EXPLORE THE EVERYDAY LIFE INFORMATION NEEDS, PRACTICES, AND CHALLENGES OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES

Dana Hanson-Baldauf Ph.D. Candidate
School of Information and Library Science, University of North Carolina at Chapel Hill

BACKGROUND
This dissertation research identifies and addresses a gap in the information and library science literature regarding understanding and meeting the information needs of young adults with intellectual disabilities (ID). Recent studies reveal significant challenges encountered by young adults with ID as they transition into adulthood. As young adults with ID experience challenges in accessing and using information, a lack of relevant resources and services may contribute to inability to participate in society. To help fill this gap, this study explores the everyday life information needs, practices, and challenges of young adults with ID.

RESEARCH QUESTIONS
1. What are the everyday life information needs of young adults with intellectual disabilities?
2. What are the everyday life information practices of young adults with intellectual disabilities? What tools/resources/strategies do young adults use to address their everyday life information needs?
3. What challenges do young adults with intellectual disabilities encounter in their attempt to address an information need?

LANDSCAPE OF CHALLENGES FOR INDIVIDUALS WITH ID
• Increased high school dropout rate
• High unemployment rate
• Greater risk for physical and sexual abuse and neglect
• Weak social/support networks
• High occurrence of loneliness and depression
• Poor health and limited access to health care/services
• Limited opportunities for personal control
• Limited accessible transportation options
• Lack of affordable housing
• Civility/communication exclusion
• Discrimination, stigmatization, and denial of rights
• Denial of and/or limited access to information services


RESEARCH DESIGN
Method: Case studies
Sample: 4 young adults with intellectual disabilities
Data Collection: (1) Semi-structured formal and informal interviews integrating participant photography, computer use, artwork, and community leisure outings; (2) observations; and (3) document & product analysis.

GUIDING PRINCIPLES
• Disability ≠ impairment + society’s response to the impairment;
• Disability does not define the individual nor his/her life experiences.
• The individual is an expert on his/her own life, and as such, his/her voice has value and must be an integral part of the research process.

STUDY PROTOCOL

Participant Recruitment & Identification
Recruitment: Young local school district and Special Olympics organization
Identification: Criteria needed age, informed willingness, and communication ability

Introduction Meeting
Purpose: To share study details, explain participant commitment, and compensation for time
To obtain informed consent
To obtain permission for access to formal and informal documents
Support building

Document Retrieval
Type: Formal documents (IDP and Person-Centered Plan)
Informal documents (calendars, homework, computer transaction logs)

Semi-structured Interviews
Interviewees: Primary research participant
Parent/Care Provider
Teacher
Data collection methods: Recording device, hand notes, participant product
Participants were provided digital cameras to document instances of everyday life and information practices

Observations & Informal Interviews
Data collection methods: Field notes, recording device, participant observation, and computer-generated products

Follow-up Interviews
Interviewees: Primary research participant
Parent/Care Provider
Special education teacher, employer, and/or care manager
Data collection methods: Recording device and hand notes
Downloading additional photos from participant cameras

Data Analyses

Follow-up Interviews and Member Check
Interviewers: Primary researcher and备案 participant
Interviews: Parent/Care Provider, special education teacher, employer, and/or care manager
Data collection methods: Digital recording device and hand notes

Data Analyses and Reporting

PRELIMINARY FINDINGS
1. What are the everyday life information needs of young adults with ID?
All participants tended to seek, use, and share information that satisfied their immediate needs, primarily those related to supporting interpersonal relationships and social inclusion, interests, and curiosities, and daily routines and activities. This emphasis aligns with the characteristic typal of individuals with ID, that of having a concrete frame of reference with orientation centered in the here and now. Parents and teachers placed emphasis on information that served both present and future everyday life needs, prioritizing information to support self-care, employment, and personal safety.

2. What are the everyday life information practices of young adults with intellectual disabilities? What tools/resources/strategies do young adults use to address their everyday life information needs?
Participants employed multiple resources to address their information needs including the consultation of trusted individuals, web searches, TV, radio programs, newspapers, magazines, and books. Multimedia websites, such as YouTube, Yahoo Video, and various interactive game sites were particularly popular. The school library center and local public library were minimally accessed.

3. What challenges do young adults with intellectual disabilities encounter in their attempt to address an information need?
Observed and reported challenges include cognitively inaccessible information (textual representations), diminished expectations of individual ability and need, institutionalized restrictions, limited community resources, and minimal opportunity for personal control.

DISCUSSION AND IMPLICATIONS
Preliminary results reveal that participants have substantial everyday life information needs. All participants exhibited a desire and need initiative to engage in their information access to social and personal information needs, outcomes, and experiences. While cognitive challenges related to reading, comprehension, and problem-solving inhibit their full information engagement among societal, institutional, and technological barriers are equally restrictive. As LIS professionals we are in a position to impact positive change in the lives of individuals with ID. To do so, we must expand our consideration and understanding of the individual with ID and his/her life-related information needs. Impacting area of need can have a ripple effect, enhancing multiple domains of life. Recent studies show that individuals with ID can improve life outcomes through the provision of meaningful resources and supports. Library collections and services have traditionally revolved around the textual representation of knowledge. For individuals with ID, this representation is insufficient and exclusive in that it is often limited and conceptually inaccessible. By acknowledging the individual's unique information needs and through the provision of resources and services that offer alternative representations of knowledge, the librarian - as an information intermediary - can be an agent of change in the lives of individuals with ID.