

# TEMPLE UNIVERSITY'S INTELLECTUAL DISABILITY COLLECTIONS

COLLABORATION, EDUCATION, AND ENGAGEMENT

*Kathryn Fialkowski*  
*Institute on Disabilities, Temple University College of Education and*  
*Human Development*

*Margery N. Sly*  
*Temple University Libraries*

*Lisa Sonneborn*  
*Institute on Disabilities, Temple University College of Education and*  
*Human Development*

**ABSTRACT:** Framed by the context of the Intellectual Disability Rights Movement of the 1960s and 1970s, this article highlights perspectives of three practitioners at Temple University as they discuss the complexities of building the documentary record of a movement through both the disability rights collections in the Special Collection Research Center and oral histories through the *Visionary Voices* program, creative engagement in history with the public, and using humanistic approaches to education in interdisciplinary programming. Each of the authors discusses the benefits of collaboration and the questions that evolve from centering work on humanistic issues and lived experience.

**KEYWORDS:** disability history, lived experience, oral histories, inclusion, preprofessional education, disability rights

## HISTORIC CONTEXT

In 1941 Joseph and Rose Kennedy's twenty-three-year-old daughter Rosemary Kennedy was lobotomized and subsequently institutionalized for the remainder

---

<https://doi.org/10.5325/pennhistory.89.3.0445>

PENNSYLVANIA HISTORY: A JOURNAL OF MID-ATLANTIC STUDIES, VOL. 89, NO. 3, 2022.

Copyright © 2022 The Pennsylvania Historical Association

of her life. That tragedy could arguably be considered a flashpoint that ignited the intellectual and developmental disability (ID/DD) movement and set off a series of cascading advocacy initiated by the Kennedy siblings. Contributions included the origination of the Special Olympics and the inception of federal policy directives on children and family supports that included new systems and policies to support people with intellectual and developmental disabilities. It was Robert Kennedy Sr, who used the media to give the first glimpse of conditions inside institutions when he deemed Willowbrook on Staten Island, a so-called state school, a “snake pit.”<sup>1</sup> In the wake of the latter, Bill Baldini’s “Suffer the Little Children” exposed conditions at the Pennhurst State School and Hospital<sup>2</sup> and Geraldo Rivera threw open the doors of Willowbrook with his unauthorized footage.<sup>3</sup> These exposés launched an era of family advocacy for better treatment, supports, and services for those with intellectual and developmental disabilities. For example, the Longfellow School in the Bridesburg section of Philadelphia was the seat of a pioneering public classroom for mothers and their children with multiple disabilities who were deemed custodial and ineducable, which proved the efficacy of education for all.<sup>4</sup>

Demonstration projects such as these, along with the collective outcry resulting from the exposés, spawned several class-action court cases in Pennsylvania. These include *PARC v. Commonwealth* and *Halderman v. Pennhurst State School and Hospital* and drastically changed the landscape of ID/DD systems and initiated the beginning of the institutional survivor self-advocacy movement.

As practitioners from various fields at Temple University, the authors have worked collaboratively on topics around disability history in Pennsylvania. We would like to share three perspectives on new ways to gather and use disability history that provide the raw material for illuminating lived experiences, educating, and engaging a variety of audiences, and documenting disability rights history. Collaborations and partnerships among multiple communities have helped us produce a robust, more complete, and valuable record of these stories, and ensure that they are available for use in both traditional academic settings and for public enrichment.

#### **BUILDING THE DOCUMENTARY RECORD**

Gathering the raw material of history, particularly as it documents the stories of the voiceless, is a significant part of Temple University Libraries’ Special

Collections Research Center (SCRC) collecting mission. SCRC's initiative around disability rights history in eastern Pennsylvania has grown exponentially in the last decade as we partner with members of that community to build their documentary record.

This collecting interest is a natural outgrowth of the work of Temple's Urban Archives, which, since its founding in 1967, has documented the urban experience in the greater Philadelphia region from the Civil War to the present as the archives acquires the records of civic, social service, cultural, and other organizations. The many social service and social justice collections in the archives include content that relates to disability and disability rights topics as well as extensive case files, all of which support research in a range of social history topics.

