Libraries and Reading

INTELLECTUAL DISABILITY AND THE EXTENT OF LIBRARY DIVERSITY

Matthew Conner • Leah Plocharczyk

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Libraries and Reading: Intellectual Disability and the Extent of Library Diversity

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Matt's Dedication

To my parents for their endless support and example, and to my mom who planted the seed of special education long before I was aware of it.

Leah's Dedication

To my parents for their love, support, encouragement, and endless sacrifice.

To my book club buddies for their inspiration, wisdom, and great gusto for life. You have opened my eyes and changed me in ways you will never know. You are all extraordinary individuals. Never let anyone tell you that you can't, and never give up…never.

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Preface

A word is in order about the serendipitous origins of this project. Matt had recently published *The New University Library* (2014) with the American Library Association (ALA). This book grew out of his work for the Librarians Association of the University of California (LAUC), the professional association of librarians at the University of California, on which he had served in various capacities, culminating in the presidency. As with the rest of the profession, LAUC was concerned about the future of libraries. A system-wide conversation on this topic was extended into the book which surveyed historical trends and applied them to case studies both inside and outside of the University of California.

Following publication, Matt attended a conference at the University of Illinois at Urbana-Champaign, one of the book's case studies, at the invitation of some of the staff. With the book published, it remained to be seen if its predictions would come true, and he recalled a study that found that a high percentage of futurists were wrong. At this conference, he met Leah who was giving a poster on an outreach program by the library at Florida Atlantic University (FAU). One of the conclusions of *The New Library* is that outreach would be important for libraries as they redefine themselves and reach out to new audiences, and Leah had taken a particular interest in outreach at her library. One of her projects is the basis of this study: the use of a book club in an academic library to advance the educational goals and college experience of students with intellectual and developmental disabilities (IDD). It seemed to Matt that this was more than another clever idea for reaching its participants. It had implications for the entire profession in policy, goals, service mission, and self-definition. As the project unfolded, it became clear to both authors that the serendipity of their meeting ran even deeper than had appeared. Individuals with ID, as will be seen, have a complex history with libraries. (We will use the abbreviation ID as a shorthand for the longer abbreviation and because intellectual disabilities were a universal characteristic of the populations we studied while developmental disabilities were uncommon.) Associated with the literacy efforts of public and school libraries, students with ID have not had a presence in higher education until recently. This came about through a relatively new movement called, Post-Secondary Education (PSE) which defines adults with ID as part of continuing education which gives nontraditional students access to college classes. It is only because one such program exists at Leah's campus that she was able to develop the book club at all.

The authorial partnership is not only reflected in the book's original circumstances but in the methodology by which it went forward. In a time of organizational change, librarians have become familiar with the terms "top-down" and "bottom-up" as ways of structuring projects. The first refers to developing a plan at the administrative level and executing it. The second refers to the opposite process where the initiative comes from the lower levels of an organization, either through ideas from staff or practices that coalesce into policy. The choice of starting above or below depends on the circumstances, and it is not uncommon for both to be employed simultaneously. That is the case here by virtue of the authors' history. The policy issues and professional trends of Matt's book illuminated Leah's case study, and her innovations shed new light on trends. The two perspectives worked in synergy. While theory and practice are supposed to be interdependent, the scientific method formulates theory as preceding experiment. So, it is worth noting that this project has operated somewhat in reverse with the practice of the library book club at FAU in robust form before coming under examination by theory. The precedence of practice over theory recurs throughout our study.

Far from resolving all the issues presented, our study often only introduces them. But it is our hope that this book will reduce the chance and serendipity that brought it about and smooth the path of others toward understanding and contributing to library services for disability.

Acknowledgments

Our wide-ranging journey in this book would not have been possible without the aid of a long list of people who gave us a warm welcome when we arrived at their shores. Their generosity and dedication are deeply appreciated and give us high hopes for the future of libraries and disability services.

We first offer our sincerest thanks to Emerald Publishing and to our very supportive editors, Charlotte Maiorana, Charlie Wilson, and Nick Wolterman for taking a chance on us and this project. It was a pleasure to work with each of them, and we hope they enjoy the finished product!

