Interview with a Deafblind User of the Louisiana Child Count Database

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Introduction

A meaningful percentage of deafblind individuals abandon their assistive technologies (Wittich et. al., 2021). What is less known is the extent to which these individuals abandon databases because of either poor screen reader-database integration, or a difficult mental conceptualization of the whole in larger databases given a disability that has a parts-to-whole approach to concept-building and can only extrapolate out so far on a mental canvas. As G, a deafblind individual once explained of mapping in a non-database context, the parts to whole way of thinking in deafblindness becomes a problem when creating maps because there is an extrapolation point at which the map is too far outward from the person and therefore too complex to understand via mental representation (Personal conversation, March 12, 2021). I interviewed C for this paper, who is adventitiously deafblind and works with the Louisiana Deafblind Child Count dataset. She intimated G's sentiment in our interview by speaking about how she organizes her world "by immediate reach", a threshold point after which she would appreciate a database for organization to outsource cognitive load.

G resolved the cognitive load of city-level mapping complexities by bringing in simple polygon geometry into his understanding. A simple shape like a parabola or a circle is within immediate reach of cognitive visualization, and as G noted, was easier to consider first before filling in the details of a city like streets and geographical landmarks. G preferred mathematical functions provided for global understanding as he could derive the complexity of any shape from an equation's parts, and this method integrated visual information in the parts-to-whole concept construction that can be characteristic of deafblindness.

First Statement of Need: Moving from Partial Inclusion to Full Inclusion

Returning this idea to database mapping, Park and colleagues (2014) summarize how database development in healthcare comprises data services and data management, orthogonal to one another. Practical knowledge with assistive technologies suggests that the former task of data services in database development may be inclusive of deafblind users for how SQL and screen reader syntax are analogously programmatic. Whereas the latter task of data management, including database development and the visual scan required of diagramming via Entity-Relationship Diagrams (ERDs) may exclude deafblind individuals in database construction where either narrative long-form alternative text can be inadequate for these flowcharts or G's geometric simplifications are not provided.

ERDs as Data Services and Data Management Tasks

Some may argue that ERDs' cardinality markers and serially-created entity-attribute tables are screen-reader readable and therefore accessible. This is true for JAWS and VoiceOver at least, two of the top three screen readers according to Web Aim's most updated screen reader use

Survey #10 conducted in January (Webaim, 2024). On my test, NVDA, used by 37.7% of respondents according to the survey, had difficulty reading ERDs that contained many-many relationships and sometimes entering the screen-reader readable regions on No-SQL ERD visualizers. Regardless, when an ERD is being 'read', this task is one of data services on the user side, similar to a screen reader reading a data entry form to allow user input of information in the correct field. An ERD is also considered as a data management task that allows a deafblind user to contribute to database development and to the diagram; it requires that the ERD is accessible in a way that mimics the visual scan of the full diagram that is available to sighted users. At this juncture, ERDs are not reliably accessible via narrative long-form alternative text, and it is unclear as to whether when this is provided, it is adequate for a deafblind person to continue diagramming. The following interview with C confirms this barrier of data management and suggests design decisions that could lessen the barrier to then include more deafblind adults in database development-related roles

Second Statement of Need: Participation in 'Disability Databases Only' Is Not Full Inclusion

It is important to acknowledge that insights from C's interview suggest 1) that the experiences of G who is congenitally deafblind and C, who is adventitiously deafblind and so has the "memory of vision" can differ. These users may each have different database needs and desires.

Further, as C notes, the Deafblind Child Count Database with which she interacts has been designed by a professional who is steeped in accessible design and assistive technology development for visually-impaired and blind-and-partially-sighted people. This background has facilitated design decisions around a born-accessible database where C reports data management-level challenges in her participation but specifically does not highlight data services or entry type challenges. Repeatedly during the interview, "I love that the form is just two columns….where I enter….I have not seen anything like it. It's not like the other ones I used" (Personal conversations, March 2024). Undergirding that positive comment about the Louisiana Child Count Database is that there are other ones—inaccessible databases that may be informed by this interview and others towards improved accessibility at both levels of data management and data services to reduce the "emotional toll" of these and facilitate broader participation.

Database Theories Miss Deafblind Users

It has been detailed above how deafblind users may need different avenues to comprehend and therefore be excluded from traditionally-presented complex entity-relationship diagrams (ERDs) due to their reliance on visual elements and visual scan without tactile alternatives or adequate long-form alternative text. When I interviewed C and tried to explain ERDs for the first time, she indicated, "No one's ever asked me that question…and I don't think it's not hard for me because I go back to my memory of vision." However, C also noted that "[she has] friends who've never

seen who've never seen and somehow they learned the concept of databases," although she was uncertain as to these friends' knowledge and use of ERDs (Personal conversations, March 2024).

