Smart Care: the Importance and Challenges of Creating Life Histories for People with Cognitive Disabilities

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Abstract

This paper presents preliminary results from an ongoing ethnographically-informed research project focused on designing technologies that support people with cognitive disabilities residing in community living settings and the distributed network of caregivers. Over the past thirty years, social and legislative reforms in the U.S. have enabled people with cognitive disabilities to steadily move from long-term care settings in centralized institutions to independent and semi-independent living in decentralized community residences. This paper will examine some of the socio-technical challenges and opportunities for improving the long-term quality of life for residents and the job satisfaction for the network of professionals who care for them. We illuminate the potential role of personal life histories in this effort, and describe a multi-tiered socio-technical architecture that addresses these challenges.

1   Introduction

Historically, approaches to *universal access* [33] focus almost exclusively on technologies that directly help individuals with disabilities to more easily access information, facilities, and activities that individuals without disabilities often take for granted. This limited approach ignores the broader social context in which people live. Individuals, especially those with *cognitive* disabilities, often have difficulties advocating for themselves and communicating their basic needs and preferences. Thus behind each person with a cognitive disability is a network of caregivers who must help them advocate by understanding each person's unique needs, methods for communicating, personality, and past history.

The *Cognitive Levers research group* (http://l3d.cs.colorado.edu/clever) at the University of Colorado is working collaboratively with a local community care organization, Imagine! (http://www.imaginecolorado.org), to design new cognitive technologies for assisted living environments. This ongoing study employs ethnographic methods [32] to gain a nuanced understanding of the existing practices and support systems used by caregivers of people with cognitive disabilities in community living environments in the Imagine! organization. A major goal of the study is to identify and design appropriate technologies that (1) directly assist individuals with cognitive disabilities and (2) empower direct caregivers and organizations with the tools and information needed to provide opportunities for lifelong learning and personal growth. An overriding theme that has emerged through this study is the absence of, and the need for, construction and access of *personal life history* information about individuals receiving care through the Imagine! network.

We begin by providing a brief background of assistive living environments for individuals with cognitive disabilities. We then present our research methodology, and highlight three findings that illuminate the need for personal life histories. Next, we present conceptual frameworks that have guided the development of a multi-tiered socio-technical architecture for creating, representing, and using personal life history knowledge. Finally, we discuss pertinent privacy related issues, and discuss related projects and research initiatives.

2   Background: History of Assistive Living Environments

Over the past thirty years, people with cognitive disabilities have moved from centralized long-term care institutions to geographically dispersed community residential environments [13]. Our society has also begun to place more value on opening doors for individuals with disabilities to participate in community activities and pursue employment. As a result, individuals with cognitive disabilities often interact with a number of different caregivers and even different care organizations in the course of a day, while over the course of their a lifetime, they may require different levels of residential care and receive aid from several care provider networks. These changes create challenges concerning the communication and documentation of relevant information about an individual in the course of the day, and longitudinal awareness of an individual's personal history and personal development.

Imagine! is a private, non-profit organization established in 1963, which provides support services to people with disabilities and their families in the Boulder and Denver metropolitan area. Imagine! clients include individuals with mental retardation, Down's syndrome, autism, epilepsy, cerebral palsy or traumatic brain injury. Imagine! works primarily with individuals outside the school system (under age 3 and over age 21). The mission of Imagine! is to create and offer innovative supports to people of all ages with cognitive, developmental, and health related needs so they may live fulfilling lives of independence and quality in their homes and communities.

Imagine! comprises a number of departments that interact somewhat like business partners. These departments include: (1) *Innovations,* which provides 24 hour residential services in individual and group home living; (2) the *Out and About Program* which provides recreational opportunities for adults living in group and supported living situations; (3) *Labor Source*, a job finding organization for people with disabilities; and (4) *Community Partnerships*, providing supporting living guidance. Clients often receive services from several departments each week and even each day. In addition to the care provided by the Imagine! network, residents in a community living environment each have a guardian, family, and friends with whom they may interact regularly.