We also thank Dr. Mary Louise Duffy for reaching out to the library staff years ago to suggest that the library host an intern from the program. If not for her wisdom, expertise, support, edits, and suggestions for the book, and for her time "lunching and learning" to teach us about exceptional education and what it means to work with adults with ID, this project would have been impossible. Her funny stories will be remembered and her friendship will be missed. We hope her retirement from FAU is going splendidly. Many thanks, as well, to Dr. Michael Brady, Dr. Gwen Carey, Professor Angelica Downey, Dr. Melody Wright, Ms. Heather Graeve, and everyone in the ACI program who gave of their time and energy toward this project. Without the support of the Academy for Community Inclusion (ACI) and its many wonderful professors, staff members, peer mentors, and students, none of this would have been possible. We are indebted to each and every one of you.

We thank Dr. Tom Fish, President and founder of NCBC, Lyna Smith, Susan Berg, Rachel Staley, Marilyn Darrow, and all of NCBC staff with whom we worked closely throughout this project. They answered questions, sent resources, provided stats, and trained us as NCBC affiliates. NCBC is a wonderful and unique organization, and we feel lucky that the FAU book club can contribute as one of its affiliates.

We thank Miss Mattie Rials, Laura Stokes, Darlene Morgan, Scooter Mouse, the staff of the McComb Public Library, and the Wednesday Special Friends who shared their warm Southern hospitality and welcomed us into their family. They hold a special place in our hearts and will never be forgotten.

We thank Dr. Meg Grigal and Debra Hart of Think College! for their inspirational and transformative research on Post-Secondary Education (PSE) Programs for college students with ID. We relied upon their expertise and vast knowledge of PSE throughout the writing of this book.

At the MacArthur Library at FAU, the site of the FAU book club, Leah particularly wishes to thank and acknowledge her co-facilitators and coders, Marilee Brown and Linda Lesperance for keeping her sane, and for their contributions, patience, time, energy, superb organizational skills, and most of all for their sense of humor to pull off something memorable. She hopes they enjoyed the ride as much as she did. Thanks also goes to Raven Mello, Ashlee Malkin, Hope Wiersma, Miranda Jones, and Sibel Bode, student staff at the MacArthur Library and peer mentors who took time out of their busy college lives to attend book club and to assist with the facilitation, reading and game playing. Everyone was integral to the smooth operation of the book club and their efforts do not go unnoticed. Leah particularly thanks Edith (Cookie) Davis, staff at the MacArthur Library, for her flexibility with her schedule and for constantly rearranging her desk duty so that Marilee, Linda, and Leah could run book club. Her keen searching skills and her assistance with fact finding and checking the library literature was a lifesaver. She is a true asset to the library team, and we are lucky to have her. And we thank Diane Arietta for the time she spent setting up our "movie theater" in the back staff area so that the book club could enjoy our end of the semester celebrations, and an even bigger thank you for her patience during the celebrations!

We thank Donna Simonovitch, Danae Montgomery, and Ximena Levy at FAU's Research and Integrity Office for their patience in answering Leah's countless questions via telephone and email. She could not have made it through the Institutional Review Board (IRB) process without them.

In the FAU Administration, we thank Ethan Allen for his encouragement, support, and for taking so much time with Leah to get our IRB proposal and application just right. He went above and beyond the call of duty in helping us to get our research project approved. Thanks to Dean Carol Hixson and the FAU Library Leadership Team for taking the time to listen to Leah's pitch and for approving and offering financial assistance so that the MacArthur Campus Library could become one of the very first academic libraries trained as an NCBC affiliate. Without their support and encouragement, Leah and her co-facilitators could not have undergone the training necessary to complete the affiliation process. Leah thanks Dean Hixson, too, for encouraging her to test her leadership skills and for allowing her to continue with a fulfilling project that gives her great professional joy.

We thank all of the coordinators and facilitators of the NCBC affiliates located throughout the United States and as far reaching as Australia who so generously gave up their time to speak to Leah and participate in interviews both over the phone and via email. Leah enjoyed speaking to each and every one of them and learned so much about how to successfully run a book club for individuals with ID. Leah enjoyed their stories and appreciates the support they offered by sharing resources, book selections, and other pieces of advice that she used in her club to make it the most positive experience possible. Although they were strangers to her when she first reached out to them, she is reminded of how supportive and giving the library world can be. She feels proud to call them colleagues.

