

**Inclusive Health Programming for Individuals with Intellectual Disabilities**

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### **Abstract**

People with intellectual disabilities face many health disparities including limited access, knowledge, communication, and quality healthcare services. The capstone experience aimed to decrease some of the gaps that the intellectual disabilities community faces. The project applied the focuses of education and advocacy to increase awareness in society of inclusive healthcare. Through the various projects completed in the capstone experience, the target populations received educational resources and materials to increase participation. The capstone was designed to assist in people with intellectual disabilities to achieve their full health potential by providing access to quality health providers, educational opportunities, and resource and feedback sharing. Through qualitative feedback and discussions, the capstone experience engaged members of the intellectual disability (ID) community to increase knowledge and independence of their own health. The capstone student gained competence in working with the ID population as well as the significance of inclusive healthcare in future career decisions and client interactions. The overall capstone experience resulted in an increase in inclusive healthcare through the organization and for a future statewide level in the community.

*Keywords:* intellectual disabilities, inclusive health, patient education, caregiver education

### **Inclusive Health Programming for Individuals with Intellectual Disabilities**

The healthcare field strives to provide quality patient care to each individual needing services. People with intellectual disabilities enter the healthcare system with varying needs often requiring a different plan of care compared to a 'typical' patient. The research gathered on intellectual disabilities examines the many health disparities that the population faces when seeking healthcare. Intellectual disability (ID) is defined as a neurodevelopmental condition characterized by differences in cognitive development and adaptive behavior as determined by standardized assessment procedures (Tassé M. J., Schalock R. L., Balboni G., Bersani H., Borthwick-Duffy S. A., Spreat S., 2012). Intellectual disabilities are conditions originating before age 18 that result in significant limitation in cognitive functioning and adaptive skills such as communication, social and self-care skills (Ouellette-Kuntz, 2005). People with ID have health disparities in morbidity, mortality, and quality of life (Krahn et al., 2006). People with ID experience poor health compared to the general population, which presents concern for healthcare service because of the lack of access, quality, communication, and knowledge (Ward et al., 2010). The purpose of this project is to provide education and advocacy for people with ID through health program development and implementation. The capstone student will gain clinical skills and knowledge working with individuals of different abilities, family members and caregivers, healthcare providers, and staff at the statewide level. The student also gained leadership skills through collaborating and planning events and meetings with other staff members, healthcare providers, and volunteers.

### **Needs Assessment**

To learn the more about the site, a needs assessment was conducted with the state-wide Health Program Director and two of the area program directors. The needs assessment occurred prior to beginning work at the capstone site to ensure the capstone experience directly helps with needs of the organization. Several informal interviews were performed during the first two weeks of capstone work to discuss any changes and updates at the non-profit organization. The capstone student wanted the projects to be meaningful to clients and the organization to foster successful and positive goal development and outcomes.

Throughout the interview and conversations held with site staff and stakeholders, some common themes emerged for project focus and objectives. A need was presented for education in a variety of groups and focus areas. Athlete education is a large component of the health programming the organization provides the community. Many common health disparities that affect the ID population were discussed to identify educational programs and resources to increase health awareness and quality. The site mentor described health programs offered. Parent and caregiver education was provided as another component to athlete education to assist in client independence and involvement in services. Communication, sensitivity, and accessibility for people with diverse learning needs training and education was also discussed for the community including healthcare workers, local police, fire and medical personal as well as business owners and staff.

Another area of need that is ongoing for the intellectual disability population is advocacy. Many question answers and discussions resulted in advocacy needs for the population on a state, local and personal level. Many health needs stem from the lack of access, quality, and communication for people with ID. The site mentor described the lack of access to quality care

and the increased need for referrals and recommendations for health professionals. Later discussions with the site mentor and stakeholder, founder of an online referrals site for health professionals, caregivers, and patients to connect, emphasized the need for healthcare services catered to people with ID. Therefore, the need for advocacy for those with ID in the healthcare system and in the community became an area of focus for capstone projects.

### **Literature Review**

To review current research regarding health care and programming for people with intellectual disabilities, the capstone student identified articles that were relevant to the project topic and goals. The databases that were searched were CINAHL and PubMed. The literature was limited to articles published within the last 10 years.