The groups within Imagine! form a complex network of people and organizations involved in care. Initial meetings with Imagine! group home coordinators indicated that complexity can lead to communication problems between the various departments and direct care providers in the group home. In this study we sought to gain a richer, contextual understanding of the issues involved in coordination and management of care, as they occur day-to-day.

3   Ethnographically-Informed Study Methodology and Findings

We are currently conducting an ethnographically-informed study in the setting of various community living environments, including group homes where four to eight residents live together with 24 hour care staff, and personal care alternatives (PCAs) where two to three residents live together with less intensive care. Research methods include semi-structured interviews with adult caregivers, and observations in group homes and community outreach activities with caregivers and residents. Researchers have also analyzed information artifacts used in the group homes to maintain and share information pertaining to care.

Interview and observation participants are identified through other participants in a "snowball" fashion, as researchers gain an understanding of the organizational structure and relationship of Imagine! caregivers. Interview participants include: group home coordinators and management staff, case managers, direct care staff who work in the homes, as well as the residents of the group homes and PCAs. Interviews typically last between 30 and 60 minutes. Interviews are conducted in the group home environment or in the Imagine! administrative office, and are focused on understanding current care practices, technological systems, training methods, and perceptions of the greatest challenges in providing care.

3.1   Finding 1: Buried in Documentation

We found that while the quantity of documentation maintained by care staff is high, it is lacking in usefulness. Much documentation is mandated by local, state, or federal regulations, but is of little use to direct care staff in providing daily care. For example, we learned that regulations dictate that the time and dosage of every medication administered must be recorded; any occurrences related to health, safety, or behaviours must be noted on an incident report; and the activities of each resident must be documented. Activities may include events such as the number of times the resident left the house, recreational and social participation, family visits, or doctors appointments and bowel movements. Staff reported that healthy residents make an average of 20 visits to doctors in a single year, in part due to state mandates. One group home coordinator explained that for homes supporting people with significant medical challenges, approximately 500 items of information are recorded each day for each resident.

In addition to the mandated documentation, direct care staff maintains informal information systems that are used in daily care. These include reminder systems that are placed around the home such as chalkboards, post-its, and wall calendars that remind and prepare staff for daily activities and alert them of special situations. Staff members also keep an informal staff log where they share important status and activity updates about residents, such as "*Joe seems tired, watch that he is eating properly*." These information systems are generally transient, disconnected from the mandated information systems, and are used purely for day-to-day coordination and communication.

In our interviews with Imagine! direct care staff, respondents explained that the primary reason they worked in challenging, exhausting, and underpaid positions was because of the close relationships they are able to build with the residents. Documentation is viewed as a burden that decreases the time that caregivers can spend with residents. This observation has also been noted in the literature, for example see [24].

3.2   Finding 2: Lost in Transition

A resident's life history plays an important role in three particular situations: *caregiver transitions*, which include a caregiver entering or leaving the organization, as well as the hand-off between various caregivers who interact with each resident on a given day; and *resident transitions*, when a resident moves to a different living environment. We observed that these transitions currently highlight the loss of personal life history.

High staff turnover contributes to the continuous loss of personal knowledge about residents. Nationally, direct care staff at group homes remain at their positions for an average of six months [13]. Group home coordinators at Imagine! report that a new caregiver is not valuable for about a year, because of the extensive hands-on training that is required. Each resident has a primary caregiver, who maintains that resident's documentation and organizes the resident's daily activities. Each time a staff member leaves, especially a primary caregiver, some knowledge of a resident's history also disappears.

While communication over the duration of a resident's life is difficult, communication over the course of a single day is likewise challenging. A resident typically interacts with several staff members in a single day. For example, one or two staff members help residents get ready in the morning, a driver takes them to a recreational or vocational activity, day program staff or a job coach works with them at these activities; and upon returning home the morning staff have been replaced with the afternoon shift. While direct care staff within the group home are required to write a brief statement of their interactions with residents, staff in other programs, such as the recreational and vocational programs, are not required to communicate with group home staff. If an event occurs involving health or safety, such as an aggressive action or a headache, all Imagine! staff must document this event on a paper-based state mandated incident report. This report is later reviewed by management who, depending on the incident, may or may not pass it along to managers in the other programs.