We thank Mrs. Pyle, Mrs. Weichel, Ms. Ettiene, and Mrs. Orofino for taking the time to answer survey questions and for offering words of encouragement and for letting Leah know that she was on the right track. Working with their sons and daughters is pure joy for her.

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Leah also wishes to give personal acknowledgments. Thanks to Dr. Erin Burns-Davies, Dr. Shireen Lalla, and Ms. Emily Meade who are some of the smartest women I know and provide inspiration to me every single day. I thank them for always believing in me and for always being there. The friendship they give knows no bounds.

Thank you to my little sister, Dr. Beth Plocharczyk, for setting the bar high. I admire her bravery, hard work ethic, endless energy, and intelligence. I look at all that she has achieved in life and it makes me want to do and be better. (I bet she never thought I'd be authoring a book!)

A heartfelt thank you goes out to my parents, Judy and Stan, for being exemplary role models. From a young age, they taught my sister and me the value of a hard day's work. But more than that, they taught us that the most important thing in life is to give selflessly to others and to practice patience, kindness, and

empathy. No matter what I attempted to do growing up, and even today, they encouraged me and believed in me. They built for me a strong foundation, and I am lucky to have them as parents. I hope that I have made them proud.

And finally, thank you to all of my remarkable book club buddies (including service dogs, Clay and Roxi). I have had the pleasure of meeting over the years, some briefly, and some whom I have grown to know quite well. Without them, none of this would be possible. I feel grateful to call them my friends. They made me laugh, and even cry (tears of joy and pride.) Each of them demonstrates the true meaning of perseverance, and the life lessons that they taught me are invaluable. I look forward to many more book club sessions spent with them now and in the future. Thank you.

Introduction

It has been widely acknowledged that the library profession is in a time of rapid change, driven largely by the rise of information technology. What form change will take remains unknown (although technology biases us toward forward-looking, futuristic developments). Yet, the forward arrow of progress has been recognized as simplistic. There are other, more complex paradigms. "And the end of all our exploring/Will be to arrive where we started/And know the place for the first time," wrote T.S. Eliot who imagined the line of progress bent back on itself into a circle of rediscovery (Eliot, 1943). A similar nonlinear model has been proposed by futurist, James Burke, who argues that the inventions of the future are already present and will consist of reassembling components that we have now (Burke, 1978). The future, he maintains, lies around us unrecognized.

These alternative paradigms of change are evident even in the rise of technology itself. The ubiquitous personal computer began as an outgrowth of mathematical theory prior to World War II (WWII) (Copeland, 2012). And the Internet, which links personal computers together, began as a military technology to enable communication amid a nuclear holocaust. What is characterized as an information "revolution" is actually a new application of concepts invented much earlier. Some of the popular and commercial uses of this technology would have been unimaginable to its designers. Marina Whitman, daughter of John von Neumann, one of the central figures in the development of computing writes: "[T]he notion that computers would sit on millions of desktops and in millions of pockets, would be used to transmit business documents, love letters, and pornography instantaneously across the miles, and would set adults to fulminating about the time their children waste on computer games – all this was beyond his wildest imagining…" (Whitman, 2012, p. 51).

The recursive pattern of progress can also be detected in another source of change for libraries: the society from which it draws its patrons (Mathuews, 2016, p. 8). Our review begins with one of the landmarks of modern American history, the Counterculture of the 1960s which enacted a global reevaluation of society's structure and assumptions. This movement also saw the birth of multiculturalism and diversity which concerns the subject of this book. From a kind of monolith that was simply accepted, society has been reframed by cultural critics in terms of the three categories of race, class, and gender (Hancock, 2016). This partition undergoes a process of continual fragmentation as the categories continue to subdivide. The process began with the Civil Rights movement to gain equal rights

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for African-Americans, introducing the category of race. Their struggle raised consciousness of injustices toward women (gender) which included inequalities of wealth and power (class). The dynamic of diversity has continued to introduce more racial, ethnic, and gendered categories up to extended taxonomies of the present day such as Lesbian, Gay, Bisexual, Transgendered, Queer, and all inclusive (LGBTQ+). The process of discovery has also brought attention to individuals with disabilities, the most vulnerable of populations, which have been silenced to the point of erasure.

