of 2018): 322,903,933

Race

As shown in Table 3, older adults (55+) in the NCI data are more likely to be non-Hispanic Whites when compared to the comparable age group in the general public. The proportion of non-Hispanic Black respondents in the older age groups in the NCI sample roughly approximates the proportion in the NHIS sample. (Notably though, non-Hispanic Black respondents are overrepresented in the younger age groups in the NCI data.) Table 4 shows that Hispanic respondents to NCI are significantly underrepresented in the older cohort when compared to the NHIS data.

Table 3
Race by Age Group

	White NHIS			Black NHIS			All other race groups NHIS		
Age	%	CI (%)	White NCI (%)	%	CI (%)	Black NCI (%)	%	CI (%)	
Under 55	57.8	56.1-59.5	63.9	13.5	12.5-14.5	17.4	8.6	7.8-9.4	6
55-64	70.6	68.7-72.4	75.7	11.7	10.6-12.9	15.7	6.0	5.2-6.9	3
65-74	75.0	73.1-76.8	82.6	9.8	8.8-10.9	11.1	6.1	5.3-7.1	3
75+	79.1	77.1-80.9	86.6	8.4	7.3-9.6	8.2	4.8	3.9-5.7	2

Note. This table represents the proportions of the samples listed as Non-Hispanic; the proportions listed as having Hispanic ethnicity are represented in Table 4.

Table 4
Ethnicity by Age Group

	Hispanic NHIS				
Age	%	CI	Hispanic NCI (%)	NHIS (n)	NCI (n)
Under 55	20.1	18.7-21.6	12.2	32,124	18,920
55-64	11.6	10.4-13.0	5.6	9,950	4,045
65-74	9.1	7.9-10.4	3.1	7,820	1,811
75+	7.8	6.6-9.1	2.8	5,092	520

Gender

The majority of the NHIS sample, as shown in Table 5, is female in all age groups. In the NCI data, the majority of younger cohorts are male. However, the majority of the 75+ age group is female.

Table 5
Gender by Age Group

	Male NHIS			Female NHIS				
Age	%	CI	Male CI (%)	%	CI	Female NCI (%)	NHIS (n)	NCI (n)
Under 55	49.4	49.0-49.9	60.2	50.6	50.1-51.0	39.8	32,124	19,104
55-64	48.3	47.5-49.1	55.3	51.7	50.9-52.5	44.7	9,950	4,056
65-74	46.9	46.0-47.7	51.0	53.1	52.3-54.0	49.0	7,820	1,822
75+	41.8	40.6-43.0	48.9	58.2	57.0-59.4	51.1	5,092	522

General Health Status

In NCI, those under age 55 are more likely to self-report excellent health (see Figure 4). However, when compared to the general population, those in the NCI sample both under and over 55 are less likely to report excellent health. NHIS = National Health Interview Survey

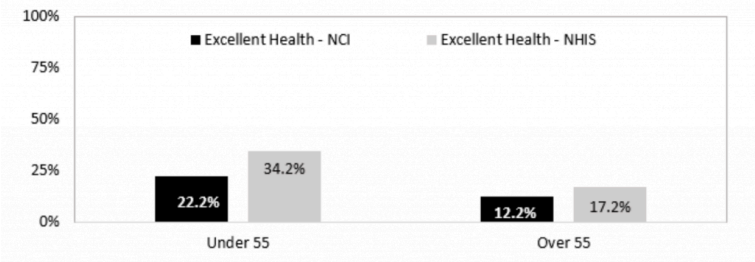


Figure 4
Excellent Health Status by NCI Age Group

Co-Occurring Conditions

The older age cohorts in the NCI data are significantly more likely to be reported as being diagnosed with mood and anxiety disorders. As may be expected, the proportions of the sample who are reported to have limited or no vision or hearing loss (severe or profound) goes up as age increases.

Comparisons to the NHIS sample should be made with caution, since the questions are not identical. NHIS asks about whether the person is “**Limited in any way** in any activities because of physical, mental or emotional problems.” If the answer is yes, the NHIS asks what causes the limitation. To make the data comparable to the NCI data, we included people who reported to be and those reported **not** to be limited in any way in any activities because of physical, mental, or emotional problems in the denominator when calculating the NHIS percentages.

As shown in Table 6, when compared to the general public, mood, anxiety, psychotic, or other mental health diagnoses are overrepresented in the NCI sample in all age cohorts. Similarly, vision problems and hearing problems, as shown in Table 7, are also overrepresented in the NCI sample.