One of the Urban Archives' first collections that directly included disability-related content arrived in 1984: the Public Interest Law Center of Philadelphia's (PILCOP) Valuing Visions of Equality Oral Histories project. The collection contains interviews conducted as part of the production of the 1984 videotape *Visions of Equality* for PILCOP's tenth-anniversary symposium. It covered the Philadelphia area and addressed issues around educational equality, labor, the disabled, senior citizens, African Americans and Hispanics, women, the environment, and public housing.

In 2009 PILCOP entered into an agreement with the Urban Archives to begin placing some of its legal records there. The first donation, which consisted of over 100 boxes, included a considerable amount of legal and court material around the PARC and Halderman litigations, and subsequent related cases argued before the Pennsylvania Eastern District Court, Third Circuit Court of Appeals, and the Supreme Court of Pennsylvania during the 1970s–90s (other subjects cover such topics as police brutality in Philadelphia.). Most of these materials are the working documents and case files of lead attorney Thomas K. Gilhool (1938–2020) and his colleagues who steadfastly pursued the cases through the courts. Gilhool was chief counsel at the Law Center for twenty-five years.

PILCOP also facilitated the donation of Judge Raymond Broderick's (1914–2000) Pennhurst case files, described by his son as "Judge Broderick's Pennhurst Litigation Resources." The collection includes court documents, correspondence, notes, clippings, and working files documenting the judge's work on *Haldeman v. Pennhurst*. As Broderick was the judge who ultimately ruled to close Pennhurst State School and Hospital (1987), his personal files and perspective are invaluable to researchers.

However, it was not until the Institute on Disabilities (IOD) in the College of Education and Human Development at Temple University approached SCRC in 2011 to work in partnership on archives and other history projects—a natural fit—that rich content truly began to arrive. The working relationship calls for IOD staff to identify and introduce SCRC to the potential donors, and SCRC acquires, processes, and makes the collections accessible for use. In contrast to past collecting practices, these also more regularly include the papers of individuals (not only the records of organizations), including attorney and parent-advocate Dennis Haggerty, parent-advocates Audrey (Dee) Coccia, Eleanor Elkin, and Leona Fialkowski, and civil rights attorney and educator Thomas Gilhool.

The Dennis Haggerty Papers are perhaps the richest of these collections. To quote from the finding aid:

As an attorney in Philadelphia, Pennsylvania, Haggerty helped secure individuals' rights in education, protection, and advocacy through litigation, education, and involvement with numerous local and national advocacy organizations. He worked alongside and in organizations such as the Pennsylvania Association for Retarded Children (now The Arc of Pennsylvania), the National Center for Law and the Handicapped, and the American Bar Association. Haggerty participated in landmark cases such as the Right to Education Case, serving as Special Master overseeing the implementation of the *PARC* consent decree, and *Halderman, et. al. v. Pennhurst State School and Hospital*. He also provided his knowledge of the law and intellectual disabilities to numerous organizations such as Research for Better Schools, the President's Committee on Mental Retardation (now President's Committee for People with Intellectual Disabilities), and the National Advisory Council on the Definition of Developmental Disabilities.<sup>5</sup>

Documentation of Thomas Gilhool's work is most concentrated in the files he created while working for PILCOP and as Pennsylvania secretary of education. His personal papers, not yet cataloged for research use, reflect only a snapshot of his pathbreaking work in disability rights and education.

Leona Fialkowski's papers are accessible for research use and contain robust content about her work as a parent advocate responsible for the first public classroom in Philadelphia for children with intellectual and physical disabilities, proving the efficacy of education for all before it was legislated.<sup>6</sup>

Elkins's and Coccia's papers, not yet organized, are less complete, reflecting a truth about advocates and activists: Activists are often so busy "doing" that they don't always generate papers with enough substance to make up an archives collection with deep research value.

The Institute on Disability's initiatives include *Visionary Voices* and *Here*, which flesh out the stories often not particularly well represented in archives collections. *Visionary Voices* is an in-depth oral history project containing interviews with many of these leaders of the disability rights movement, as well as their children, self-advocates, and community members. *Here* includes the stories of individuals who lived and worked at Selinsgrove Center and at KenCrest Services, a sheltered workshop.