Residents also transition to different living environments, and these transitions often mark a significant loss of personal information. We learned that for most individuals transitioning from the school system to Imagine!, the incoming resident's history is transferred in a single meeting that often lasts approximately one hour, and has very little accompanying documentation. In cases where the individual arrives from a different region or from a home environment, there may be no documentation or transfer of knowledge about the individual's past. Since many of these individuals are unable to describe their own history and their current needs, interests, and desires, this knowledge needs to be slowly recompiled after each transition or is lost entirely.

3.3   Finding 3: Losing the Forest in the Trees

Re-examination and analysis of mandated or informal documentation is difficult because the information, largely paper-based, is stored in various places throughout the house and is removed and archived after one year. For example, medical information is kept in binders near the secured medicine cabinet; and daily activities and incident reports are filed in yearly notebooks. Each year the annual notebooks are filed in boxes in the basement or at the main office. There is no single electronic documentation system, so policy requires that all documentation be printed out and filed manually at the main office. Because the previous year's recorded are stored at the office offsite, documentation for the direct caregiver becomes inaccessible after one year. Furthermore after 10 years, information is often "purged" and lost altogether.

Little documentation is used by group home coordinators or management staff for future planning, such as organizing recreational activities, living situations, vocational opportunities, or medical cautions. For example, a day

program coordinator lamented that community outreach activities are planned without the ability to review residents' preferences, or any resident feedback from previous activities. Case managers, charged with helping residents plan their future, must rely on their own information, what the resident is able to express, and conversations with those who are directly involved in the resident's life. Management staff described their need, currently unfulfilled, to conduct historical trend analysis as well as future predication modelling in order to improve care services, allocate budget more effectively, and improve caregiver training.

To summarize, there is no shortage of documentation created by caregivers about residents; but currently the regulation based documentation is not organized nor necessarily the most valuable information important in building a useful personal life history.

4   Conceptual Frameworks

Early analysis of our ethnographic data support the conclusion that there is likely no single conceptual framework that can effectively guide all design aspects of a social-technical system to suit the complex and evolving needs of residents, caregivers, and managers. It is unlikely that any single system can be designed to address all or even most needs of residents over their lifespan, or caregivers over their careers. Instead, several conceptual frameworks will be necessary to inform the collaborative design of a "system of systems" which can incrementally be designed, deployed, tested, and refined over time to support the changing needs of all stakeholders.

Conceptual frameworks that may contribute to a more coherent analysis of the problem and design of socio-technical solutions include *distributed cognition, context-aware environments, incremental formalization, sensemaking,* and *utility theory*. Each of these will be briefly described in the context of this problem domain.

Distributed cognition [21, 35] provides an effective theoretical framework for understanding what humans can achieve through a variety of artifacts, tools, and information that are physically and logically distributed throughout an individual's world. An important notion from distributed cognition is that people often find useful answers to complex problems from a variety of information sources. By supporting distributed cognition, intelligent systems can be designed to reduce the overreliance on a single data source and reduce the likelihood that a total system failure could result from a single failure point. Some problems with distributed cognition include designing appropriate strategies for detecting and resolving conflicting information, and acting in the face of late, missing, or incomplete data.

Context-aware environments [17] offer an exciting opportunity to provide residents with cognitive technologies that help them live more independently. They also have the potential to revolutionize the quality of services available for the community support network serving persons with developmental disabilities. The challenges described above highlight the need for a multi-tiered approach to developing technologies that directly support residents and in doing so, empower the caregiver network to provide better quality care.