The category of disability has subdivided as well. Physical impairments such as missing limbs and limited vision and hearing have been clear to perceive. Less obvious and understood are internal disabilities that include psychological and cognitive impairment. Our study concerns the latter category defined as those with IQ below 75 and with associated difficulties with self-care, communication, and socialization. Related developmental disabilities can include chronic physical conditions such as cerebral palsy and multiple sclerosis as well as mood and anxiety disorders, such as autism (AAIDD, 2004; Mutua, Siders, & Bakken, 2011, p. 104; Walling, 1995a, pp. 7–8). As a subset of persons with disabilities, those with intellectual disability (ID), misunderstood by observers and unable to advocate for themselves, culminate the study of multiculturalism as the most excluded and disadvantaged members of society.

Out of their service ethic, libraries have embraced diversity and multiculturalism. In 1939, on the 150th anniversary of the original Bill of Rights of the United States, the American Library Association (ALA) promulgated its own bill of rights for its patrons, which has been updated to the present day (Wiegand, 1999, p. 11). The current version explicitly mentions individuals with ID.

> Library staff should be proactive in reaching out to persons with disabilities and facilitating provision of resources and services. Library staff also should be aware of the available technologies and how to assist all users with library technology. All library resources should be available in formats accessible by persons of all ages with different abilities. These materials must not be restricted by any presuppositions about information needs, interests, or *capacity for understanding*. The library should offer different, necessary modes of access to the same content using equipment, electronics, or software. All information resources provided directly or indirectly by the library, regardless of technology, format, or method of delivery, should be readily, equally and equitably accessible to all library users. Libraries should make every effort to *support the needs of their users with disabilities* and when necessary, should seek financial or other assistance to do so. (added emphasis)[1]

[1]American Library Association (2017a, 2017b), and Lerner (1998, p. 149).

However, when applied to the case of persons with ID, this sentiment runs up against difficult realities. Libraries are stretched to the limit with funding cuts that affect the entire educational system (Mathuews, 2016, p. 7). More has to be done by fewer people, and in a time of change, librarians are not certain where to apply their limited resources. In the case of instruction and outreach, it is tempting to let technology do the work of direct teaching and consulting and let high tech replace high touch. "The 'information science' that has developed in the last years of the twentieth century constitutes an arena of study in which the technology to which it is harnessed defines the field" (Wiegand, 1999, p. 24). Into this milieu, individuals with ID with their intensive specialized needs, represent a new and significant challenge. For all its recent redefinition, the core of library service, since antiquity, has been its collection, which assumes the ability to read. Yet, many individuals with ID not only lack reading skills – a problem addressed through literacy instruction – but have significant obstacles to learning to read. This is a fundamental problem. It is entirely fair for a working librarian to ask why patrons with ID should command their attention and how to help them.

Individuals with ID, then, represent a conundrum with equal and opposite imperatives for libraries to intervene or not. This paradox results in part from how persons with ID represent a historical iteration, returning the future to the past. Patrons with ID are a core constituency for libraries that seeks only the most basic of reading access, not newer developments of information literacy, 3D printing, and other innovations (Koldenhoven & Koldenhoven, 1995, p. 233). Moreover, as the most disadvantaged members of society they demand the attention of a service profession, especially one committed to diversity. However, their learning needs are new and specialized and beyond the scope of librarian training. Thus, the condition of individuals with ID that demands the library's intervention impedes it at the same time. The clash between values and practicality is another aspect of this conundrum. How the profession responds to it will define both its commitment to diversity and its fundamental mission. This puzzle can be broken down into more specific questions. Is there, after all, a limit to the library's mission of diversity with certain populations simply out of scope? If so, which ones? Or, despite the best intentions, is a limit to diversity imposed by a lack of resources in the form of funding and specialized training? Or is it a matter of mission as well? If librarians are stewards of texts and reading, does their responsibility end with those capable of learning to read at some minimum level? Moreover, if librarians are defining themselves as guides to critical thinking, a more sophisticated type of reading, does this purpose diverge from remedial and special education? And whose decision is it to make? Is it up to individual institutions or types of libraries? Or are there obligations that must be recognized across the profession as the ALA's Bill of Rights seems to indicate? And, ultimately, if libraries wish to support patrons with ID, how can this be done? This book seeks to answer these and other questions about the implications of persons with ID for the library profession.

