Untapped Markets in Cloud Computing: Perspectives and Profiles of Individuals with Intellectual and Developmental Disabilities and Their Families

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Abstract. People with intellectual and developmental disabilities (I/DD) and their families represent an untapped market for the cloud computing industry. There is a great need to develop alternative cloud-based care supports as traditional methods of care become more difficult to obtain. Contrary to some perspectives, many people with I/DD are capable of using cloud computing technology; they and their families are a viable consumer market. Advances in civil rights and self-determination principles regarding people with I/DD have secured their acknowledged position as a natural constituency of society; however, too often they are left out of consideration of social design. Excluding the needs of people with I/DD in cloud computing consideration, design and structure may put them at risk for further marginalization in human society. This paper discusses the profile of the global I/DD population, self-determination principles, and family perspectives of technology.

Keywords: disabilities, intellectual, universal access, family perspectives, underserved populations, developmental disabilities.

1 Introduction

The population of people with intellectual and developmental disabilities (I/DD) and their families represent an important untapped market resource for the cloud computing industry. Families of individuals with I/DD are receptive to acquiring and using new technology-based support alternatives to improve their quality of life and self-determination outcomes for their loved ones [1]. There is a need to invest in technological personal support options for individuals with I/DD and their families that augment expensive traditional and human labor-intensive personal supports. Cloud computing represents one such alternative. Contrary to some perceptions, many individuals with I/DD are fully capable of using technology with training. Individuals with I/DD can provide critical insights into the needs of this particular consumer

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market. Without mindful attention to their inclusion into the design of cloud computing as the global communication network, there is a real risk that this population will not gain equitable access to the network, and as a result may become perpetual peripheral spectators to the rest of the world in the infrastructure ofweb-based social communications. Yet few cloud technology developers, people with I/DD, or their families are fully aware of cloud computing and its potential for providing much needed supports and connection to society

2 Population Definition and Demographics

Generally, people with intellectual and developmental disabilities are included in and are a subset of the broader population of "people with disabilities." They are also considered a subset of the population of people with "cognitive disabilities," which include disabilities stemming from brain injury, Alzheimer's Disease and other dementias, severe and persistent mental illness, and, in some cases, stroke [2]. In the United States, intellectual disability is defined as a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills [3]. I/DD occurs in all ethnicities and social classes. Developmental disability is an umbrella term that includes intellectual disability but also includes physical disabilities which manifest themselves before the age of 22 years and are likely to continue indefinitely. It should be noted that in 2010, the former term of "mental retardation" was officially retired in the United States federal government, replaced with "intellectual disabilities" by Congress and signed into law by President Obama in response to advocacy efforts by self-advocates who found the former term offensive [4].

Across the globe, there are millions of individuals with intellectual and developmental disabilities. Estimating the number of people with I/DD that exist globally is challenging. Prevalence estimates of I/DD derived from epidemiological studies in developed nations range consistently from three to five per 1000 of the general population [5]. Published prevalence studies of I/DD in developing nations within the past decade report rates ranging from 5.3 to 20 per 1000 persons [6] with even higher levels in the poorest countries [7] due to effects related to higher levels of developmental risks that influence the rate of intellectual disability [8,9,10]. This information suggests that the full measure of disability lies beyond the current capabilities of structured statistical surveillance methods, and that the nuances of disability identity and identification are impossible to capture in a singular numerical index [11].

Fujiura et al., 2005 captures this point most eloquently:

"There is no single correct answer (to how many people there are with intellectual disabilities in the world) just as there is no singular best definition of disability. Rather we must accept the existence of multiple conventions, each more or less suited to a particular purpose. The lesson for intellectual disability is the importance of clarity in how we employ numbers in our policymaking and advocacy… However, numbers can also serve as a means to an end, used to elevate awareness of the relationship between societies and their citizens with intellectual disabilities. 'Simple' statistics hold the potential for galvanizing policy and advocacy in the developing nations of the world."