### **Current Disparities**

People with intellectual disabilities have complex health conditions that are often poorly managed and recognized due to several disparities. Healthcare providers that are educated and skilled in intellectual disabilities are limited; therefore, services are hard to access because of limited staff and appointment times (Ward et al., 2010). There are often assumptions made about the individuals, such as having challenging behaviors or communication skills, causing insufficient attention to health promotion and lack of provision of preventative health screenings (Krahn et al., 2006). The prevalence of cardiovascular disease risk factors, obesity, oral disease, diabetes, and mortality are all heightened for people with intellectual disabilities (Marks et al., 2010; Drum et al., 2005). The onset of most of these comorbidities is associated with a lack of participation in physical activity and poor nutrition. Additionally, these comorbidities are associated with lowered rates of education, fewer social activities, and higher unemployment rates for people with intellectual disabilities (Drum et al., 2005). As Krahn et al. (2006) states,

“Poor health was accepted as being an inevitable consequence of having a disability”. However, the aforementioned health risks may be decreased through health promotion and health management.

### **Health Programming**

To increase healthcare effectiveness and decrease disparities for people with intellectual disabilities, some areas of change have been researched. Krahn et al., 2006 found benefits of health promotion interventions on several areas including nutrition, physical activity, preventative care, rest, and stress management. Marks et al. (2010) researched the pilot of several health promotion programs provided by the non-profit organization and discovered many similar benefits to Krahn et al. including improved self-confidence, engagement in physical activity, and nutrition, as well as improved physical strength and endurance. Hardee, J. P., Fetters, L. (2017) found exercise interventions have positive outcomes on activities of daily living and social participation for those diagnosed with Down Syndrome. Some physical improvements were noted as well including improved balance, cardiovascular endurance, muscle strength and endurance, and overall increased life satisfaction rates (Hardee, J. P., Fetters, L., 2017).

### **Communication Barrier**

People with intellectual disabilities often lack the ability to recognize and state health problems (Aparicio, A., Arango, P., Espinoza, R., Villate, V., Tenorio, M., 2021). Oulelette-Kuntz (2005) found that those with intellectual disabilities are less likely to voice their physiological and psychological complaints. People with ID have historically been categorized as subjects of care, rather than individuals who are part of the conversations and decision-making processes that guide their health (Aparicio, A., Arango, P., Espinoza, R., Villate, V., Tenorio, M., 2021). Although the current healthcare system is designed for individuals to recognize health

concerns and seek help themselves, this is not a design that works well for people with intellectual disabilities, necessitating a need for health providers and caregivers to recognize signs of discomfort and abnormality in this population and assist with obtaining health services (Ouellette-Kuntz, 2005).

A significant concern necessitating education for health providers and caregivers is communication skills. Facilitating communication skills for people with intellectual disabilities may allow them to center themselves in their plan of care and increase involvement in programs designed to benefit their health. According to a research study, over half of the individuals with intellectual disabilities reported communication difficulties with professionals and non-familiar individuals (Smith, M., Manduchi, B., Burke, E., Carroll, R., McCallion, P., McCarron, M., 2020). The community can benefit from education on intellectual disabilities, communication styles, program development and creativity as well as a larger system increase in availability of healthcare to this population (Drum et al., 2005). Smith, M., Manduchi, B., Burke, E., Carroll, R., McCallion, P., McCarron, M., 2020 emphasizes the important of increasing opportunities for successful communication for those with ID; this requires more training and educational opportunities for community partners and staff. Many of these areas of educational need and understanding have roots in the practice of occupational therapy involving social and self-care skills.

### **Best Practice and the Gap**

Current research on health disparities and disability is focused on physical disabilities rather than intellectual and developmental disabilities. Research has found four areas of healthcare disparities and inequalities for those with intellectual and developmental disabilities including access, knowledge, communication, and quality (Ward et al., 2010). People with



intellectual disabilities often have difficulty finding health providers, causing many individuals to not receive treatment regularly or remain with their pediatrician for a lengthened period (2010). The number of individuals seeking medical treatment outweighs the available health providers that are comfortable and skilled in treating adults with intellectual disabilities.