Table 6
Co-Occurring Mood/Emotional/Behavioral Problem

	NHIS: Depression/ anxiety/emotional problem causes limitation (N = 9,273)		
Age	%	CI	NCI: Mood, anxiety, or behavior diagnosis (%) (N = 24,637)
Under 55	26.2	24.3-28.2	42.7
55-64	15.1	13.3-17.1	50.7
65-74	9.1	7.6-10.7	48.7
75+	4.5	3.6-5.5	45.2

Table 7
Co-Occurring Vision or Hearing Problem

	NHIS vision problem ^a (N = 9,273)			NHIS hearing problem ^c (N = 9,273)		
Age	%	CI	NCI vision problem ^b (N = 24,300)	%	CI	NCI hearing problem ^d (N = 24,113)
Under 55	7.2	6.1-8.5	8.8	2.9	2.3-3.7	4.9
55-64	8.3	6.9-9.9	11.2	3.6	2.9-4.6	7.6
65-74	7.6	6.4-9.0	13.6	4.8	3.9-6.1	11.0
75+	9.5	8.3-11.0	15.0	10.2	8.7-11.8	18.1

^a “Vision/problem seeing causes limitation.”

^b “Diagnosis of limited or no vision.”

^c “Hearing problem causes limitation.”

^d “Diagnosis of hearing loss, severe or profound.”

NCI Data (Without Comparisons to General Public)

There were several relevant NCI measures that did not have comparable data points within the NHIS data. These data points are presented in this section.

Other Disabilities

The cohort under age 55 is much more likely to be reported to have a diagnosis of autism spectrum disorder and similarly more likely to have a diagnosis of cerebral palsy when compared with the older cohorts. Table 8 shows that the proportion of the sample reported to have Down syndrome goes down as age goes up, which is not surprising given early onset Alzheimer’s in this group of participants and a shorter life expectancy.

Table 8
Other Disabilities

Age	Autism spectrum disorder (%) (N = 24,663)	Cerebral palsy (%) (N = 24,790)	Down syndrome (%) (N = 22,562)
Under 55	25.6	16.6	9.7
55-64	7.6	12.2	7.4
65-74	4.4	12.7	2.5
75+	2.3	13.4	1.1

Other Conditions

In the NCI sample, as shown in Table 9, the incidence of cardiovascular disease, diabetes, cancer, high blood pressure, and high cholesterol increases as age increases. The incidence of Alzheimer’s or other dementia also increases—19% of people

over age 75 (nearly 1 in 5) are reported to have Alzheimer’s disease or another dementia.

Table 9
Other Conditions by Age Group

Age	Cardiovascular disease (%) (N = 24,302)	Diabetes (%) (N = 24,464)	Cancer (%) (N = 24,553)	High blood pressure (%) (N = 24,204)	High cholesterol (%) (N = 23,610)	Alzheimer's or other dementia (%) (N = 24,464)
Under 55	5.4	8.5	1.3	14.8	13.1	1.1
55-64	11.3	18.3	4.3	37.6	35.7	6.4
65-74	17.2	21.2	6.1	44.9	39.4	8.5
75+	24.8	23.6	12.5	49.7	44.6	19.0

Preventive Health Screenings

Perhaps not surprisingly, the NCI data, included in Table 10, indicate that proportions of respondents who received vision exams, hearing tests, flu vaccines, and/or mammograms in the past year increase as age increases.

Table 10
Preventive Screening by Age Group

Age	Vision exam in the past year (%) (N = 20,889)	Hearing test in past year (%) (N = 16,520)	Flu vaccine in past year (%) (N = 19,902)	Women age 40+ mammogram in past year (%) (N = 4,120)
Under 55	54.4	52.2	68.8	68.5
55-64	66.7	65.9	85.6	81.8
65-74	68.4	67.6	90.3	72.1
75+	71.2	75.6	92.3	60.7

Where People Who Are Aging Live

Tables 11 and 12 describe the places where older adults in the NCI sample live and have lived. Those over age 55 are significantly more likely to live in an Intermediate Care Facility for People with Intellectual and Developmental Disabilities (ICF/IID), nursing facility, or other institutional setting than those under age 55. Older individuals are also significantly more likely to live in a group residential setting as opposed to an individual setting. Those over 55 are significantly less likely than the younger cohort to live with family or parents. As stated previously, in their lifetimes, those in the NCI sample who are over 55 are significantly more likely to have lived in a state hospital or state developmental center for people with

IDD, a private ICF, and/or a nursing home for longer than a year than those under age 55.

