

**Empowering the IDD Community:  
Enhancing Care and Advocating for  
Funding**

**Learning Community 14 in Partnership with  
St Joseph Home**

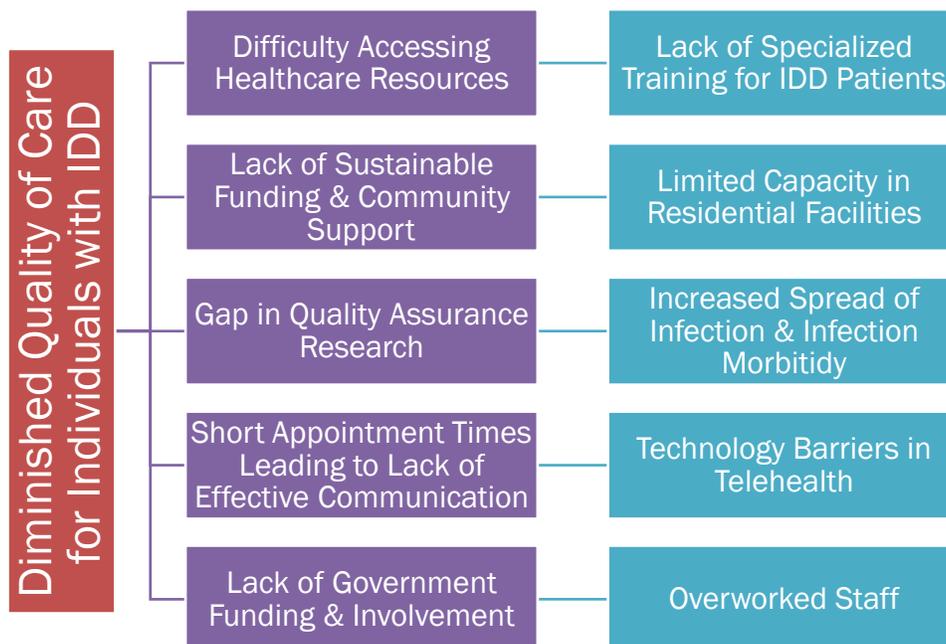
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**Introduction:**

St Joseph Home, a Cincinnati-based non-profit organization, is dedicated to empowering individuals with complex disabilities and their families through various services including residential spaces, respite care, and day programs. They aim to elevate the standard of disability care while fostering a supportive community, playing a crucial role in improving overall community health by offering caregivers essential respite support.

Our exploration of St Joseph Home’s mission unveils the multifaceted challenges confronting individuals with intellectual and developmental disabilities (IDD) to receive quality healthcare, encompassing access, funding, infection control, workforce, training, communication, technology, and capacity limits (**Figure 1**). Emphasizing the indispensable role of government, funding, and collaboration, this investigation aims to enhance care for the IDD community.



**Figure 1.** Factors leading to a diminished quality of care for individuals with IDD.

**Access to Healthcare & Comprehensive Solutions:**

In the United States, there are estimated to be 6.2 million people living with IDD<sup>1</sup>. Individuals with IDD face challenges in accessing quality healthcare, including difficulties finding providers who can effectively manage their unique needs, inadequate community support, and communication barriers with medical professionals. St Joseph Home addresses this health determinant by offering personalized resident care, employing dedicated IDD-trained staff, and providing opportunities like respite stays for families. This comprehensive approach helps to bridge the healthcare gap for individuals with developmental disabilities.

**Sustainable Funding for Personalized Care:**

St Joseph Home takes pride in delivering personalized care tailored to the individuality of each resident, ensuring dignified and respectful treatment. However, most of their program funding relies on Medicaid, supplemented by corporate sponsorships, individual contributions, and planned giving initiatives. Annual fundraising events, such as golf outings and 5k runs, are also held to

support their efforts. Establishing a more sustainable funding stream would enable St Joseph Home to continue prioritizing care quality, alleviating the need for extensive fundraising efforts.