Communication is often another area of difficulty for people with intellectual disabilities and health providers. Clients and providers find a barrier in communication because neither feels as though the other will understand and interpret their information accurately (Ward et al., 2010).

The non-profit organization provides several programs designed to improve access to healthcare and training for healthcare professionals, athletes, and caregivers. Healthy Athletes, Healthy Leap and Health Messenger as part of the Athlete Leadership program strive to close the gap in services offered to individuals with intellectual disabilities by breaking down barriers of language, bias and availability and increasing exposure and understanding. Occupational therapy is not currently a health profession involved in the Healthy Athletes program. Getting occupational therapists involved in non-profit organization and overall expanding screenings and networking events would benefit health professionals and athletes alike.

### **Guiding Theory**

Occupational therapy is not currently a health profession involved in non-profit organization TX health programming, though many of the services and resources provided are based on similar principles to the occupational therapy framework. Overall research findings have presented more research is needed to identify interventions factors that help increase social participation in the ID population (Aparicio, A., Arango, P., Espinoza, R., Villate, V., Tenorio, M., 2021). By using the theoretical model Person-Environment-Occupation-Performance (PEOP) and Occupational Justice framework, the capstone student will gain clinical skills and knowledge

on interventions to help increase the people with ID and the community's ability to navigate healthcare, increase positive communication, and improve functioning and skills (Smith, D., & Hudson, S. (2012). The PEOP model considers the interactions between the person, environment and community surrounding, occupations engaged in and performance levels (Smith, D., & Hudson, S. (2012). The non-profit organization had a goal to improve the quality of life for individuals with intellectual disabilities by providing them with physical fitness opportunities and competition, social participation, screening and health services and advocacy. The Occupational Justice framework shows the inequalities in the healthcare system for people with intellectual disabilities. Occupational therapy's role in the healthcare system is to increase understanding and competence of providers to increase occupational justice. By providing education and advocacy, the capstone student strived to decrease health inequalities through health programming for athletes, clinicians, and the community. The capstone student hoped to increase support and care to increase participation and satisfaction in occupation.

### **Project Plan and Process**

The plan for this project included student engagement in hands-on clinical experience, population education and advocacy. Based on research and the needs of the site, the student provided and gained skills related to inclusive health for the intellectual disability population. The capstone experience was designed to help address inclusive healthcare for those with intellectual disabilities involved with non-profit organization and the community. Projects were planned and implemented on a state-wide level to increase awareness accessibility to health services.

### **Project Goals**

The following goals were developed and focused on in project planning.

Project Goal 1: Student will gain hands-on clinical experience through Non-profit organization and community programs to enhance knowledge and competence.

Objective 1: Student will communicate with state and regional program directors to determine areas of need.

Objective 2: Student will assist with Healthy Athletes programming and planning as well as present to various health programming groups.

Objective 3: Student will participate in competition events to interact closely with athletes and communicate with the community to get involved in events and education through Non-profit organization.

Project Goal 2: Student will successfully learn to advocate for athletes and educate athletes on self-advocacy to increase confidence and independence.

Objective 1: Student will participate in and lead Health Messenger's program for athletes.

Objective 2: Student will create educational resources for caregivers and community to promote positive communication skills and independence for the ID population.

Objective 3: Student will participate in planning session and create list of items for sensory rooms and kits at Non-profit organization events.

Objective 4: Student will participate in Non-profit organization needs assessment and focus groups to increase inclusive health for the ID population.

Project Goal 3: Student will identify and educate on the role of occupational therapy within Non-profit organization programming and integrate OT lens.

Objective 1: Student will develop program series focused on areas of occupation for athletes and educate on role of occupational therapy.

Objective 2: Student will educate Non-profit organization on current connections between program designs and occupational therapy practice.