3 Disability Construct

It may be of interest to discuss briefly the construct of disability. Among prevalent disability theories include the medical model of disability, which locates the disablement within the individual; the moral model of disability, which asserts that disabilities are a result of moral failings and are therefore a punishment from divine sources; and the social model of disability, which asserts that disability is a socially-derived construct that occurs when the environment is not equipped to reduce or eliminate barriers to full social participation [12]. There is also the family model of disability, which holds that families connected to disability also have a disability identity that is unique and separate from families not connected to disability [13]. The social model of disability is the one most widely held among disability advocates; who acknowledge the presence of biological diversity within the body yet firmly assign responsibility to social, cultural, political, and environmental settings to provide an equal playing field for those with biological diversities or impairments. If society responds and eliminates social and environmental barriers to full participation for those with impairments, then disability ceases to exist; if it does not, then society has in effect constructed the disability. For individuals with intellectual and developmental disabilities, the social model resonates. They hold that their impairments do not deny their status as full members of society and that impairments can be mitigated by the proper supports, albeit taking on a different form that supports such as wheelchairs, guide dogs, or hearing aids. Supports may need to be in the form of a human being – or alternative innovative support - to help them negotiate intellectual territory, assist with decision-making, help with personal travel and manage daily personal decisions. Therefore, an individual's impairment only imperfectly defines disability status; the experience of disablement occurs within a social, cultural and political context, and those contexts can be vastly different within and across national borders [14] as well as across time and circumstance for individuals and families.

4 Profiles of Individuals with I/DD

There is no "norm" of typical profiles or personal supports needed by individuals with intellectual and developmental disabilities. In many cases, an individual may have functioning skills sets in one area of behavior, yet demonstrate a need for support in others. In other cases, significant needs exist in every area of adaptive behavior. Sometimes, training can help the individual to learn how to do things and they will retain that knowledge; in other cases, issues relating to memory, cognitive, or physical impairments may limit an individual's ability to accomplish a long-term mastery of a skill. Expressive and receptive language may be affected by I/DD, some individuals may be non-verbal and avoid making eye contact with others. Some individuals with I/DD are highly social; others may be more withdrawn. Individuals with I/DD may have speech impairments; many use sign language to communicate. Many learn how to read at an early age; others may take years to acquire reading skills, and still others read word icons. Some can make extraordinary calculations in an instant or may know in-depth histories and statistics of a topic such as a sports team, but have difficulty with remembering a name or how to tie shoes. Many people with I/DD appreciate and

benefit from accessible language; that is to say, language that simply conveys concepts or messages, and information that can be provided at a slower speaking rate. People with I/DD often have vibrant personalities, friends, like sports or have hobbies, read books or play video games. Many can and do use cell telephones and computers as a natural part of their communication skills. Some individuals with I/DD are able to function independently without significant oversight; others have significant behavioral issues that are difficult for caregivers to manage in public and private spaces. These individuals often require the most intensive amount of personal care. Mobility impairments, visual and hearing impairments, manual dexterity, and chronic health issues may be experienced by some individuals with I/DD. Often, the individual may demonstrate different levels of skill mastery at different points along a continuum, including surges of progression and regression of acquired skills.

5 Systems of Support

Close to 90% of individuals with I/DD rely upon their families as the primary caregivers [15]. With longer life expectancies and growing governmental fiscal constraints, reliance on family caregivers for adults with disabilities will likely grow [16]. Families caring for adults with developmental disabilities have reported high unmet needs for respite services, case coordination, transportation, recreational services, and information regarding housing, financial plans, and guardianship [17,18]. Formal and informal supports to these families, including assistive technologies, can substantially affect their overall quality of life. Adults with disabilities who live in their own homes, apartments, or small group homes may contract to receive outside supports. The most prevalent service model for supporting consumers with disabilities is through a standard care model with the use of onsite support staff [19]. In addition to living with family or in ones' own home, the array of community living options for individuals with developmental disabilities includes congregate care, host family, and supported living [20].

Depending on social attitudes, family supports and services, and other resources for education, residential, employment, and aging care needs, people with I/DD may or may not live with their families. Many countries including the United States are still struggling with the concepts of self-determination and acknowledging that individuals with I/DD can and should have personal choice in where they live, who cares for them, where they work and what they do, and the myriad of personal choices made in course of a typical day. In developing countries, options are few. There are high frequencies of family abandonment which is sometimes forced, extreme poverty often leading to homelessness, abuse, institutionalization, poor health and high mortality rates, lack of education and employment options, and social disinterest in their welfare.

6 Self-determination Principles and Policy Frameworks

The principle of self-determination shifted the trajectory for individuals with intellectual and developmental disabilities from one of social exclusion and marginalization

to one aimed for full participation in all aspects of society. This is an important construct to know for those unfamiliar with the civil rights perspectives that are gaining in popularity among this population and their families, as self-determination often drives the goals, objectives, and strategies for individuals with I/DD in their daily lives. From the earliest calls in the disability literature for self-determination [21] to today, the use of the construct has been contextualized within a disability rights and empowerment emphasis [22]. Wehmeyer defined self-determination as "the outcome that people with intellectual and developmental disabilities and other disabilities have opportunities to exert control in their lives and are provided supports than enable them to take advantage of such opportunities in ways that respect their values, beliefs, and customs and those of their family and culture [23]."