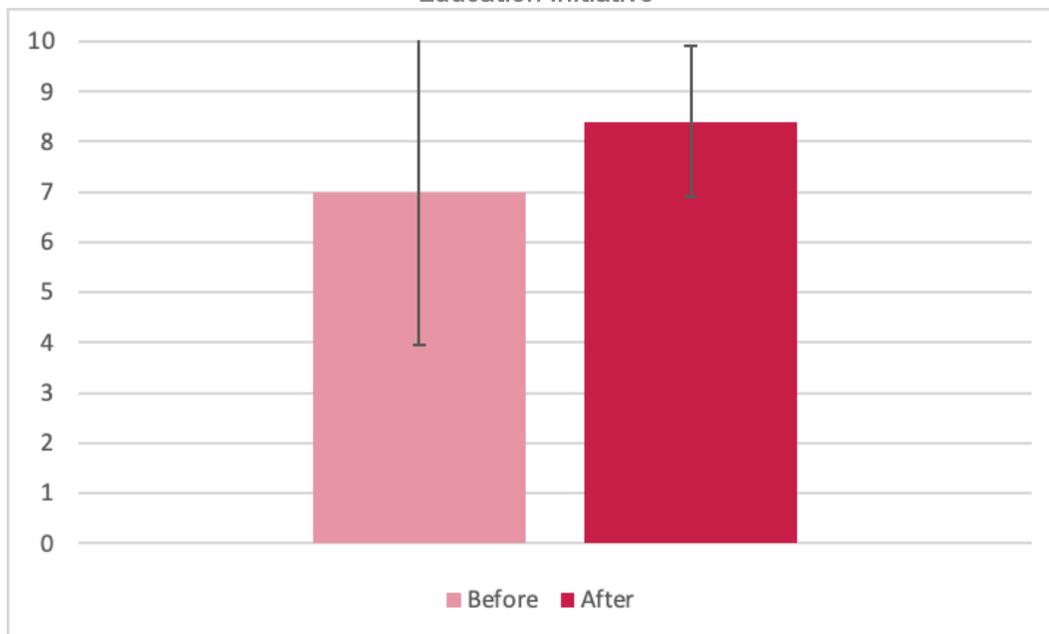
**Infection Control & Quality Assurance:**

Central to St Joseph Home’s mission is managing and preventing infections within their medically complex IDD population. They achieve this through standardized clinical procedures, meticulous maintenance of medical equipment, well-stocked sanitation resources, and vigilant infection tracking. However, spatial and staffing constraints pose challenges, particularly concerning airborne infections within the community. Additionally, the interconnectedness of residents with external family and caregivers increases the risk of inadvertently introducing pathogens into the facility, impacting the immunocompromised population. Thus, “people with IDD who live in community-based settings continue to have poorer health than their non-disabled peers<sup>2</sup>”.

Our collaboration with St Joseph Home highlighted the urgent need for an improved infection control system. Their existing system was no longer meeting requirements effectively. This experience prompted us to delve into research and work closely with St Joseph Home to identify gaps in quality assurance (QA) and infection tracking within the IDD community.

Our joint efforts have led to the development of an enhanced system tailored to their specific needs, already yielding significant positive impacts (**Figure 2**). This revamped approach benefits not only the residents but also extends its positive influence on the families and staff at St Joseph Home, enhancing overall healthcare quality and safety within the facility.

Staff Confidence in Performing a Standardized Tracheostomy Care Procedure Pre- and Post- an Expanded Education Initiative



**Figure 2.** St. Joseph Home’s staff averaged 7±3.1 before brochure implementation and 8.4±1.5 after (paired t-test, p=0.045). The introduction of a training brochure aimed at standardizing tracheostomy cleaning and maintenance to reduce infection spread increased the confidence of suctioning providers (Physician & Society 101/102 Final Project, 2023).

**Workforce Challenges & Professional Training:**

Conversations with our community partner over the past year have consistently highlighted staffing as a pressing issue impacting the delivery of high-quality healthcare to individuals with IDD. Overworked employees at Saint Joseph Home often work overtime and extended shifts, negatively affecting the quality of life of those they serve. Increased funding for the IDD community could facilitate more attractive job offers, thereby reducing employee burnout and enhancing the quality-of-care residents receive.

A critical need exists for trained professionals within the IDD community. Discussions with individual families have illuminated their experiences within the healthcare system, revealing a common concern: physicians, medical students, and residents often lack the necessary training to effectively communicate with IDD patients. Our experience within a residential facility has further underscored this issue, as there is a shortage of healthcare staff equipped to provide both personalized care and standardized, quality-controlled healthcare.

Government involvement is imperative for allocating funds to support research programs and comprehensive training initiatives focused on meeting the unique demands of the IDD community within healthcare trainees and professionals alike. Increased funding for research not only encourages student engagement but also fosters the development of standardized, evidence-based procedures. These procedures aim to reduce the spread of infections and address gaps in medical knowledge and resource availability specific to IDD communities. This need is particularly important to address, considering, “A significant difference exists between the quantity of research in infection control practices for nursing homes and hospitals compared to what little exists in disability care settings<sup>3</sup>”.

Additionally, advocating for an integrative curriculum in healthcare training for all providers, including physician assistants, nursing staff, occupational therapists, physical therapists, and dentists, is essential. This integrated approach aims to improve communication between the healthcare team and the IDD community, ultimately enhancing the overall healthcare experience.

**Effective Communication, Technology, & Empowerment:**

Communication barriers and technology issues present significant obstacles to delivering quality care to individuals with IDD. In today’s era of shortened appointment times, professionals are frequently under pressure to make rapid medical decisions, hindering their ability to establish genuine connections with patients and fully comprehend their responses, whether through verbal expression or nonverbal cues like body language.