Table 11
Living Arrangement by Age Group

Age	ICF/IID, nursing facility or other institutional setting (%)	Group residential setting (e.g., group home) (%)	Own home or apartment (%)	Parents/ relatives home (%)	Foster care or host home (%)	<i>n</i>
Under 55	3.7	25.7	16.7	50.0	3.8	18,684
55-64	10.6	45.0	24.9	13.9	5.7	3,955
65-74	10.6	53.5	22.7	7.8	5.5	1,764
75+	13.7	56.5	17.1	5.0	7.7	504
Total	5.5	31.5	18.5	40.2	4.3	24,907

Table 12
Past Institutional Residence by Age Group

Age	Longer than a year in state hospital or state developmental center for people with IDD (%)	Longer than a year in a private ICF (%)	Longer than a year in a nursing home (%)	<i>n</i>
Under 55	3.0	2.0	0.6	18,979
55-64	14.0	5.0	2.1	4,023
65-74	20.0	6.0	3.7	1,805
75+	25.0	10.0	4.3	520

Medication

Table 13 indicates that respondents over the age of 55 are significantly more likely to take medications for mood or anxiety disorder. Respondents over the age of 55 are significantly less likely to take meds for behavior challenges.

Table 13
Medication by Age Group

	Takes meds for mood, anxiety, psychotic		Takes meds for behavior challenges	
Age	%	<i>n</i>	%	<i>n</i>
Under 55	45.0	12,314	21.2	12,310
55+	55.3	4,120	16.5	4,098

Mobility Impairments

In the NCI sample, Table 14 shows that among older adults the need for mobility assistance increases as age increases.

Table 14
Mobility by Age Group

Age	Moves self around environment without aids (%)	Moves self around environment with aids or uses wheelchair independently (%)	Nonambulatory, always needs assistance (%)	<i>n</i>
Under 55	81.3	10.3	8.4	19,004
55-64	72.1	19.0	8.9	4,034
65-74	60.1	27.8	12.0	1,804
75+	42.4	42.6	15.1	515

What People Do During the Day

Based on the data in Table 15, as age increases, people in the NCI sample are less likely to have either a paid community individual or group job or a job in a community business that primarily hires people with disabilities. Participation in an unpaid community activity also goes down as age goes up, while participation in paid and unpaid facility-based activities goes up but decreases again after age 75.

Table 15
Employment by Age Group

Age	Paid community job ^a (%)	Unpaid community activity (%)	Paid facility-based activity (%)	Unpaid facility-based activity (%)
Under 55	18.2	21.2	13.8	35.6
55-64	11.4	20.9	17.6	46.2
65-74	6.2	18.4	14.7	50.7
75+	1.5	15.1	8.0	49.3

^a In an individual, group, and/or community business that primarily hires people with disabilities.

Transportation

There is no statistical significance in the differences between the percentages of people in each age cohort who reported almost always being able to get where they need to go. However, Table 16 shows that the percentage of those who report that they are almost always able to get places when they want to do something outside of the home—like going to see friends or going to do something fun—declines as age increases.

Table 16
Transportation by Age Group

Age	Almost always able to get places to do something enjoyable ^a (%)	<i>n</i>
Under 55	84.5	12,698
55-64	81.4	2,661
65-74	81.0	1,198
75+	79.0	333

^a Like going out to see friends, for entertainment or to do something else fun

Relationships

According to the data in Table 17, as age goes up, older NCI respondents are less likely to have friends who are not family or staff.

Table 17
Friendship by Age Group

Age	Has friends who are not staff or family (%)	<i>n</i>
Under 55	78.8	12,787
55-64	75.6	2,680
65-74	71.8	1,211
75+	70.9	340

Community Inclusion

Table 18 shows that those over age 55 were less likely to have gone into the community for shopping, for entertainment, to go out to eat, or to attend a religious or spiritual practice/ service at least once in the past month.

Table 18
Community Participation by Age Group

	Shopping		Entertainment		Out to eat		Out to religious or spiritual practice	
Age	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Under 55	90.1	18,600	75.2	18,598	86.9	18,624	41.1	18,432
55+	87.2	6,210	70.5	6,215	84.4	6,221	38.3	6,175

Discussion

What we have learned about people with IDD who are aging—both based on the NCI data and existing research—has implications for the design of policy and programs targeted to older adults with IDD. Specifically, these findings point to the fact that older adults with IDD are more isolated, have smaller social networks than their younger peers, and have less access to transportation to get where they want to go. One important way to address this isolation is to facilitate access to community programs geared to older adults in the general population—including senior centers and other resources geared to socialization, nutrition, wellness, housing, and benefits counseling. Yet, efforts to bridge the gap between systems that serve older adults and those that serve people with IDD have been minimal despite federal efforts beginning in the 1980s and 1990s to incentivize such collaboration, including legislative changes, federal grants, and the development of memoranda of understanding (MOU) at the federal and state level between developmental disabilities and aging agencies. According to Factor et al. (2012), these efforts were undermined over time by changing leadership and changing federal and Congressional priorities. Renewed efforts between aging and IDD agencies will be required to bring about a sustainable partnership to make individuals with IDD welcome in generic aging programs.