Undergraduates, graduate students, and scholars have used these collections to research a variety of issues in the movement and to learn how primary sources can make their work richer and more real to their readers. SCRC staff, in organizing and describing them, and working with the creators and their families to ensure accurate cataloging, have become more sensitive to appropriate descriptive language. They have created a "Statement on Potentially Harmful Language in Archival Description and Cataloging."<sup>7</sup> The Library of Congress's standard subject headings do not change quickly enough to follow current language and concepts, and, in the case of disability, topics. These terms date from the 1960s. We were able to capture and differentiate between historical terminology and current description. SCRC's statement has been studied and adapted by other archives to inform their work on disability history collections as well as those of other under-represented and marginalized communities. SCRC is grateful for these varied partnerships and collaborations which enhance our work and ensure a much richer history of disability and disability rights in Pennsylvania.

#### CENTERING EDUCATION AND ENGAGEMENT ON LIVED EXPERIENCE

Between 1908, when the first patient entered Pennhurst State School and Hospital, through the year 2000 reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), there occurred a period of immense social and political change for persons with intellectual and developmental disabilities in the United States.<sup>8</sup> Perhaps most important was the transition from institutionalization to deinstitutionalization, and meaningful inclusion of individuals with intellectual and

developmental disabilities in public life. This movement includes President John F. Kennedy's disability policy directives as the backdrop to the inception of University Centers for Excellence in Developmental Disabilities (UCEDDs).<sup>9</sup> Since 1963, sixty-seven UCEDDs emerged throughout the United States and territories. By federal statute, the UCEDDs have several required functions: research, information dissemination to the public, service to the community, and pre-service instructional programming. The Institute on Disabilities (IOD) at Temple University College of Education and Human Development is one of these sixty-seven UCEDDs and serves the entire state of Pennsylvania.

By virtue of federal policy, pioneering advocacy, and landmark court cases in Pennsylvania, the work of the IOD has been and is directed by individuals with intellectual and developmental disabilities and/or their families. From our community advisory councils, through to staff employment in the IOD and collaboration and participation in specific initiatives, the voices and experiences of individuals with disabilities and their families are central to the way the IOD develops programming and influences collections, engagement, and education.

The remainder of this article will discuss two programs at the IOD: Media Arts and Culture (MAC) and Pre-Service Instructional Programming.

#### CREATIVE ENGAGEMENT WITH DISABILITY HISTORY

For nearly a decade, the IOD has used arts-based methodologies to engage people with and without disabilities in the persistent issues encountered by people with intellectual and developmental disabilities and their families. Our work in Media Arts and Culture (MAC) is boundary crossing, spanning oral history, performance, multimedia installation, and community-led archival exploration.<sup>10</sup> Each project (and the medium) is driven by questions ideated with the intellectual disability community and each question necessitates its own creative response. The IOD and the advocates, artists, historians, and technicians with whom we partner challenge their own practices to discover what is possible when people with and without intellectual disabilities meaningfully collaborate. The IOD and its partners acknowledge and routinely grapple with the complications of creating public-facing, artistically excellent work when the artmaking process itself feels equally, if not more important, than the public encounter.

Foundational to all MAC projects is our commitment to offering experiences that are meaningful and inclusive of all participants, including those who do not communicate traditionally. Two projects in particular, *Visionary Voices* and *A Fierce Kind of Love*, provided the IOD with opportunities to consider how art can be used to break down points of impasse, redefine organizational values, and serve as an intervention for both the IOD and the community we serve.

*Visionary Voices: Leaders, Lessons, Legacy*

In 2011 the IOD realized the stories of Pennsylvania's Intellectual Disability Rights Movement were being lost with the passage of time. With initial support from the Pennsylvania Office Developmental Programs (ODP) the IOD created the *Visionary Voices: Leaders, Lessons, Legacy* project.<sup>11</sup>

Key decisions, including recording formats and interview candidates, were made in partnership with an advisory group of people with disabilities, professionals, and family members. The collective goal was to preserve first-person accounts of the movement through oral history interviews with its leaders. The advisory group supported the IOD's project planning and helped generate an initial list of over 200 interview candidates. The IOD narrowed the list to 30 individuals whose stories would collectively lend insight into the movement. We considered our choices by the age and health of interview candidates; the elderly or those in poor health had priority. Additionally, the project sought to interview those who had donated their personal papers to Temple University Libraries, in the hopes that those first-person accounts would lend depth to the library's holdings (e.g., Dennis Haggerty, Eleanor Elkin). We video-recorded the *Visionary Voices* interviews, creating generative content that served as source material for three IOD-produced documentary shorts: *Visionary Voices: Visionary Voices: Philadelphia's Journey*; and *From Wrongs to Rights*.

