

JAYDA

(Joining Adults & Youth with Disabilities through Access)

An Albert Schweitzer Fellow Approach
2020 -2021

Problem

- Millions of Americans and Canadians with intellectual and/or developmental disabilities (IDD) do not have access to specialized social and medical services for their specific needs due to a lack of accessibility either physically, financially, or in discovery.
- A profound issue that is deeply rooted in the healthcare systems across Canada and the U.S. is the lack of integration; which disproportionately impacts individuals with disabilities, who are more vulnerable than other individuals with different needs.
- This disparity is highlighted in the transition years (18-26) when youth have to transition to adult programs
- A particularly challenging time is the “transition years” (between 18 and 26 years old), when one ages out of pediatric services, and must re-establish their healthcare network, and eligibility criteria for social service programs.
- Waitlists for individuals with disabilities to receive social service care often take months
- Currently, 1 in 4 Americans and 1 in 5 Canadians have a disability that limits their activities of daily living (ADL) (Centers for Disease Control and Prevention, 2019; Statistics Canada, 2018) and Family Quality of Life (FQOL).
- Among the multifaceted barriers faced by this vulnerable population, accessibility has been identified as a major concern, as it pertains to obtaining comprehensive care.
- An individual with a disability requires comprehensive care consisting of an interdisciplinary team of healthcare and social service providers that each serve to care for a different aspect of their needs
- The bottom line. Until now, individuals with disabilities have been forced to use a system that was not built for them and their needs, but are expected to navigate it just as efficiently as someone with typical development.
- Ultimately, people are complex and unique; the care that they receive should be all encompassing, in order to maximize their quality of life. Fundamentally, this is an interdisciplinary problem that needs to consider individuals with disabilities first so that the highest level of accessibility can be met, thereby being optimally inclusive and efficient for everyone.
- With respect to accessibility, both the literature and personal experience testimonials support the notion that when caring for a child with Intellectual and/or developmental disabilities (IDD), there exists three main sources of vulnerability impacted by the problem of integration: family quality of life, healthcare/social service resources, and healthcare/social service wait times.

Family Quality of Life

Early intervention is the best intervention when attempting to improve ones' quality of life, particularly for individuals with intellectual and/or developmental disabilities (IDD). There is no existing resource that can direct an individual to the best medical specialist, physical therapist, and speech language pathologist with individualized matching specificity all in one step, while providing an integrated booking service to manage appointments. The current municipal telehealth and online social service resources tend to be overly compartmentalized while lacking matching specificity (College of Physicians and Surgeons of Ontario, Doctor Search; Development Services Ontario, DSO). The same can be said about other applications in the telehealth market which are not comprehensive enough to handle the breadth of specialization that individuals with disabilities need. Without the right information, selecting a doctor or social service provider becomes arbitrary and inefficient. The lack of accessible features and integrated appointment booking of online/telehealth resources significantly reduces the autonomy of a patient with disabilities, thereby increasing the responsibilities of their family and caregivers. These are issues that reduce accessibility to comprehensive care because they impede the ability to discover appropriate health and social service providers.

Healthcare/Social service resources

On the other hand, healthcare resources are not being utilized efficiently. Every time an individual does not show up to their appointment, or attends an appointment for which there is no follow-up, government resources are lost. Considering the current lack of matching specificity and appointment booking integration, there remains an excessive amount of opportunities for resources to be lost in this way. This reduces the amount of resources left over to fund additional services and

solutions for individuals with disabilities, resulting in budget cuts and reductions to services that may have been avoided had there been a more efficient system in place.

Healthcare/Social service wait times

The quality of life for individuals with disabilities and their family is significantly impacted while waiting for intervention services because they are left to manage their challenges on their own for the duration of their waiting period. Patients often have to join long waitlists to get into programs without even knowing whether or not they are actually eligible to participate; collectively lengthening the wait time of other individuals who are eligible.

Years of Comprehensive care loss (YCCL) refers to the amount of time that an average family spends in their search for comprehensive care that gets wasted because they were moving in the wrong direction or taking appointments with the wrong professionals. Years of potential life lost (YPLL) or potential years of life lost (PYLL), is an estimate of premature mortality defined as the average number of years a person would have lived if they had not died prematurely (World Health Organization). Lengthy wait times reduce accessibility through time and effort, which directly inflates both YCCL and YPLL. The collective of mis-matched individuals with programs/care providers proves to be a significant opportunity for reducing the accessibility barrier.

Approach

"I plan on developing a student run free clinic specific for individuals with disabilities. This clinic will not only have physician's and student physicians, but will include social workers, occupational therapists, nurses, pharmacists and respective students from their own fields."

In order to address this statement, over the course of the fellowship many boulders presented themselves, with the COVID 19 Pandemic as baseline. However, I believe that relationships create unimaginable connections that eventually connect over time, like nodes in a network. By connecting the

Jayda.Network, Authority Health & the Disability Network we have created Unimaginable possibilities to significantly shift Health Care, Education, Social Service search and allocation, as well as Independent Living for individuals with Disabilities - by Joining Adults and Youth with Disabilities Through Access (JAYDA). By creating these Sentinel Nodes, I have created a trusted and powerful pipeline of Access to 16% of Michigan's Population through Technology to Health Care Health Care, Education, Social Service search and allocation, and Independent Living for Adults with Disabilities. What I have not been able to accomplish over the period of time of the Fellowship is create connections to Occupational & Physiotherapists. I believe that we can achieve this by the end of Q4 if made a priority by all partners.