### **Project Process**

In the early stages of the project, the focus was on site orientation and needs to increase familiarity with team members onsite and project timelines (see Appendix B for timeline). Project ideas from meetings prior to the start of the capstone rotation were re-evaluated based on current needs of the site and population. Capstone objectives and goals were reviewed and updated accordingly to ensure all members agreed with the direction of the project. The site mentor and student organized weekly meetings to discuss project updates through the entirety of the capstone experience. The first project addressed by the student and site mentor was the Healthy Athletes program at the statewide games' competitions. The student was involved in planning and organizing clinical directors providing services and logistics for the event. The program partnered with an online referral system for clinicians and patients that required advertisement and coordination of profile creations.

In the middle stages of the experience, a variety of projects were discussed and confirmed based on impact and importance. The student was to hold meetings and presentations addressing health topics also related to occupational therapy for people with intellectual disabilities, caregivers and family members, and the community. The site mentor and student planned for involvement in programs including Health Messengers, Young Athletes, S.O. Connected Live, family liaison committee meetings, and inclusive healthcare education on social media. Involvement in these programs was determined to be implemented based on population reached and impact level. The middle stages of the project involved feedback discussions for areas of improvement for the summer Healthy Athletes event as well as preparing and creating

educational resources and presentations for groups. A formal midterm meeting was held at a longer length than the weekly meetings to discuss progress of each project in detail and re-establish the plan for the remainder of the experience.

The final stages of the project were to include presenting at multiple meetings for different groups including athletes and caregivers. Additional projects from other areas of the site were presented for student involvement as well. The student planned to assist in the needs assessment for inclusive healthcare involving research of a target health agency, people with ID, and caregivers. Research was also completed for the creation and sustainability of sensory spaces and kits for athletes at events. During the final two weeks of the experience, meetings were held with the site mentor to discuss impact of the project on the site's target population as well as the student's clinical skills.

### **Project Implementation and Evaluation**

The populations addressed through the capstone experience included people with intellectual disabilities, family members and caregivers, site staff, and the community. Projects were implemented to advocate for the ID population and to provide services and education to these populations. The participants with intellectual disabilities were all athletes involved in the Non-profit organization sports and health programming. The athletes the student worked with were of various ages and functional levels. The majority involved in the Health Messengers program were adult aged and various independence levels. Family members and caregivers involved in the liaison committees and focus groups were parents or loved ones of person with intellectual disabilities who live with their dependent. Participation in the projects the student completed was open to all members of the Non-profit organization community. Many of the educational opportunities were provided to groups and teams that were already organized.

Communication was completed through emails and alerts for group regularly scheduled meetings.

The capstone experience projects included focus on advocacy, education, program development and hands-on clinical skills. These focus areas will be described in further detail in the following sections according to the student's core projects. Evaluation of the projects' implementation is reported according to program reach and participation as well as educational materials and resources provided.

### **Advocacy**

Involvement in the Healthy Athletes program included event planning and logistics, communication with clinical directors and promotion for the event. The Healthy Athletes events take place at the location of the state-wide competitions and involve a total of 8 health discipline areas. The health screenings are free and accessible for all athletes. At the Winter Games event, the student assisted in a leadership role to organize the space and health disciplines set-up for the 5 attending. Prior to the Winter Games as well as the future Summer Games, the student attended weekly virtual planning meetings for the events with the site mentor and stakeholder throughout the capstone experience. Discussions and planning included the development of a referral system for assisting athletes in finding follow-up care providers as needed. The referral desk was successful in helping families locate clinicians specialized in working with those with ID. To expand reach, the referral desk will be implemented at each health station for summer. An online VideoAsk questionnaire was created for clinical directors to increase awareness and comfort for athletes prior to event. VideoAsk questionnaires were also created for feedback following participation in the event from athletes and caregivers. Flyers were created to promote athlete attendance to athletes and caregivers as well as volunteering for the community and healthcare

students. The Healthy Athletes program is designed to advocate for accessible and quality healthcare services for the ID population. Clinical directors volunteer time and expertise to provide safe and free screenings for athletes. A total of over 300 athletes attended the winter event. Flyers and questionnaires regarding Healthy Athletes event are located in Appendix C.

Some of the social media sharing through the Inclusive Health Facebook page included educational and awareness materials that advocated for the ID population. These inclusive health posts and infographics are described further in the education section with deliverables attached in Appendix F.