Self-determination as a social movement powers the need to design access to and provide options for cloud computing for people with I/DD. Cloud computing technologies and other assistive technologies provide people with I/DD with more choice and more opportunities to engage in and with their world in which they live. Shifting the environment and the choice options within that environment has a positive effect on self-determination outcomes [24].

6.1 United Nations Supports Full Inclusion of People with Disabilities

According to the United Nations [25], the equalization of opportunity concept, which emerged from the UN World Programme of Action, reframed the disability agenda from a medical or rehabilitative perspective to one of basic human rights. The Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted in 2006 and entered into force in 2008. The Convention marks a "paradigm shift" in attitudes and approaches to persons with disabilities. It confirms the abandonment of viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced.

7 Technology for People with I/DD

Many individuals with I/DD use assistive technology devices at some point in their lifetime. An assistive technology device is defined as "any item, piece of equipment, or product system, whether acquired commercially, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities"[26].

It is through the lens of assistive technology that the intersection between cloud computing and people with intellectual and developmental disabilities may be viewed as aligned yet unlooked for allies. While many in the disability field tend to think of technology for people with I/DD as devices, such as augmentative and alternative communication or a switch to control the environment [27], product engineering is evolving from stand-alone devices and applications to distributed, connected, integrated, and multi-technology systems [28, 29, 30]. State-of-the-art technological advances in computer science, engineering, communications, rehabilitative science, and microelectronics have rarely been adapted for people with cognitive disabilities, although this population may derive deep benefit from responsive design. Braddock et al. surmised several areas of technology that has significant potential for both the technology industry and the population of those with cognitive disabilities [31], and which may also have potential implications on the developing cloud computing technologies. They are within personal support areas, including personal digital assistants, computer assisted learning and communication, universal design, assisted care systems technology, Smart Houses, smart transportation and tracking, personal robots, and virtual technologies. These kinds of technologies – and those that perhaps have not yet been created - have enormous potential to help those with I/DD and other cognitive disabilities to achieve greater independence, productivity, and quality of life [32].

8 Family Perspectives

The Arc of the United States launched a national data collection effort in 2010 to identify issues of strength and concern among adult individuals with I/DD and their family or professional caregivers, called The Family and Individual Needs for Disability Supports (FINDS) Survey. Areas covered in the on-line survey included education, home and living, college, work, transportation, health, emergency preparedness, social, technology, support needs, and caregiver needs. Limitations of these results include that data was generated by an on-line survey that required participants in the United States to speak English and have access to an internet-connected computer. This effort was not successful in engaging a representative sample of those from other minorities, ethnicities, or other countries, and may not have engaged those living at or near poverty or in rural environments where internet was not available. The design of this data collection effort may also have limited participation by respondents who do not use a computer.

9 Results

There were 5,845 individuals that responded to the survey from every State in the United States, plus the District of Columbia and Puerto Rico, with approximately 90% identifying as caregivers. Of the caregivers, slightly more than 70% lived in a household with three to five members; of those that answered, 29% reported a family income before taxes in 2009 of between $60,000 and $99,000 with another 23% reported family incomes of between $100,000 and $200,000. Sixty percent of the

respondents reported having four year college degrees or graduate degrees. Almost 90% of the caregiver respondents reported being White. Out of 3,391 respondents, 52% stated that they wished to receive more information about new technologies that could make their lives easier. We present highlights of early data findings (see Table 1) from the caregiver perspective specific to the area of assistive technology, which includes technologies that support cloud applications. Data was stratified according to disability identity: intellectual disability (I/DD), Autism Spectrum Disorder (ASD), and Other developmental disabilities (Other.)