*Visionary Voices* comprises over thirty interviews and was made publicly available on the IOD's website in Spring 2012. Almost immediately, students, scholars, advocates, and young professionals in the field embraced the collection as a teaching tool. Despite their resonance in the disability community, the collected interviews did not engage people outside of it. The IOD began to imagine how we might share these stories with a wider audience, creating opportunities for in-person dialogue, learning, and attitudinal shifts. A project grant from the Pew Center for Arts & Heritage made it possible for us to try something new: a live performance devised with and performed by artists with and without disabilities.

*A Fierce Kind of Love*

In 2012 the IOD commissioned and produced *A Fierce Kind of Love*, a play that told the story of Pennsylvania's Intellectual Disability Rights Movement.<sup>12</sup> Our intention was to use the efficacy of theater and storytelling to elevate this "hidden history" and inform and activate dialogue about current intellectual disabilities rights issues. The IOD developed the play, which was written by playwright Suli Holum and directed by David Bradley, over a four-year period with a cast of nine actors with and without intellectual disabilities. Together, we learned what it meant to tell a story that is both historical and emergent. The idea that people with intellectual disabilities could and should talk back to traditional written accounts of their community's history became an anchor for the play and for future MAC projects.

*A Fierce Kind of Love* premiered at Christ Church Neighborhood House in Philadelphia, in 2016, where it enjoyed a two-week run. There were additional runs in 2016, 2017 and 2019, with a final performance at the FringeArts High Pressure Water Service Festival. An evaluation conducted by Animating Democracy (a program of Americans for the Arts) found that, as an artistic experience, *A Fierce Kind of Love* had a powerful effect on audiences. Many people commented that the play's artistry caused them both painful and joyous moments that lent meaning and understanding to the experience of living with intellectual disability. Playwright Suli Holum suggested the reason the play had this effect "is because the performance itself is a moment in the intellectual disabilities' life history. . . . It pushes the Movement forward toward justice and inclusion."

Although the values of justice and inclusion have always been a central to the IOD's mission, putting those values into action for a public performance required us to expand our thinking and practice around accessibility. To that end, each performance of *A Fierce Kind of Love* featured embedded ASL interpretation, audio description, and assistive listening devices (ALDs). There was plentiful accessible seating, and relaxed seating areas designated for the theater space as well as the lobby, where a livestream of the play meant that those who needed a break from the performance could continue to watch from the comfort of a quiet space. Additional offerings included large-print and Braille programs, performance and venue guides, and a "Know Before You Go" fact sheet, all available at the theater and through the production's ticketing website. Recognizing that people with disabilities experience poverty on a disproportionate scale, tickets were made available on a "pay what you can" model. A message on the ticketing site—"Your Presence Is Your Gift"—made it clear



that all were welcome regardless of ability to pay. This approach to audience engagement created a culture of “yes” that had immediate and dramatic results. Significantly, the play was the first theater experience for many audience members with disabilities, a reflection of what is possible when cultural spaces are equipped to welcome those who are not neurotypical.

While *A Fierce Kind of Love* is a play, it could equally be described as an “event” that engaged audiences on multiple levels. At each performance venue, the producers utilized the lobby space to set the tone for the play’s content by highlighting significant moments in the Intellectual Disabilities Rights Movement. Upon entering the performance space, patrons were greeted by cast members, who thanked them for attending and engaged them in conversation. Cast members also participated in post-performance discussions or ‘talk backs’ with the audience, creating what an audience member described as a “sense of camaraderie with strangers after the play.”

Audience surveys indicated that more than half (65%) of all respondents said the play helped them understand something new about disability. All respondents (100%) “agreed” or “agreed strongly” that the artistic presentation helped them tune into issues of intellectual disabilities in a new way and 89 percent of all respondents “agreed” or “agreed strongly” that they saw people with intellectual disabilities in a new way. People became more aware of and sensitized to the meaning, usage, and policies surrounding terms related to disabilities. Audience members discussed and defined the term “disabled” in sharing their reactions during post-performance dialogues and lobby interactions. Post-performance dialogue gave audience members the opportunity to more deeply consider the relationship between the outdated terminology used to describe disability and the stigma still experienced by people with disabilities today.