### **Population Education**

Population education was provided to athletes through the Health Messengers program as well as family and caregivers through the Family Liaison committees. Research online and use of textbooks were supports in creating the presentations. The student presented to the Health Messengers in April for the virtual monthly meeting in addition to attending the monthly meetings to familiarize and interact with the participating athletes. The student presented on occupational therapy and sensory processing to increase health education and awareness as the topic is a heightened health condition in people with intellectual disabilities. The student prepared a sensory processing style questionnaire on Kahoot for the athletes and staff members that resulted in an increased self-understanding of sensory processing. Meetings are held virtually in the evening to maximize participation as many athletes work during the day and have limited access to transportation. Non-profit organization periodically offers Health Messenger training to be certified; originally a course was planned during the student's project, though it was cancelled due to low interest and availability.

In addition to educating athletes, the student provided an educational opportunity for caregivers and family members. An organized presentation was given virtually to a previously established Family Liaison committee and to a newly established committee in different areas of the state. 10 to 20 families attended each of the meetings to learn more about occupational therapy and ways to increased independence in activities of daily living and instrumental activities of daily living for their differently abled family members. Through asking questions and providing tips to one another in the discussion following the presentation, families reported learning new ideas to explore at home.

Inclusive health and educational resources and infographics were created for Non-profit organization Facebook and social media pages. The reach and engagement of the page was still in the beginning stages, though anyone with internet can access the page. Educational resources were created on current health topics such as COVID-19, winter freeze safety, nutrition and healthy eating, mental health and creativity, and self-advocacy. Additionally, posts of relevance and importance were shared from other profiles and resources. The site mentor, area lead, and online resources were all supports for this portion of the project.

### **Program Development and Clinical Experience and Skills**

The student gained clinical experience through all the capstone experiences. Hands-on, in person experiences included Healthy Athletes event and an area basketball competition. The capstone student gained leadership skills through co-leading Healthy Athletes with site mentor and area lead and being a games management team member for the basketball competition. Throughout the capstone experience, the student was able to meet and connect with a variety of groups within the site and community. Through the Healthy Athlete program, the capstone student worked on an interprofessional level with multiple other health disciplines. The local



Young Professionals Board was attended for monthly meetings to connect with other young professionals working to fundraise for Non-profit organization programming. The student self-reflected on leadership development and clinical experience with the site mentor on a weekly basis in meetings. The capstone project was to include a local Young Athletes event, though the execution and planning with the local school system was delayed and will be occurring post-capstone experience. The student used verbal feedback from site mentor to gauge development over the semester. The site mentor provided written feedback via online midterm and final evaluations of the student in which the student received a score of 4/4 for educational and professional outcomes.

The capstone project originally planned to host Wellness Wednesdays through the site's online state-wide program, though was deviated to presentations on group meetings due decreased of interest and reach the online platform was receiving at the time of capstone start. The site mentor and student also added a project focused on mental health and self-reflection for athletes and the community. The program will run in the month of May through the inclusive health social media pages based on a calendar the student created with daily mindful activities. The student also collaborated with the Health Messengers to educate athletes on mindfulness. Two Health Messengers expressed interest and created presentations based on areas of interest to share with other athletes. Through verbal discussion after the presentation was provided to the monthly Health Messenger meeting, athletes shared success and interest in learning more about meditation. Refer to Appendix G for the May Mindfulness calendar.

Non-profit organization International initiated an inclusive health needs assessment focused on health programming and training for local and state health agencies. The project included research on prevalent health disparities among those with IDD statewide and health

agencies that provide services for the community. After initial research was collected, the site mentor and student created a proposal for the focus area and contacted people to participate in the focus groups. State health department workers in various areas, caregivers, and family members of those with ID, and athletes were contacted to engage in 3 focus groups. Each focus group consisted of 2-6 participants to consider questions and discuss quality, awareness, and access to health services for the IDD population. The student had the leadership role of notetaker for all focus groups. The site mentor and student discussed information and areas of need following each focus group as well as recapping the meeting again after watching the recording and taking notes.