Many older adults with IDD experience changes in their

physical and cognitive abilities. The NCI data show that those over 55 are more likely to have vision and hearing challenges than the general public and have a greater need for mobility supports. In addition, our data demonstrate that older adults in the NCI sample are more likely than the general population to have a mood and/or anxiety disorder. To tailor supports to meet these challenges, assessment protocols geared to older individuals will be important. Further, these findings point to a need to design services and supports that accommodate age-related limitations and to help people adjust to sensory, psychological, and mobility changes.

Given these changes, older adults with IDD can also benefit from a range of technological advances including but not limited to remote monitoring, communication devices, GPS trackers, medication organizers and dispensers with timers or enabled with remote monitoring, security systems, home sensors, and voice-activated assistants. To ensure that individuals can receive technological support through HCBS waivers, person-centered service plans should include goal(s) linked to the need for a specific device and the steps necessary to ensure that the individual is able to use it. Low-interest loans may also be available from federally funded assistive technology centers.

The data demonstrate that those over age 55 are significantly less likely to work in a paid community job and are more likely to be involved in unpaid, facility-based activities. For those in unpaid facility-based activities, person-

centered approaches would dictate that we ask them whether they want to remain there, want to retire, or want to participate in more community-oriented activities. Further, for those who do not have a job, the data suggest that many older adults would like a job—23% of those between ages 55-64, 12.9% of those between ages 65-74, and 12.9% of those over 75. Plans for these individuals should include employment goals.

Dementia in later years is also an issue for people with IDD, especially for individuals with Down syndrome for whom the onset of Alzheimer's starts 20 years earlier than for the general population (Alzheimer's Disease International, 2003). Jokinen et al. (2013) in *Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia* note that the first step in treating Alzheimer's is to maintain the individual's quality of life. The authors recommend shared initiatives "across agencies and organizations that involve the aging, disability, and dementia care systems, whether for family supports, day respite, residential, or other supports and services" (p. 40).

The increase in mobility issues noted above may necessitate home modifications or relocation to more accessible housing. As part of person-centered planning, support coordinators should anticipate mobility challenges and explore the availability of federally funded low-income rent supplements for older adults as well as housing available through the HUD Section 202 program.

Direct support professionals (DSPs) play an important role in supporting individuals to make the transitions that older adults with IDD face. According to Sedlezky (2013), DSPs need to be knowledgeable about the following five aging-related areas: (1) awareness of physical and mental health changes, (2) supporting aging in place, (3) retirement and later-life social networking, (4) grieving and loss, and (5) end-of-life planning.

Finally, though racial and ethnic disparities among older adults with IDD were not explored in this analysis, further research is needed into racial and ethnic disparities that may appear or become exacerbated as the population of adults with IDD ages. The differential impact that COVID-19 has had on minorities and low-income communities has provided adequate evidence of serious health disparities in the general population. It will be important to explore whether these disparities occur among older adults with IDD receiving public long-term services and supports.

Limitations

The analyses presented in this paper are from a dataset collected from the NCI. The sample includes a random sample of people who are receiving services from state systems responsible for people with IDD and, therefore, does not include people with IDD who do not receive public services. Consequently, any conclusions cannot be extrapolated to the

larger population of older adults with IDD. In addition, states participating in NCI may create slightly differing sampling frames. Further, the findings are not adjusted for differences in demographic characteristics between the different age cohorts within the NCI sample.

Comparisons between NCI and NHIS data should be approached with some caution given differences in survey administration and methodology. For example, the sampling methodology for NCI and NHIS differ, so the populations may differ by more than just the receipt of state IDD services. In addition, many questions are worded differently across surveys. Despite these factors, the differences between characteristics of older adults with IDD and the general population identified in this study highlight potential topics for further examination.

Conclusions

State IDD systems should be prepared to examine their policies, programs, and practices to ensure they can adequately support older adults with IDD and their families as they age. The needs of older adults with IDD should be anticipated and planned for in advance. This requires shifting to planning formats that take into consideration the supports needed across the lifespan. One successful approach to such planning is being employed by The Community of Practice (COP) for Supporting Families of Individuals with Intellectual and

Developmental Disabilities, which is working with six states to develop systems of support for families throughout the lifespan of their family member (<http://supportstofamilies.org/>). The COP is supported by the National Association of State Directors of Developmental Disabilities Services, the University of Missouri Kansas City-Institute on Human Development (UMKC-IHD), and the Human Services Research Institute (HSRI). The COP website includes valuable resources regarding the application of Charting the LifeCourse tools: <http://www.lifecoursetools.com/planning/>.

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This is where you can add appendices or other back matter.