#### RELATED COMMUNITY ENGAGEMENT

*A Fierce Kind of Love* created a space for validation and self-expression that was vitally important to audience members with disabilities. But the IOD also wanted to create opportunities for the entire audience to connect the history that was the focal point of the play with the present-day lived experience of disability. Performances of *A Fierce Kind of Love* were supported by several activities that invited the community to take a deeper dive into the experience of disability. Projects designed to engage the community in dialogue

and advocacy included: a story slam for siblings of people with disabilities (SibSlam), an academic symposium, and an acting workshop.

The most ambitious of these offerings was *Here. Stories from the Selinsgrove Center and KenCrest Services*. Developed concurrently with *A Fierce Kind of Love*, *Here.* brought eighteen community members together with nineteen individuals with intellectual and developmental disabilities who lived and/or worked in segregated settings. Participants were invited to meet people they would likely have not otherwise encountered, get to know a little about their lives, take photographs, and record interviews. In 2015 the State Capitol Building in Harrisburg and City Hall in Philadelphia exhibited and played interview excerpts and large-scale images of participants.

The images and stories in the *Here.* exhibition evoked emotional responses from visitors. One Capitol Building employee, so moved by one of the narrator's stories about flags, returned the next day to provide a small flag as a gift to thank that narrator for sharing his story. He remarked, "I will not forget him, and I wanted him to know that." For some visitors the emotional impact of the connections created by the narrator's stories was unexpected. A few expressed that they were uncomfortable and/or not sure what to make of what they saw and needed some time to process the message. The *Here.* exhibition revealed some of the complexities of self-expression and representation of people with intellectual disabilities. Our external evaluation concluded that the process of collecting stories for this project supported the narrators' voice, especially the shift made for people with nontraditional communication from the traditional oral history interview to more informal conversation.

As a whole, the ancillary activities to *A Fierce Kind of Love* provided opportunities for empowerment and learning for members of the creative team, cast members, participants, and audiences alike. The work touched and connected individuals beyond the intellectual disability community. Survey comments included: "I am disabled and proud." "This is my story!" "Encouraged," and "privileged to be part of the community."

As the IOD continues its work in Media Arts and Culture, and particularly those projects that seek to explore the history of our community, we invite the question "who is this work for?" We can only answer this question by listening to people with disabilities and their family members and committing to meaningful co-collaboration. Our work begins with processes that can be complicated, even uncomfortable. This provocation exists hand in hand with the joy of artmaking and those transformative moments when we

“convince someone else to get uncomfortable with us.”<sup>13</sup> That is where we discover—and allow ourselves to be changed by—the unexpected.

**ILLUMINATING THE HUMAN EXPERIENCE IN PRESERVICE AND PUBLIC INSTRUCTIONAL PROGRAMMING**

With financial support from the Administration on Community Living, the IOD’s preservice and public instructional programming emphasizes the lived experiences of people with disabilities and family members and, through a humanistic lens, uses education and reflections on history to help us interrogate and advance scholarship, policy, and practice.

The topic of disability history is slippery, cautionary, and potentially traumatizing. It is both about man’s humanity (as disability is a natural part of the human experience) and about man’s inhumanity to man.<sup>14</sup> The Aktion T4 program, for example—a Nazi program that deliberately targeted genocide of individuals with disabilities—was a rehearsal for more expansive genocidal policies to come.<sup>15</sup>

In teaching disability history, we teach historical accuracy, including key dates, turning-point events, and leaders and pioneers. As a movement we explore the full cultural context. When we teach, we ask ourselves: how should we frame the truth of disability history, including intellectual and developmental disabilities, without traumatizing and stigmatizing or without engendering inspirational tropes of disability?<sup>16</sup>

The IOD’s obligation as a UCEDD centers our work on full and meaningful inclusion and participation. If we acknowledge that contemporary educational settings are inclusive of individuals with disabilities, then we need to understand that history speaks directly to and even about individuals experiencing disability in the present or possibly in the future. As we engage with the past, we have an obligation of care for the subject as we expose it, as well as the audience to whom it is exposed. Framing is critical, more so when the topics are unstable.