Finally, the student's occupational therapy experience and knowledge was applied to creating an itemized list of ideas, items, and online links for equipment to include in sensory spaces. The Fundamental Sports event leads met with the student to discuss ideas and planning for spaces at Summer Games. The leads and student determined benefits of sensory spaces for athletes at competition events and began initial planning for the space. The student also included items for sensory kits that each local area could use for all events with easy set-up, transportation, and limited storage space. The project was initiated later in the capstone experience timeline, so the Non-profit organization staff is working to create sensory spaces at Summer Games and apply for grant funding for future sensory kits. Appendix H includes the sensory lists. In addition to the sensory space and kit development, the student was able to add a sensory checklist to the Healthy Athlete passport profiles for participants. The passports include important athlete information such as height, weight, blood pressure and more (see Appendix I for sensory checklist). This checklist prompts athletes to describe any sensitivities they have as well as share important information the health professional working with them

would benefit from knowing. This checklist will debut on the Healthy Athletes Summer Games event to reach all participants and healthcare professionals.

### **Discussion and Impact**

Overall, the capstone experience combined a series of projects directed to increase inclusive healthcare for people with intellectual disabilities. Non-profit organization continuously works toward this goal by providing education and advocacy to the ID population, caregivers, healthcare providers, stakeholders, and the community. The project goals and objectives were designed to increase independence and involvement for those with ID in the community.

The problems the capstone projects addressed included poor communication between healthcare providers, the community and ID population and access to quality healthcare services. The capstone also addressed the limited knowledge and awareness to health education in the ID community. To address the gap of healthcare services for people with intellectual disabilities, the capstone experience projects strived to increase inclusive health programming to provide increased access to services and knowledge on health and advocating. The gaps and challenges those in the ID community face were reinforced throughout the project themes similar to the literature found by previous research publications discussed.

The student was able to achieve all the goals and objectives developed throughout the experience with updates and changes discussed with the site mentor on a weekly basis. The project changes that occurred were due to aiming to impact the most individuals and target the areas of current need. Limitations to the capstone experience includes time to implement projects. Non-profit organization has a wide variety of health programming services and areas of need. The capstone student and site mentor had to narrow down projects based on impact,

sustainability and timelines that were plausible for the 14-week capstone experience. With more time, the capstone experience could be evaluated further based on Summer Games successes and areas of improvement.

### **Impact**

The capstone experience had an impact on the student, Non-profit organization athletes, and site and for all healthcare professions including occupational therapy. The athletes and families at Non-profit organization received education, resources, and referrals to continue to grow their health network and knowledge. Health is an important part of education and advocacy for the ID population. The capstone experience helped bring awareness to working with those with ID and training for future professionals through interacting with athletes at events. Most impactful, the student gained clinical skills and knowledge to carry on to future practice as a healthcare professional. This capstone experience's broad implications and purpose for the community was to increase awareness and understanding about intellectual disabilities.

### **Sustainability**

All educational materials and handouts were provided to Non-profit organization throughout the capstone experience. The student assisted in many meetings for planning and organizing Summer Games Healthy Athletes events and sensory spaces for this upcoming season. The

Non-profit organization International focus groups for the inclusive health needs assessment were completed during the capstone timeline and will be used to further analyze for future plans of action for the statewide health department and Non-profit organization programming as following the project timeline.

### **Conclusion**

People with intellectual disabilities have a history of health disparities, though often have limited access, knowledge, communication, and quality healthcare services. These limitations in healthcare for those with ID is a significant problem that needs to continue to be addressed by all healthcare providers and the community. The capstone experience strived to increase awareness of the limitations that continue to be present in the society. The capstone project included providing accessibility to quality health services through the Healthy Athletes clinicians and volunteers. The project aimed to increase services provided by non-profit organization and community resources through educational opportunities, resource sharing, participant focus groups and other projects. There are many consistencies between previous research studies and themes of the capstone experience, though additional research needs to be done to continue to improve care for those with ID. Overall, the capstone experience increased health services and resources for the ID population and provided the student with clinical skills and impact for future involvement with the ID community and client-centered care.

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