Incremental formalization [36] is the process of expressing, capturing, and representing information in a manner that can be interpreted by a computer. Representations such as natural language and free-form diagrams or pictures are considered informal because their semantics are largely uninterpretable by machines. By incrementally interpreting this information into a more formal structure that can be searched and retrieved, this information becomes more accessible and usable by future users for novel situations. This is an important design concept in our project because our studies reveal that imporant information is often shared through informal media, such as conversation and handwritten notes and our system will likewise need to capture and support such informal representations.

Sensemaking [6] also provides a useful theoretical and social framework for understanding how individuals and social networks process and communicate information in order to interpret the past and better understand the present, and anticipate the future. This is relevant because our ethnographic research reveals that (1) no single caregiver is responsible for 100% of the care of a resident and (2) no single person in management can assess what training and support is appropriate for each direct care staff as they enter and work within the caregiver network. Instead of designing with a "one size fits all" approach that may result in staff waiting to explicitly be told *what must be done*, sensemaking could support the development of systems that empower individuals to use the information around them to better understand and assess what *should be done*. Sensemaking may also be employed to "connect the dots" between otherwise episodic data points, and present a more coherent picture of a resident when introducing and training new staff within a work environment.

Context awareness, incremental formalization and sensemaking can be synergistically combined. Information may be available from disparate sources (including environmental and biometric sources) in a context-aware environment. This information may also be incrementally formalized with meta-information, such keywords or and activity summary, so it may be used in other distributed systems at a future time. Sensemaking can be facilitated when users are offered formal and informal knowledge that is meaningful and relevant to the task at hand, and feedback about such information may be useful to further formalize the knowledge, or to find more appropriate contexts for the future needs.

Utility theory: [8] All information systems ideally should provide some value or utility to the group of users they are designed to serve. Utility theory may provide insight about why some systems are broadly accepted, while others are not. There are three main traditions in how people make decisions, such as whether to use a system: (1) descriptive approaches which measure the subjective or perceived value of a system to an individual; (2) normative approaches which assess utility to construct a rational model of decision making; and (3) prescriptive methods which bridge descriptive and normative approaches by considering limitations people have with respect to a goal.

We postulate that a relationship exists between the perceived utility of a system to an individual or organization, the value it provides, and the effort required to obtain it. This utility is described by the following relationship:

Utility = f (value/effort)

where *value* is a "perceived" benefit of the system to an individual or organization, and *effort* is the work necessary to provide the information. This heuristic will be used to (1) *descriptively analyze* how direct care staff and management currently perceive the value of information systems they currently use, such as daily staff reports, journals, medication documentation, etc.; and (2) to *prescriptively design and assess* proposed systems in order to maximize the benefit of information to the organization.

5   Design Challenges and Implications

In our initial analysis we have identified three key steps to creating a personal life history to improve the quality of care for a resident:

- *collecting appropriate information* from a variety of distributed sources and activities to better understand a resident's preferences, experiences, and ambitions;
- *representing, storing, summarizing, and indexing information* so relevant knowledge can be created and used during relevant tasks or caregiver transitions (described earlier). Incremental formalization approaches may be especially useful given the vast amount of distributed information is now available from sensors (e.g. video, bio-medical, environmental state, etc.) as well as the ever-evolving nature of data storage technologies.
- *intelligently protecting, accessing and sharing appropriate information* with other organizations during transitions, or when a resident's support network evolves, while carefully respecting the privacy and security of residents. Privacy and security enhancing mechanisms can be embedded in the other two steps if necessary.

The ability to collect, manage, and utilize a resident's history is problematic for several reasons. From utility theory, we understand that motivation plays an important role in any knowledge management endeavor because the required effort is often not aligned with a perceived direct benefit. In trying to increase a system's value it is necessary to identify ways to align effort with value, and more generally, reduce effort and increase value. For example, using sensor technologies to create context-aware systems can reduce user effort by implicitly collecting data that currently requires explicit collection. It is also possible to increase a system's value by implicitly collecting data that is currently not collected at all.