“Disability” and “history” are commonly used broad-stroke words with amorphous definitions. Disability can be, for example, individually and collectively visible/invisible, physical/cognitive, temporary/permanent, static/fluid. While disability may be self-identified (which may or may not include overt public disclosure), it is also defined by diagnostics, sociocultural environments, and institutions, as well as government regulations and policies.

When we interrogate “history,” are we merely speaking of the past? The past human events? The past human events cultivated and fabricated, derived and constructed from records and archives?<sup>17</sup> Who are we including and how are we including them in this “human” past? The answer is seemingly self-evident, but when we speak of disability it is not. The label of “disability” has been an argument for demoting one’s human status and those with cognitive disabilities have been categorized through various schema through time including categories of subhuman status.<sup>18</sup> Still true today, some contemporary philosophers posit that, based on intellect, certain individuals do not warrant the moral status of personhood.<sup>19</sup> When we teach disability history—to who and to what are we referring? How do we address these complex issues of inclusion/exclusion?

### *Reflecting on Equity: Questions We Considered*

In response to the question of “to whom/what are we referring,” the IOD strives to be deliberate in the way we commemorate the lived experience of real persons with disabilities and their families.

In planning our annual Disability and Change symposia, we work collaboratively with other disciplines and use our Interdisciplinary Faculty Council on Disabilities as well as a student advisory council as a sounding board for interdisciplinary and intersectional discussions. In order to attend to equity, during the planning of our 2022 Disability and Change Symposium we asked the following questions of ourselves, which also helped to frame the content:

- *What disability data is missing?*<sup>20</sup> All collections reflect the perceptions of the creator and are incomplete. There is always potential for the records we reference about disability to be inaccurate or incomplete. We had a significant conversation, for example, about how stigmatization can affect individual disclosure/nondisclosure and subsequently effect representation and data accuracy.<sup>21</sup> Users need to be discriminating and use primary source literacy techniques to evaluate the records.
- *When recommending resources, do we ensure diverse and accurate representation including individuals with lived experiences?* In our educational programming, we have to intentionally seek diversity in speakers, references, and content. We scour oral histories and other sources as well as traditional archives in order to achieve adequate representation. For example, when we include famous personages (e.g., Kennedy, Baldini, and Rivera) do we also ensure inclusion of the advocates with lived experiences

(e.g., Roland Johnson, Audrey [Dee] Coccia, Debbie Robinson, and Eleanor Elkin)?

- *How should the audience affect our framing? Are we teaching in a culturally competent manner?*<sup>22</sup> Scholars and professionals are now inclusive of persons with the lived experience of disability. Persons with disabilities are equals in the room, not just in the files.
- *When recounting histories that may traumatize, how do we leave room for students or audience members to self-regulate leaning into or out of a conversation that may be traumatizing or they feel demands redress?* One example we've used is introducing materials with trigger warnings such as "this is a space for critical and civil dialog. Some content in this session will include topics that you may find offensive and/or traumatizing." We encourage audience members to attend to their emotional needs during the conversation.

It is the present that interrogates the past. Our preservice graduate students represent multiple disciplines as diverse as fine arts, school psychology, public policy, and social work. We host preservice seminars for graduate assistants who work at the IOD. The Fall seminars are anchored in history, policy, and culture and move forward to present day and include, for example, the history of employment for persons with disabilities, the history of the intellectual disability movement. In the seminars we teach disability history as a collective history, our history. History discussions leads us to purposeful philosophical conversations such as wrestling the personal definition of disability into a definition that can be included in policy, or the role of intellectual capacity and consent, whether it be sexual or contractual. More recently, in our preservice seminars, students have wanted to explore the nature of systemic ableism in segregated settings. For example: whether, when, or if work requirements are a duty or a privilege? When is work exploitation or peonage?

One of the most challenging and robust conversations in our classroom continues to be about the use of language. The use of the "R" word has been eliminated through a federal statute for its derogatory nature, yet it appears throughout artifacts such as newspaper articles, private notes, and policy documents.<sup>23</sup> How should this word, and others with a similar history, be navigated in the materials we selected, in discussions, and in the student reflections? This is a question similarly asked in the SCRC Statement on Potentially Harmful Language.<sup>24</sup> It is a question all of us need to address in all our collection, education, and enrichment activities.