The inquiry begins with a chapter on the history of American libraries to understand their involvement in literacy training as a context for individuals with

ID. Literacy was a service that began long before the appearance of formal programs which remain active to the present day. It was inherent in the first public (subscription) library founded by Benjamin Franklin which took the form of a book club for self-education. With Franklin's original library as a paradigm, this chapter traces the development of the modern profession under a range of social forces with special attention to literacy training. While libraries do not offer systematic services to patrons with ID, the provision of reading skills is a core service of libraries that could be adapted.

With this historical context, the second chapter turns to consider the current state of individuals with ID, tracing their legal recognition through a series of laws in the postwar era and their incorporation into public education. Educators have achieved much by integrating students with ID into schools, but this has raised new problems, especially in the aftermath of high school where, lacking social and educational support, students with ID sink into isolation that negates much of their schooling. Responses to this problem have not come from vast bureaucratic structures but from grassroots movements such as the Next Chapter Book Club (NCBC) and Books for Dessert which offer informal reading clubs for individuals with ID, some of which are based in public libraries. Academic libraries, as the continuation of the public school system, would seem to be more remote from students with ID and their education. Yet, this turns out not to be true. A relatively new movement called Post-Secondary Education (PSE) for students with ID has inspired a number of vibrant programs at colleges across the United States. Their rationale and their ingenious cooperation with academic units will be discussed in detail. They offer an outreach opportunity that academic libraries have so far overlooked. Both for public libraries and academic libraries, there is a good deal of potential for including individuals with ID of all ages that remains unrealized and largely unsuspected.

From practice, the third chapter shifts back to theory to consider theories of special education as another context for persons with ID. The chapter reviews philosophies and influential individuals in general education from which special education derives. We discuss something of a sea-change in special education from simple tasks of learning by rote to teaching meaning in context in a way that mirrors changes in general education. This discussion culminates with Universal Design for Learning (UDL), a theory that purports to be a theory for all education. As they do for libraries, individuals with ID pose a particular challenge to UDL. The chapter discusses the distinguishing features of UDL and the degree to which it meets the challenge of persons with ID.

The fourth chapter returns from theory to practice with the case study of a library book club at the MacArthur Library of Florida Atlantic University (FAU), the only book club for college students with ID in an academic library that we know of. The chapter discusses the origins, development, and discoveries of this club over the three years of its existence. We analyze the data for conclusions and compare them to data for 30 book clubs for individuals with ID in public libraries whom we surveyed. In addition to offering practical recommendations, we also use this information to reflect on theories of special education for which these book clubs offer a new testing ground.

The final chapter moves back to theory to reflect on the implications of this work for the library profession as a whole and to address our original conundrum and related questions. We consider the state of social justice librarianship. To understand it deeper, we go back to the originating disciplines behind this theory such as Cultural Studies and English. Here we take advantage of unique work by Professor Michael Berube, Professor of English with expertise in both Cultural and Disability Studies. A highly distinguished public intellectual, Berube's work spans both the academic and popular realms. We follow him in both areas with readings of his recent work on the representation of disability in literature and his memoirs chronicling the development of his son with Down syndrome, Jamie, over 25 years. Jamie's story allows us to relate theory to lived experience and lived experience to library policies, and we discuss a number of recurrent issues throughout our study. We also suggest that Berube's work from English literature offers new ways for libraries to understand and practice social justice that go beyond various programmatic initiatives. We conclude with answers to our original questions as well as specific recommendations for libraries to offer services to patrons with ID.