To support this process we have also designed a distributed, multi-tiered architecture (Figure 1). This architecture is intended to serve as a coherent framework for designing new technologies and applications beyond the personal history application described in this paper by illuminating the relationship between information systems and stakeholders they are designed to support.
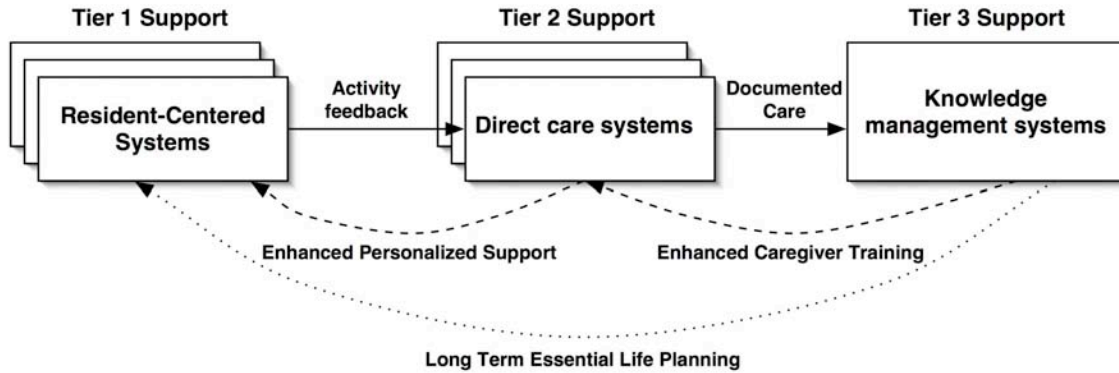
Figure 1: A multi-tiered system architecture for Smart Care

Tier 1 technologies directly support home residents, and provide cognitive aids that increase residents' self-determination and independence. These technologies provide reminders and guidance in performing Activities of Daily Living as well as vocational tasks. In addition to complementing the abilities of the residents, these technologies unobtrusively monitor user activities and transfer this information to Tier 2 technologies, caregiver support tools. Collecting this information as a by-product of the tool's use helps address the documentation and resident transition problems described in Findings 1 and 2 respectively.

Tier 2 technologies provide information to distributed direct care staff [34] about residents' needs and preferences, and prompt and coordinate caregiver support. Information about the nature of care provided is automatically collected in Tier 2. As in Tier 1, the information collected as a by-product of use helps address the documentation and resident transition problems described in Findings 1 and 2.

Information about resident activities (Tier 1) and care provided (Tier 2) is aggregated in Tier 3, knowledge management support systems. Tier 3 technologies serve as an organizational memory [9, 37] that support system-analysis and dissemination of information. This helps the care organization to see patterns that exist throughout the organization as well as view long-term trends for individual residents and caregivers. This addresses the difficulty of "seeing the forest in the trees," as described in Finding 3.

Each architecture tier supports and provides feedback to other tiers. The resident-centered technologies provide feedback to the direct care staff by automatically and unobtrusively gathering data about resident activities. The caregiver-centered technologies improve the quality of documentation without increasing the burden on direct care staff. The management support then provides valuable information to enhance caregiver training and support trend analysis and long-term life planning for residents.

Tier	Primary Goals	Secondary Goals
1	Create opportunities for self-directed living.	Collects usage and context data that provides feedback about activities and social interactions
2	Support caregivers in providing appropriate care	Documents care provided to resident
3	Provide "big picture" of longitudinal trends	Improved policies and procedures Enhanced direct care staff training Enhanced Life Planning for Residents

Table 1: Primary and secondary goals of technology support tiers

As discussed earlier, collecting documentation is often problematic because caregivers perceive it to be a secondary task that does not have a primary impact on their work. This is an example of the classic question, "*Who does the work and who gets the benefit?*" [23, 24]. A common element of the proposed technologies is that they are self-documenting. While the tools provide a primary benefit to the user, secondary benefits are realized by automatically collecting information about the actions being performed. Utilizing this information to create an evolving life history

of the resident creates a feedback loop that in turn can lead to better support from the caregiver. Table 1 outlines the primary and secondary goals of each support tier.