## ENGAGE WITH US

There are several ways in which readers can engage with the Temple University materials mentioned in this article: (1) Book an appointment with the SCRC to learn how to access and explore the disability rights collections. In addition, the SCRC is always interested in introductions to individuals and institutions that might have robust archives that add to the documentary record. (2) Refer to the *Visionary Voices* materials, including both video and transcripts. These materials include, for example, voices of self-advocates, family members, legal counsel, and policy administrators. They provide a wealth of perspectives from throughout Pennsylvania. (3) Make use of the online learning module for the 2022 Disability and Change Symposium, “Disability and Justice: The Evolution and the Revolution.”<sup>25</sup> The learning module will be available at the time of this publication. It is free and open to the public, accessible, and can be used within educational programming for high school and college.

KATHRYN L. FIALKOWSKI is the Associate Director of Academic Programs at the Institute on Disabilities and Disability Studies Coordinator and adjunct at Temple University College of Education and Human Development. Fialkowski is an EdD candidate with a research interest in disability narratives. She is a sibling advocate as the Fialkowski family were pioneers in the Pennsylvania ID/DD movement. They were active in establishing the right to education, the urban model demonstration project, community living for individuals with multiple and complex disabilities, and supported (nonsheltered) employment.

MARGERY N. SLY is director of the Special Collections Research Center at Temple University Libraries. A certified archivist and Fellow of the Society of American Archivists, Sly holds a BA in history and German literature from Dickinson College and an MA in history and an MS in library science with an archives administration emphasis from Case Western Reserve University. For over thirty years, she has worked to build research collections that tell the stories of the underrepresented.

LISA SONNEBORN is the Media Arts and Culture Director at the Institute on Disabilities, Temple University College of Education and Human Development. Sonneborn develops and directs arts initiatives within the

Institute, which feature innovative, fully accessible cultural programming. Her work produced for the Institute and its partners includes *A Fierce Kind of Love, Here.*, and *Visionary Voices*. For more than twenty-five years, Sonneborn has produced media that is focused on issues meaningful to the disability community. She earned her BA in art history from Arcadia University, and her MFA in film and media arts from Temple University.

## NOTES

1. US National Park Service, "Rosemary Kennedy, The Eldest Kennedy Daughter," accessed January 6, 2022, <https://www.nps.gov/articles/000/rosemary-kennedy-the-eldest-kennedy-daughter.htm>; Special Olympics, "1968 Games," accessed January 6, 2022, <https://www.specialolympics.org/about/history/1968-games?locale=en>; John F. Kennedy Presidential Library and Museum, "John F. Kennedy and People with Intellectual Disabilities," accessed January 7, 2022, <https://www.jfklibrary.org/learn/about-jfk/jfk-in-history/john-f-kennedy-and-people-with-intellectual-disabilities>; Minnesota Developmental Disabilities Council, "Robert Kennedy Visiting Institutions in NY," *Parallels in Time: A History of Developmental Disabilities*, accessed January 6, 2022, <https://mn.gov/mnddc/parallels/five/5b/bobby-kennedy-snakepits.html>.
2. Temple University and College of Education and Human Development (hereafter CEHD), "Visionary Voices: Bill Baldini," *Temple Institute on Disabilities*, accessed January 6, 2022, <https://disabilities.temple.edu/voices/interviews/baldini>.
3. John J. O'Connor, "TV: Willowbrook State School, 'the Big Town's Leper Colony,'" *New York Times*, February 2, 1972, accessed January 6, 2022, <https://www.nytimes.com/1972/02/02/archives/tv-willowbrook-state-school-the-big-towns-leper-colony.html>.
4. Leona Fialkowski Papers, SCRC 243, Special Collections Research Center (hereafter SCRC), Temple University, accessed January 6, 2022, [https://library.temple.edu/finding\\_aids/leona-fialkowski-papers](https://library.temple.edu/finding_aids/leona-fialkowski-papers).
5. Dennis E. Haggerty Papers, SCRC, accessed January 6, 2022, [https://library.temple.edu/finding\\_aids/dennis-e-haggerty-papers](https://library.temple.edu/finding_aids/dennis-e-haggerty-papers).
6. Fialkowski Papers.
7. SCRC, "SCRC Statement on Potentially Harmful Language," *Temple University Libraries*, accessed January 6, 2022, <https://library.temple.edu/policies/scrc-statement-on-potentially-harmful-language-in-archival-description-and-cataloging>.
8. "Pennhurst Timeline," *Pennhurst Memorial and Preservation Alliance*, accessed January 6, 2022, <http://www.preservepennhurst.org/default.aspx?pg=93>;

