

TRENDS IN
ARCHIVES
PRACTICE

MODULE 6

**BALANCING
ACCESS AND
PRIVACY IN THE
RECORDS OF
ORGANIZATIONS**

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Appendix B: Case Study—Developing an Access Policy for a Rehabilitation Student Case File

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In 1948 the University of Illinois at Urbana-Champaign (UIUC) became the first postsecondary institution in the world to develop a comprehensive program and set of services for students with disabilities. Founded by Dr. Timothy Nugent, the University's Division of Disability Resources and Educational Services (DRES) initially focused its efforts on removing physical barriers to campus buildings. Nugent believed that education was crucial to helping people with disabilities become productive, engaged members of society and that, if given the opportunity, they could succeed academically. Through the years, DRES engaged in research programs designed to make the world more accessible to people with disabilities. Many legislative actions that affect employment, housing, and public building access and equal rights for people with disabilities grew from activities launched at the University of Illinois. Innovations associated with DRES include the first wheelchair-accessible fixed-route bus system; the first postsecondary institution to introduce curb cuts; and the first national wheelchair sports program.

In 2007 and 2008, the Timothy Nugent Papers and official records from the Division of Rehabilitation-Education Services at the University of Illinois were transferred to the custody of the University Archives.⁸¹ We arranged and described more than 110 cubic feet of records documenting the structure and services provided by the core administrative leaders of DRES. Although the 66 cubic feet of official DRES student records (1943–2005), including correspondence, medical histories, registration forms, and academic records were part of the noncurrent records surveyed, these records were not transferred until 2012, due to privacy issues.

The initial step in creating an access policy for DRES student records was to consult DRES administrators. Before the first meeting,

⁸¹ The unit was initially known as the Division of Rehabilitation-Education Services but kept the DRES acronym when it was renamed Disability Resources and Educational Services.

University Archives staff reviewed FERPA.⁸² While FERPA does not apply to deceased students, it is unclear if it applies to pre-1974 records. However, the UIUC Student Records Policy (Campus Administration Manual, X-6), retroactively applies FERPA to records of all living students.⁸³ DRES administrators wanted to ensure that researchers would not be allowed to directly contact students but that such requests be routed through DRES; they also suggested placing an embargo on the use of more recent records. DRES also reminded the Archives to consider relevant state laws, such as the Illinois Mental Health and Developmental Disabilities Confidentiality Act.⁸⁴ Mindful of current institutional policies and federal and state legislation, we communicated our plan: to draft an approach that would safeguard the privacy of students while making these holdings available for research to the greatest possible extent, within a controlled setting.

As indicated above, the University already has a well-documented student record access policy.⁸⁵ For research involving living subjects, researchers seeking access to archival student records must have their request approved by both the University Archivist and University Registrar and must seek Institutional Review Board approval from their home institution; if IRB consent is granted, users of the archives are permanently prohibited from releasing any personally identifiable information without the written permission of the student. Failure of researchers to comply with the conditions of the student record access policy will lead to revoked research privileges and possible legal prosecution.

Given the effectiveness of this general student record policy, many of the same conditions of access were incorporated in the DRES student record policy. All researchers must complete a user application form. Researchers must also indicate safeguards (administrative, technical, and physical) they will use to prevent unauthorized use or

82 20 U.S.C. 20 U.S.C. § 1232g; 34 CFR Part 99; and Tamar G. Chute and Ellen D. Swain, "Navigating Ambiguous Waters: Providing Access to Student Records in the University Archives," *American Archivist* 67 (Fall/Winter 2004): 212–233.

83 University of Illinois at Urbana-Champaign, "Guidelines and Regulations for Implementation of the Family Educational Rights and Privacy Act of 1974," *Campus Administrative Manual*, May 28, 1996, <http://cam.illinois.edu/x/x-6.htm>.

84 Illinois Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110/), <http://www.ilga.gov/legislation/ilcs/ilcs3.asp?ActID=2043&ChapterID=57>.

85 University of Illinois at Urbana-Champaign, "Guidelines."

disclosure of records. They must obtain written permission for the research project from the University Archivist and the Director of DRES. In all instances, researchers are permanently prohibited from releasing any personal information without the written permission of any living student. Conditions of access, specified for each request from a set list, must also be met; this includes anonymizing any personally identifiable information at the earliest possible time in the research project and destroying all notes/copies with any personally identifiable information. While seven possible conditions of access are enumerated, additional conditions may be imposed where appropriate. By including this clause, we sought to create a policy restrictive yet flexible enough to create opportunities for meaningful research.

Our access policy was also informed by the National Library of Medicine's History of Medicine Division (HMD)'s approach to HIPAA.⁸⁶ Because the University has elected to self-designate as a hybrid entity and DRES is not included in their list of recognized health care components, HIPAA is not applicable to these records.⁸⁷ However, following HMD's example, we restricted these student records containing medical information to protect individuals' privacy. Our final step was to share the draft of our access policy with University Legal Counsel and DRES to ensure the policy met with their approval.⁸⁸

Following Tamar G. Chute and Ellen D. Swain, we strongly believe that "researchers should be able to use student records even if still under FERPA regulations for any *organizational or historical study* as long as they follow procedures to destroy all personal identifying information."⁸⁹ These records are the crucial resource for understanding both individual and collective experiences of DRES students. The fundamental mission of DRES is to ensure that students with disabilities are afforded an equal opportunity to participate and benefit from the University's programs, services, and activities. The University

86 National Institutes of Health, National Library of Medicine's History of Medicine Division (HMD), "Access to Health Information of Individuals," last revised May 10, 2004, <https://www.nlm.nih.gov/hmd/manuscripts/phi.pdf>. See also Pub. L. No. 104-191, 110 Stat. 1936 (1996).

87 University of Illinois Board of Trustees, "HIPAA Privacy & Security Compliance Policy," November 14, 2013, <http://www.trustees.uillinois.edu/trustees/agenda/November-14-2013/018-nov-HIPAA-Privacy-Security-Compliance-Policy.pdf>.

88 A copy of the access policy is available upon request from the University of Illinois Archives.

89 Chute and Swain, "Navigating Ambiguous Waters," 230.

Archives' efforts to describe and enhance access to DRES student records underscore our commitment to creating opportunities for enduring discovery and research of these high-achieving but under-recognized students.