Perhaps from what C called "a lifetime of adapting to blindness," despite reporting memories of vision to understand ERDs, her analogical verbal descriptions back to me about ERDs was tactile. She used lending out her craft and yarn collections to others as an example, with a frequent mention that once something visual was identified, like relationship or composite key—color or type of yarn in her example—she'd "put a Braille label on it [so] when I want to use the yarn," (her analogy for calling on the relationship in the ERD) "[she didn't] have to ask for help again." This suggests that the entity-relationship model, even amongst those for whom it is comprehensible may require facilitation by a sighted guide that a deafblind adult may not prefer.

A Space Within Task Technology Fit Theory for Deafblindness

Task-Technology Fit (TTF) Theory can be "diagnostic" and determine if a database is meeting user needs (Goodhue & Thompson, 1995). As Howard & Rose (2019) summarize, TTF theory has been misapplied and misunderstood in past literature as being a theory whose primary outcome is database usability, and recent research has been more critical. Howard & Rose (2019) broach that TTF is uniquely placed to assess "aspects of fit or matching" but not just in the positive circumstance; they raise that TTF has the theoretical space to consider task-technology misfit. This is where partial accessibility or even database feature evaluations for deafblind access might fall.

They also argue that when this theory is properly considered, task-technology *misfit* (TTM) is not simply the absence of fit but its own construct with "novel effects" that are "largely independent" of TTF. This independence is important theoretical space.

Deafblind adults, even outside the database context, often must align with deafness or blindness to access assistive technologies, in forced-choice paradigms and resource competitions that dishonor the uniqueness of a disability. The opportunity that TTM creates to generate independent effects validates a disability and its needs. Further, if Howard & Rose (2019)'s TTF critiques the assumption that a user can "perceive" when a technology does a task well, and declares that TTF is aware of its uselessness when "technologies are not used", then this is an apt theory to conceptualize database development for combined vision and hearing loss where the "trauma" of poorly-designed databases does lead to database abandonment (C, Personal conversations, March 2024).

The Misson (in the New Integrated Deafblind Database):

The Integrated Deafblind Resource Database centralized database for collecting and managing census and community resource use data for deafblind children, enabling better access to assistive technologies and resources and a better count of deafblind children in the state and country. Our goal is to improve support and outcomes for deafblind children by facilitating data-driven decision-making and collaboration among stakeholders.

This mission statement provides space for the current Deafblind Child Count to integrate with other state resource database for deafblind children in the state of Louisiana. Although the person whom I interviewed had trouble conceptualizing an entirely inter-linked system, that could be because of the level of abstraction required to process this. Better linked and more interoperable services for the disabled people generally in the state of Louisiana was raised as a local need by various presenters and stakeholders during the Rehabilitation and Assistive Technology Conference that took place in New Orleans in July 2023.

Desired Features in a Database According to a Deafblind User:

User: “C”, adventitious deafblindness

- Email: (permission obtained to provide, March 26, 2024): guillcat@gmail.com
- Consent to record interview: not provided

Current database used: Louisiana Deafblind Child Count

- **Database description:** collects basic demographic, geographic, gender, age, and etiology of deafblindness information. From C’s descriptions, I gleaned this database is a single table with 113 rows and is a flat file with SQL queries that select certain columns from the table to create a data form in which C enters 2-3 attributes only. Another data collector enters the rest of child information.

What user likes most about current database:

Two column working area: The entry form has only two columns, with all data entry occurring in the second column. The first column is formatted systematically in spoken English (For example, “Child First Name” and “Child Date of Birth”) in the field labels so that there are no screen reader errors with JAWS in announcing the field. User reports that “she hasn’t seen another database like it” and it is not as “traumatizing” as other databases that she has used like those during her Master’s in Social Work degree that were not “designed by someone who knew accessibility and how screen readers worked.”

Clean interface: C reports, in comparison to databases that she has encountered, the Deafblind Child Count is preferred, and says of the alternative, “I've seen forms that were created to look pretty on the page, I've seen databases that were 26 columns wide. I never have confidence that I'm not messing up the row, especially when it gets into tirelessly entering loads of data, if

you mess up one thing, you could create chaos, and that makes me very very nervous" (Personal Conversations, March 2024)

That it is a Flat File: Although C did not use this term, it was clear during the interview that her only real cognitive conception of a database was one that was a single table or spreadsheet. Teaching her about relational databases in order to develop the concept and then ask if she would want more complexity in a database prompted her to note that for any complexity beyond a single table, she preferred "narrative explanations" like "case files" and would attach "braille labels" to find these.