- “History of the DD Act,” *Administration on Community Living*, accessed January 6, 2022, <https://acl.gov/about-acl/history-dd-act>.
9. Laura Walker Jackson, Kellie Ellerbusch, and Sarah Swanson, “History of the UCEDD Module I 2,” 2015, <https://www.unmc.edu/mmi/center-grants/ucedd/UCEDDHistory.pdf>.
  10. Funding for MAC projects: Major support for *Visionary Voices: Leaders, Lessons and Legacy* was provided by the Pennsylvania Office of Developmental Programs. Additional support provided by the Philadelphia Office of Intellectual and Disability Services; Chester County Department of Mental Health /Intellectual and Developmental Disabilities; and generous support from private donors. *From Wrongs to Rights*, commissioned by the United Way of Allegheny County, Southwestern Pennsylvania. *Visionary Voices: Philadelphia’s Journey*, commissioned by the Philadelphia Office of Intellectual Disability Services. Major support for *A Fierce Kind of Love* was provided by the Pew Center for Arts and Heritage, with additional support from the Virginia Brown Martin Fund, Ken Klaus, the Wyncote Foundation, and generous support from private donors.
  11. CEHD, “Visionary Voices Interviews,” *Temple Institute on Disabilities*, accessed January 6, 2022, <https://disabilities.temple.edu/voices/interviews>.
  12. CEHD, “Media Arts and Culture,” *Temple Institute on Disabilities*, accessed January 6, 2022, <https://disabilities.temple.edu/advocacy/media-arts-culture>.
  13. Ronnee Penoi, “The Creative Producer (noun): A Definition,” *HowlRound Theatre Commons*, accessed January 18, 2016, <https://howlround.com/creative-producer-noun>.
  14. Sara Newell-Perez, “DD Councils and P&As: Trailblazers for Inclusion,” *Administration on Community Living*, accessed January 6, 2022, <https://acl.gov/news-and-events/acl-blog/dd-councils-and-pas-trailblazers-inclusion>.
  15. United States Holocaust Museum, “Euthanasia Program and Aktion T4,” *Holocaust Encyclopedia*, accessed January 6, 2022, <https://encyclopedia.ushmm.org/content/en/article/euthanasia-program>.
  16. Tropes, for example, where the ordinary is deemed extraordinary or stories that rest on a non-disabled savior?
  17. Keith Jenkins, *On “What Is History?”: From Carr and Elton to Rorty and White* (New York: Routledge, 1995).
  18. Gerald O’Brien, *Framing the Moron: The Social Construction of Feeble-Mindedness in the American Eugenic Era* (Manchester: Manchester University Press, 2013).
  19. Peter Singer, “Speciesism and Moral Status,” *Metaphilosophy* 30, nos. 3/4 (2009): 567–81.
  20. Mitchell Loeb, “Disability Statistics: An Integral but Missing (and Misunderstood) Component of Development Work,” *Nordic Journal of Human Rights* 31, no. 3 (2013): 306–24.



21. Brianna Blaser and Richard E Ladner, "Why Is Data on Disability So Hard to Collect and Understand?," University of Washington, 2020, accessed January 6, 2022, [https://www.washington.edu/doi/sites/default/files/atoms/files/RESPECT\\_2020\\_DisabilityData.pdf](https://www.washington.edu/doi/sites/default/files/atoms/files/RESPECT_2020_DisabilityData.pdf).
22. Cheryl Irish and Monica Scrubb, "Five Competencies for Culturally Competent Teaching and Learning," *Faculty Focus*, November 12, 2012, accessed January 6, 2022, <https://www.facultyfocus.com/articles/teaching-and-learning/five-competencies-for-culturally-competent-teaching-and-learning/>.
23. 111th Congress, "Public Law 111-256," Pub. L. No. 2643 (2010), <https://www.congress.gov/111/plaws/publ256/PLAW-111publ256.pdf>.
24. SCRC, "SCRC Statement on Potentially Harmful Language."
25. CEHD, "Disability Studies at the Institute on Disabilities," *Temple Institute on Disabilities*, accessed May 6, 2022, <https://disabilities.temple.edu/ds/symposium2022>.