In order to create a positive feedback loop and challenge any assumptions I may of had across this journey, as I once did when I pursued the MI-LEND fellowship to ascertain if the problems across the disability community was the same in Canada and the United States; I decided to pursue an opportunity with the AUCD/HERSA/AAP on a telehealth project titled: *Supporting Providers and Families to Access Telehealth Services for Pediatric Care*. From this experience among many lessons I learned that the Federal Government's approach to finding a solution in light of COVID 19 focus was on creating new training programs and education on telehealth delivery; From my point of view this was not addressing the fundamental problems faced by the disability community and the translation of knowledge into practice was too slow, for the amount of suffering and frustration I was hearing about from the disability and healthcare community throughout my fellowship.

“By expanding this program, not only will more students have a more tailored learning opportunity but the community and future doctors will mutually benefit and the community will have an influence on future physicians and the students can aid the families to the best of their capacity.”

Over the course of the Fellowship and the two years proceeding I have been the director of the ARIE home visit program at Wayne State School of Medicine. I continued this role throughout the Pandemic and my Fellowship. However, roles needed to change within the organization and outreach

shifted in order to still be able to reach our target population. We ended up, like the JAYDA Series, shifting to video visiting/check-ins with families. In addition, along with my colleagues we used this as an opportunity to write a paper that highlighted the importance of didactic learning for medical students as it pertains to training future physicians on how to care for individuals with disabilities regardless of the field of medicine they choose to embark on.

Evaluation

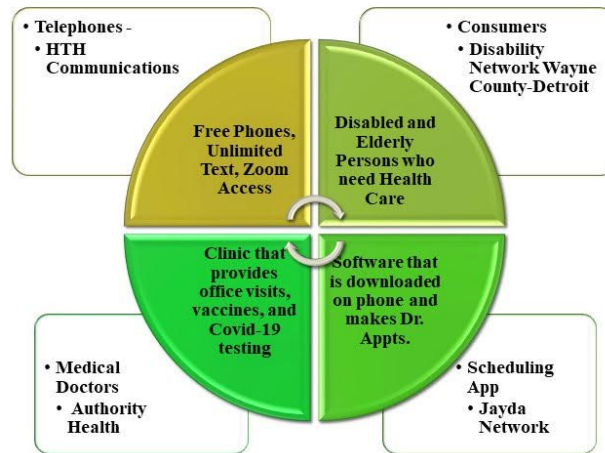
Throughout my journey evaluation has been the top priority, but for the first time in my life I am at a crossroads as to how to evaluate what we are doing with JAYDA.Network. How do you evaluate persistence and creativity of connecting organizations and the development of technology that creates a cloud information system architecture to support that of the physical infrastructure. Yes, I can evaluate my time directly working with the population through mediums such as JAYDA Series Interviews with the disability community and healthcare providers, or patient encounters, or the time I have worked with HERSA/AAP and ARIE, but action through a collaborative effort is the best approach to bringing about sustainable change. With the JAYDA.Network in partnership with the Disability Network and Authority Health we will be able to collect meaningful insights that will enable us to facilitate HealthCare, Social Services, Education, and Independent Living for the disability community.

Sustainability & Status

Over the Past few months (April, May, June), I have made great strides in strengthening the partnership with the Disability Network and have been able to obtain free phones for every member of our population that we serve. Each phone will act as a node on the network, so that when it is time we can seamlessly connect Healthcare providers to the population we serve and vice versa. This has been

an exciting development that has taken a tremendous amount of time and effort. But we are here now and this has become a pivotal part of our sustainability plan.

Impact Partnership Roles



Phase Roll-Out



Recommendations

Based on my experiences to this point across multiple domains, an Interdisciplinary approach is Vital and to some degree absolute. The problem is that this recommendation is rampant throughout the literature; Therefore, to me recommendations on best practices should be baseline and only action can truly raise Quality of Life for individuals with disabilities and their families & caregivers above baseline. What is more is that with the passing of the past year there has been great strides in many domains to help bring us forward to a new norm, but, this is being done for the masses not the 16% of michigan for whom we work with. So it is in my estimation that there is a high possibility of a dismal outcome - as it pertains to health and quality of life outcomes, if things do not change. What makes this more difficult is that there

must be coordination efforts in action, onboarding, integration, and outcomes tracking at the core of solutions, which will presumably increase the probability of successful outcomes.

Reflection

At the beginning of my fellowship, I had a few months prior embarked on my journey to bring JAYDA.Network to life, by one gathering my team and two gathering my mentors that would support me along this journey. At this time I was pursuing my MBA in Information Systems Architecture and management. When the opportunity presented itself for me to apply for the Albert Schweitzer Fellowship, recommended to me by one of my mentors MJ Upshaw - I did not have much time, but I had to think what project would be substantial enough to significantly impact the disability community for the better. Although it was an audacious proposal, to create a fully functioning clinic to provide interdisciplinary care to individuals with disabilities was what was needed here in Wayne County. Although I was not able to provide direct care to the disability community through Health care means, we were able to gather valuable information and test our assumptions by performing video series, where I was able to converse directly with the community and healthcare providers. Over the course of the fellowship I was able to partner with the Authority Health PopOff Clinic and with the Disability Network and bring these two constituents together to strengthen an already established relationship that had not been acted upon in a few years, nor what each party envisioned when they first established their MOA.

The collaboration between all three constituents has brought about endless possibilities, some of which I once believed to be a fragment of my imagination. The strength and commitment from all parties has reassured me that there is a bright future in providing healthcare to this vulnerable population and these partnerships in themselves have reassured me that I am serving my community now, and for the future. This project will not end with the closing of the fellowship, but I look at this as just the

beginning. I have gained knowledge that can only be gained by having my feet on the ground and having hard discussions with both organizations that serve this population as well as health ministries, to try and find common ground. JAYDA. Network is what will Join Adults and Youth with Disabilities through Access and help pave the way for an equitable future, one that works with the community to address their needs.