5.1 Making Life Stories Usable and Useful

There have been a number of projects aimed at improving quality of care by using digital technologies for capture and access. However, it is a common characteristic of many existing projects that they are "data rich and information poor" [28]. It may be the case that capturing the discrete events that compose life histories is relatively simple when compared to considerations of how to make this information useful [20]. For example, it is relatively easy to take photos of family events and archive them in a "shoebox," yet it is time consuming and difficult to organize and create a thematic "scrapbook" that highlights the accomplishments of each child within a family

A simple but naive computational strategy is to keep everything ("just in case"), since it is not always possible to predict what information will be useful in the future. Bush [14] insightfully predicted that, "*The difficulty seems to be not so much that we publish unduly ... but rather that publication has been extended far beyond our present ability to make real use of the record*." Not only does this approach ignore privacy guidelines that suggest minimum data capture [27], it also fails to recognize that information and information storage devices are not the scarce resource; it is the human cognitive resources required to identify and utilize information. Information overload can make a repository virtually useless because of these limitations. Context-aware systems and incremental formalization can potentially address the overload problem by facilitating the delivery of *the right information at the right time, in the right place, in the right way to the right person* [19].

For example, sensor networks can be used to monitor resident activities and collect vital signs. This can help mitigate the problems of collecting documentation, described in Finding 1. Kiosks and handheld devices can prompt and document caregivers as they provide care to the resident, which further addresses problems described in Finding 1 and also address the transition issues described in Finding 2. Finally, this information can be summarized into longitudinal activity and health trends for nurses and case managers, which address issues highlighted by Finding 3.

5.2 Privacy-related Social Implications

Societal concerns about privacy are revealed in the common comparison of human tracking through sensor technologies with Orwellian surveillance. Privacy is a complex issue in environments such as life histories, where smart technologies are used for mediating social interactions. Some of what people take for granted in face-to-face interactions may be reduced or lost in interactions mediated by technologies such as smart sensors. In order to moderate the collecting and conveying of information, architectures and mechanisms that *provide residents with appropriate feedback and control* [12] are desired.

Our life histories approach raises a multitude of questions about designing for appropriate feedback and control, including: (1) What information is collected, who controls it, and how long will it be accessible? (2) How, when, and to whom should data collection and its purposes be disclosed? (3) Who has control over information derived from data processing, mining and aggregation? (4) When is it in the interest of the individual to grant permission, and when is it not? (5) How are information permissions mediated for groups? (6) How can conflicting needs (e.g., privacy and safety) be reconciled? (7) How can we reduce the risk of information being captured today cause unintended damage in the future? (8) When is anonymity desirable, and when might it contribute to a dangerous situation for vulnerable populations, such a people with cognitive disabilities? (9) Are privacy permissions and boundaries different for people with cognitive disabilities?

Boundaries that separate and connect one's personal information spaces and the rest of the world are not defined only by physical distance, but are also shaped by one's activities and social contexts. For example, information about the objects employees touch can be public when they are at work in a warehouse. Understanding and dealing with specific contexts is a challenge even though privacy guidelines and legislations (c.f. fair information practices) can provide generic frameworks for a privacy-aware design.

6 Related Work

In order to address the challenges outlined above, our life histories approach includes a suite of three tiers. This approach has been informed by our ethnographic studies, as well as related work in resident-centered systems (Tier 1), direct care systems (Tier 2), and knowledge management systems (Tier 3) in elder care and clinical settings.

Research related to Tier 1 includes various smart homes that focus on resident support. A senior living residential center at Oatfield Estates [2] uses smart ID badges and embedded sensors to track and assist senior residents. Other smart homes [4, 7, 38] track household objects and residents' biosignals to provide context-aware feedback to residents. Handheld-based prompting systems such as MAPS [15] and AbleLink's PocketCoach [16] are designed to support persons with cognitive handicaps in their outdoor as well as indoor activities.