What user wants to see in this database:

Features to reduce entry error: Anxiety and nervousness around making mistakes in data entry prevents this user from exploring more complex functions of the database. In databases larger than the Child Count Database, this user loses her place and does not know until she has already entered incorrect data or data in the wrong field. Data Validation rules can ensure that only valid data can be entered into the database fields. This could include formats for dates, numerical ranges, and required fields. The only data validation that this user has worked with so far has been dropdown menus for data entry. In the interview, C and I discussed that databases with deafblind users often lack data validation to reduce mistake frustration as confirmation dialogs and real time error feedback for a validated field often appears via dialog boxes that can be frustrating to enter and exit with a screen reader. However, C's opinion on the subject is that "when making the database, you need to find someone who knows what they're doing, and then we can have both help to make sure mistakes don't happen and JAWS works with it." C also noted that if error feedback is provided, then there should also be "a way that tells you how to fix it," speaking to concise guidance that might be needed.

Adjusted Autocomplete Options: Providing autocomplete options is often a way to reduce error in redundant data entry. However, C raised that built-in autocomplete is unhelpful to screen readers and causes her to "mess up more." This could be because the Tab key and arrow keys that form the core of keyboard navigation in a screen reader double as the same keys required to fill autocomplete options. Secondly, while some screen readers are programmed for letter-by-letter read out, this is a) often turned off by practiced screen reader users and b) only available for real text in the field. Autocomplete options are visual ghost text in a field; they cannot be accessed by screen reader readout. Alternatively, the same benefit of autocomplete can be accessed via clipboard history (Windows Key + V for keyboard users, Insert + Space + H for JAWS, F12 series for NVDA, VoiceOver Key + Shift + C for Mac) if the first field is filled in full without an autocomplete option and a parallel field note suggests that this piece of entered data may require multiple subsequent entries and so need to be copied to the clipboard.

Proposed Data Structures:

A flat-file structure with a single table can contain all necessary fields related to the data being

collected. Alternatively, a normalized structure with multiple tables linked by relationships could work if each table represented a distinct entity and relationships were capped at 2 to manage both the cognitive abstraction required to understand these and the lack of visual scan in this population. Relationships will have to be bounded by a screen reader's ability to sensibly read them. A hierarchical nature, such as parent-child relationships might be appropriate with single tier hierarchies if there are "also Braille labels" and "tactile ways of understanding the hierarchy." C did broach that she knows people with adventitious deafblindness who learn how to use databases differently than she did with her "memory of vision," and these "people do it and they learn" but have "more tactile access points." While C could not speak to these access points, a review of American Printing House for the Blind's Tactile Town toolkit suggests that tactile analogies of hierarchies or layouts are precursors to actual application of these in abstraction (personal communication, September 6, 2021).

Examples of SQL Commands in New Database:

Define new table:

```
CREATE TABLE ChildInfo (
        ChildID INT PRIMARY KEY,
        FirstName VARCHAR(50),
        LastName VARCHAR(50),
        Address VARCHAR(100)
```

Alter table structure:

This command adds a foreign key constraint named "FK_dbSiblingID" to the "ChildInfo" table. The constraint references the "ChildID" column in the same table, indicating that the "SiblingID" column must contain valid child IDs from existing records in the "ChildInfo" table. This constraint maintains referential integrity, ensuring that sibling relationships are properly established within the database when both children in a family are part of the deafblind child count. It also allows querying these data to examine the prevalence of multiple instances of deafblindness within nuclear families which is something this database does not currently calculate.

```
ALTER TABLE ChildInfo ADD CONSTRAINT FK_SiblingID FOREIGN KEY (SiblingID) REFERENCES
ChildInfo (ChildID);
```

Retrieve information, add information, or update information:

```
SELECT FirstName, LastName FROM ChildInfo WHERE City = 'Bogalusa';
INSERT INTO ChildInfo (Middle Name, DateOfBirth, Price) VALUES ('Emily', '11202003');
```

INSERT INTO ChildInfo (phoneNumber, ATuse, ATdetail) VALUES ('+1-585-777-5555', 'yes', ‘exoskeleton, kalogen cushion, ssp, bump dots’);

UPDATE ChildInfo, SET Age = 10, Diagnosis = 'CHARGE' WHERE ChildID = 093;

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