10 Discussion

The data suggests that 76% of caregiver respondents reports that their family members with I/DD, autism, or other developmental disabilities either use or need to use technology or assistive devices. In this sample, roughly one out of two individuals with

Table 1. Questions for Parents/Caregivers about technology and assistive devices

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		Disability Type					
Technology & Assistive Device Needs	%	IDD	ASD	Other	F/X2	Sig.	
Special equipment, technology or other assistive devices needed by not currently available	3753						
Yes, our family member with I/DD uses AT	29%	32%	37%	49%	20.00	***	
No, our family member with I/DD does not use AT	53%	68%	63%	51%			
I use this now:	1872						
Smart home technology	3%	3%	2%	2%	0.40		
Portable GPS guides	4%	3%	6%	3%	3.14	*	
Cell phone	47%	45%	52%	39%	5.73	**	
Video communications	6%	5%	7%	4%	1.15		
Wheelchair, cart, scooter	28%	27%	5%	61%	147.72	***	
Home modifications for accessibility	14%	13%	3%	30%	55.84	***	
Computer/software	32%	30%	40%	28%	8.42	***	
Picture communication software (reading and writing for non-readers)	11%	11%	15%	7%	5.62	*	
Audio books	11%	11%	9%	13%	1.38		
Communication board device	13%	11%	17%	15%	6.24	**	
Exercise equipment	16%	17%	14%	14%	1.02		
I need this but don't have it now:	1755						
Smart home technology	33%	31%	33%	37%	2.01		
Portable GPS guides	19%	17%	27%	12%	14.80	***	
Cell phone	16%	15%	18%	16%	1.09		
Video communications	15%	14%	17%	14%	0.96		
Home modifications for accessibility	21%	22%	8%	40%	55.29	***	
Computer/software	40%	39%	45%	34%	4.34	*	
Picture communication software (reading and writing for non-readers)	35%	38%	37%	24%	10.39	***	
Audio books	27%	28%	27%	26%	0.14		
Communication board device	25%	26%	27%	18%	5.09	**	
Vision assistance	9%	10%	4%	11%	6.80	**	
Exercise equipment	38%	37%	39%	43%	1.82		
If at least one item was checked, non-responses were coded as unchecked.							
Significance *** p < .001, ** p < .01, * p < .05							
# - No variance within groups							

I/DD, ASD, or other developmental disability use a cell phone, and one out of three report using computers, suggesting that many in this population are already connected to cloud platforms. The results also suggest that families connected to I/DD that are not currently using technology are receptive to acquiring and using technologies. The findings indicate that families are interested in knowing more about innovative technologies that could have a positive effect on the personal support needs of their family members with I/DD. Families report that they need but don't have technologies in the areas of smart home technology, portable GPS guides, computers/software, picture communications for non readers, audio books, communication board devices, and exercise equipment. In the category of smart home technology, there is a wide gap between current use of the technology by individuals with I/DD (3%) and the reported need for the technology (33%). This gap in use and desired used needs further exploration to determine why smart home technology is not being used with high frequencies by individuals with intellectual and developmental disabilities. There is also an indication that families are concerned with health and physical activity supports for their family members with I/DD as almost 40% reported a need for exercise equipment. These numbers reflect an untapped consumer market for technology developers, including those in cloud development. In terms of difference found between disability groups in both current and desired use, the results indicate that there were significant differences found among the disability groups of those with I/DD, those with ASD, and other developmental disabilities. Overall, those caregivers connected to individuals with ASD reported the highest frequency of use of assistive technologies as well as the highest rates of need for assistive technologies, but families in all categories. While more research is needed to fully understand this phenomenon, this data suggests that families connected to individuals with ASD are more likely to have provided their family members with assistive technology, and are more likely to have identified a need for additional assistive technology.

11 Conclusion

In conclusion, this brief discussion has presented an overview of the profiles of individuals with intellectual and developmental disabilities and their needs as a potential consumer market for the cloud computing industry. The data presents a clear opportunity for those in the technology industry to consider the unique though not insurmountable needs of this population, and lead efforts to include them in cloud solutions. However, the issue has much larger implications; indeed, there is a much greater human rights issue at stake. These opportunities may well represent the last unchaining of social restrictions for people with I/DD if solutions are developed deliberately to bring them into the mainstream of society and alleviate restrictive environmental barriers. Without the deliberate engagement of people with I/DD and their families by the cloud computer technology industry, without infusing their needs in the development and use of cloud technology and designing effective solutions, and without an industry-wide assumption that people with I/DD must be, should be considered as a key consumer audience from development to market, there is a potentially tragic outcome. This outcome could foster the creation of a permanent, insurmountable chasm between people with I/DD and the rest of the cloud-connected society, erasing many gains made in civil

rights and self-determination arenas that have advanced if not secured their rightful place as valued members of society. By not including them, the effect will diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of a global society. There is a sense of urgency for the cloud computing industry to recognize this audience, their potential as consumers in the market, or have a sense of urgency to engage people with intellectual and developmental disabilities in developing needed technologies. There is great risk before us. Presume competence.

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