Furthermore, the advent of Telehealth appointments adds complexity, requiring patients to adapt their verbal and nonverbal communication to interact with physicians through a camera. This underscores the need for government intervention to allocate funding for research and training programs aimed at undergraduate and professional students pursuing healthcare careers. Such investments are crucial in preparing future healthcare providers to meet the unique demands of the IDD community.

Increased funding directed towards this community would also facilitate longer appointments, enabling providers to conduct more comprehensive assessments. These extended appointments not only promote thorough evaluations but also foster positive and empowering communication

relationships between healthcare professionals and individuals with IDD. This empowerment allows them to actively participate in decisions about their own care, ultimately improving the overall quality of healthcare services provided.

### **Expanding Care Capacity:**

To avoid large, impersonal group homes and ensure the IDD community receives the attention and care they deserve, government regulations impose size limits on facilities like St Joseph Home. These limits have been reached, effectively halting the organization's expansion, and creating an extensive waiting list for acceptance into their programs. However, St Joseph Home has devised an innovative solution to this predicament. They are strategically developing smaller satellite locations to augment their patient capacity while adhering to the stipulated guidelines. This approach, short of legislative change, offers the most viable path forward, enabling the organization to address other existing barriers to providing top-tier care to the IDD community effectively.

### **Direct Government Involvement:**

Government involvement is crucial for expanding training, research, and recruitment within the IDD community. While Cincinnati boasts a robust network of IDD organizations and healthcare providers, communication gaps persist. To bridge this divide and ensure the IDD community and supporting organizations receive the attention and care they deserve, a dedicated representative in Cincinnati from the Ohio Department of Disabilities could serve as a liaison between city organizations, hospitals, and educational institutions, like the University of Cincinnati College of Medicine, to build upon the wonderful programs that the department currently offers<sup>4</sup>. Such a representative could facilitate collaboration and support in education, research, and recruitment, ultimately incentivizing and prioritizing care for individuals with disabilities.

### **Conclusion:**

In conclusion, St Joseph Home's unwavering dedication to the IDD community exemplifies the potential for enhancing the quality of care provided to individuals with intellectual and developmental disabilities. Despite numerous challenges, including funding limitations, workforce issues, communication barriers, and infection control, the organization continues to strive for excellence. Government involvement, increased funding for research, and collaborative efforts among healthcare providers, educational institutions, and IDD organizations stand as essential steps toward advancing care for this vulnerable population (**Figure 3**). By addressing these challenges and advocating for improved standards of care and resources, we can empower the IDD community and ensure they receive the high-quality care they rightfully deserve.

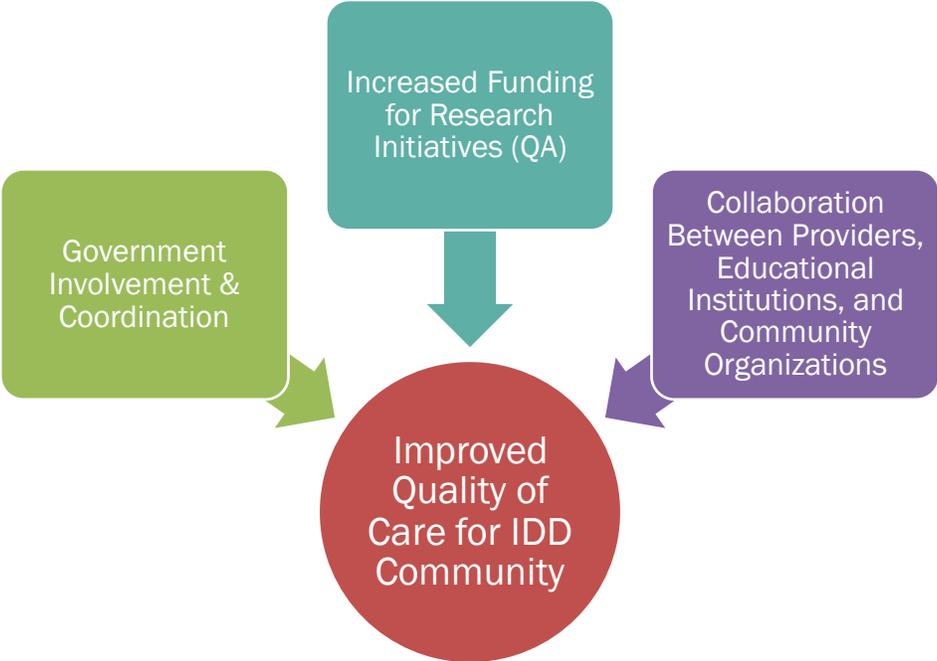


Figure 3. Essential steps towards advancing care for the IDD community.

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