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Opening Editorial: The Origin and Aims of the *Developmental Disabilities Network Journal*¹

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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

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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.

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,

² 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.

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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