Technologies that relate to Tier 2 include wireless handheld devices, which have been used for patient monitoring and charting in hospitals since the mid-1980s [5, 18, 29]. While initial work focused on showing the usefulness of the technology, the emergence of HIPAA legislation [3] has created an additional focus to identify and address basic privacy and security issues [10, 26, 30, 39]. While clinical information systems are akin to the caregiver systems being proposed, there are also distinct differences. Current clinical information systems are designed for (1) highly trained clinicians and medical professionals working in formal work settings and (2) use with patients who are generally admitted for relatively short durations and can answer questions about their medical care. This is very different from most long-term community living settings where caregivers usually have little or no clinical training, face high turn-over of staff, and care for people with cognitive disabilities who may not be able to self-advocate.

As Meyer & Rakotonirainy [31] explored, there is a difference between developing context-aware technologies [17] for formal work versus informal home settings. There are simplifying assumptions that can be made in both settings, but in general, formal work environments are associated with well-defined tasks that take place in well-defined locations. Community living settings will present a unique challenge as they are a hybrid of home and work settings.

Many of the above-mentioned smart home projects additionally support caregivers; however, other projects explicitly focus on caregiver support. Barger et al. [11] explore in-home monitoring system that uses sensors to capture residents' activities and provides feedback to informal as well as formal care providers. The Independent LifeStyle Assistant [25] is a smart home environment "to help elderly people to live longer in their homes by reducing caregiver burden." Carmien et al. [15] integrate MAPS, a handheld prompting system, with a caregiver support component called Lifeline based on a socio-technical architecture for enhancing residents' mobility options outside of the home.

A recent project that reflects the requirements of Tier 3 includes MyLifeBits [22], which is a lifetime store of everything. It is the fulfilment of Vannevar Bush's 1945 Memex vision [14] including full-text search, text and audio annotations, and hyperlinks. Privacy issues need to be addressed in order to use such data not only for personal memory aids but also for monitoring and assisting others.

While there are many systems designed to support individuals with disabilities and caregivers, corresponding to Tier 1 and Tier 2 technologies, as described above, there has been little or no work in Tier 3 technologies designed specifically for the disability or caregiver community. The Caregiver Alliance Toolbox [1] is a commercial suite of systems designed to integrate resident and caregiver information. The functionality of this system spans Tiers 2 and 3. The Caregiver Alliance project considers privacy measures central to its design, yet information sharing and caregiver accountability are also two primary goals. Residents who are able to self-advocate can control information access and caregivers are granted permissions consistent with their need to know, expertise and responsibilities. Administrators and researchers can gain access to aggregated information for trend analysis and evidence-based policy reform.

7   Conclusion

Our research has illuminated the potential for personal life histories to play a valuable role in improving the lives of residents living in community environments and their network of caregivers. We identified three dimensions of care that represent opportunities for improvement: (1) direct care staff are burdened with large amounts of mandated paperwork, which is generally of little use to them; (2) caregiver and resident transitions are particularly challenging for maintaining consistent awareness of residents' life histories; and (3) documentation that is physically dispersed and not appropriately organized is not useful for essential planning, organization, and training. We have identified these issues by working closely with the Imagine! organization, and future work includes exploring whether these findings generalize across other community care organizations, and more broadly in the United States.

Providing *smart care* through personal life histories is not merely a technical challenge, but requires a socio-technical perspective. The creation, representation, summarizing and sharing of personal life history information is a socio-technical problem that hinges on understanding what constitutes, and how to deliver, the *right* information for

the *right* person at the *right* time. Beyond the technical challenges, the myriad social aspects of this issue that must be considered include privacy, as well as motivational issues and perceived utility by caregivers. Sensor-based and other automatic data collection mechanisms may ease the burden of documenting important events, but with increased complexity and new privacy concerns. We believe that a human-centered approach is crucial in this setting, and a socio-technical system must reflect and address these significant social issues in order to be effective, usable, and accepted by all communities of users.

Acknowledgments

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