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Chapter 1

The History of Libraries and Literacy in the United States

The history of library service to individuals with intellectual disability (ID) is minimal prior to the twenty-first century. Yet, to explore potential services it is necessary to examine this history, especially the development of literacy programming which makes the closest approach to serving patrons with ID. As Wayne Wiegand writes more generally, "That is unfortunate, because without a deeper understanding of the American library's past we cannot adequately assess its present and are thus unable to plan its future prudently" (Wiegand, 1999, p. 2). While some themes in librarianship go back to antiquity, it is convenient to begin our review at the start of the American Republic which, as we will see, provides a continuous and vital context for the library profession in the United States.

The Junto and the Origins of the American Library

An argument can be made for an "Ur-library," the founding library from which the entire profession sprang, in Benjamin Franklin's Library Company of Philadelphia. Founded by one of the architects of the American Revolution, it remains in existence today (Kaser, 1980, p. 13). The circumstances of its founding are relevant. To facilitate the wide-ranging exploration of ideas, which, no doubt, contributed to a new country, Franklin organized a group of like-minded individuals into a discussion group which he called the Junto (Shera, 1965, p. 31). The Junto featured regular discussions of philosophical questions, and to enhance the conversation, they sought for books. Franklin proposed that the members consolidate all of their books together into one location for the convenience of everyone; however, the owners of the scarce commodities did not like to be deprived of them. In response, Franklin, in 1776, formed the Library Company of Philadelphia, the first subscription library. Franklin describes his rationale and the outcome of his idea. "These libraries have improved the general conversation of the Americans, made the common tradesmen and farmers as intelligent as most gentlemen from other countries, and perhaps have contributed in some degree to the stand so generally made throughout the colonies in defense of their privileges" (Franklin, 1997, p. 1372). So successful was this idea that it remains in operation as a living artifact of the Revolutionary Republic.

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What stands out in this story is the clever business model that addresses a public need. For certain, economics has always been a foundation for library services that determines its limits. Less obvious but more central to our discussion is a conceptual tension in the vision of this original library which we will follow as a driving force for the profession, especially as it concerns diversity and individuals with ID. This tension is latent in the concept of "service" which contained two opposite meanings. One sense, associated with "order," "discipline," "standards," and other such meanings, focused on self-improvement. The Library Company, as part of the milieu of the early Republic, helped develop the individual to make him (admission of women was a later development) more knowledgeable, which in turn could make him wealthier, more ethical in the mold of the "Christian gentleman," and a more effective citizen. The second sense of "service" was the opposed concept of "accommodation" for pleasure. As Franklin's ebullient tone signifies in his description of his library, its users derived great enjoyment from the books apart from benefits they received, and Franklin takes evident satisfaction in sharing his own pleasure in books with a wider audience. In sum, one sense of service took an authoritative position by subjecting the individual to order and control, as in the term "military service." (While this may seem foreign to their mission, librarians need only recall the imperial façade of older library buildings and the ongoing phenomenon of library anxiety to recover this authoritarian dimension.) The other sense of "service" provided the individual with recreation and enjoyment. Two opposed concepts of master and servant were encompassed in the original concept of the library. The seam between them was not evident in the original Library Company because they were melded together, as they were in the Junto that inspired it. This brilliant company of young men rejoiced in study and improvement as they contemplated a new nation in which they could exert their will. However, this unified concept of service was not to last.

Types of Libraries

Starting from the colonial period and running into the early years of the Republic until the Civil War, three distinct types of libraries emerged, the social, the subscription, and the circulating libraries.[1] While these have been widely recognized and subject to extensive commentary, they have not been examined through the creative tension in "service" that can unify them together. These types of libraries will be traced up to their eventual absorption into public libraries in the post-Civil War era. The development of academic libraries

[1]Jesse Shera's authoritative history of public libraries recognizes only two types, the social and the circulating. Indeed, these correspond to the only two types of business models. The social library required annual dues from its members, who then had access to the entire collection. Circulating libraries required fees for the borrowing of individual titles. Nevertheless, we offer a finer subdivision of three categories to reflect the social functions of libraries and the spectrum between the extremes self-improvement and recreation that they represented.