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Fostering Independence
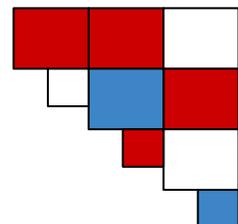
Empowered lives.
Resilient nations.

Suggesting Programs to Promote Independent Living for Intellectually Disabled Young Adults in Albania

An Interactive Qualifying Project Report
Submitted to the Faculty of the
WORCESTER POLYTECHNIC INSTITUTE
in partial fulfillment of the requirements for the
Bachelor's Degree

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Chapter 1: Introduction

Disabilities affect 15% of the global population. Disabled individuals experience impairments which significantly impact daily life (CDC, 2019). Over 200 million people worldwide live with an intellectual disability (ID) (Special Olympics, 2019). IDs range from mild to profound, resulting in varying magnitudes of impairments. ID can impair communication and daily life skills (Matson, 2009). Seemingly simple tasks like brushing teeth may be more challenging for individuals with profound ID.

Many support structures are available to assist people with intellectual disabilities. In the United States, families, schools, and community programs work to improve disabled individuals' quality of life. Parents of intellectually disabled individuals are heavily involved in their child's upbringing and continue to support them as they transition into adulthood (Gauthier-Boudreault, 2017). As of 1991, American schools provide transitional services to disabled students in accordance with the Individuals with Disabilities Education Act (IDEA). IDEA mandates that schools administer pre-college educational services to students under the age of 21 (Grigal, 2011). As individuals progress into adulthood, they rely more on community programs for support. Non-government organizations (NGOs) help disabled individuals by teaching life skills such as cooking, cleaning, and grooming (King, 2016). Curriculums also include vocational training to promote independence (Hagner, 2012).

In some countries, such as the United States, NGO services cater to both children and adults with ID. NGOs in Tirana, Albania, such as Help the Life, assist disabled children, however no Albanian community services support intellectually disabled individuals over the age of 21 (A. Bregu, personal communication, September 12, 2019). Albanian NGOs may lack funding, networking, or governance within the organization which can make it challenging to implement new services (Felix, 2013). The Leave No One Behind Program (LNB), a subsection of the United Nations Development Program (UNDP), acknowledges the lack of community resources and works to implement social services in Albanian municipalities. This program began in June
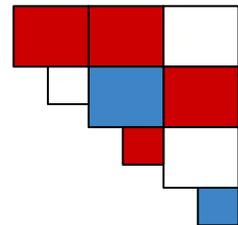
of 2017 and will remain in effect until December of 2021. LNB promotes the inclusion of vulnerable individuals in society (UNDP, n.d.).

Our project goal is to propose programs and policies to LNB which will foster independent living for intellectually disabled young adults in Albania. This assists LNB with their broader goal of including vulnerable individuals in society and improving their quality of life. We will assess the needs, desires, and limitations of disabled individuals, families, NGOs, and government officials through several interviews in Tirana. These interviews will be part of a comparative case study where each disabled individual and their immediate family members form each case. The team will ask families and disabled individuals about their daily lives and hopes for the future. We plan to speak with NGOs and government officials about their limitations in providing services. The team will apply supplemental information from these interviews to each case as deemed appropriate. By comparing cases, the team will identify themes shared by families in varying circumstances. This will enable us to create a proposal which addresses the disabled community's most prevalent concerns. Through our project, we hope to improve disabled Albanians' quality of life.
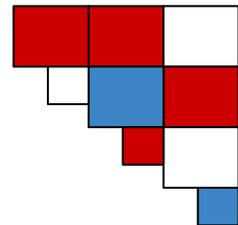
Chapter 2: Background

This chapter examines the relationship between disabilities, independent living, government policies, and support structures in the United States and Albania. Section 2.1 discusses various disabilities and the challenges they pose for living independently. Later sections, focus on programs outside of Albania, and explore how families and NGOs impact a disabled individual's transition into independent life. The final sections describe the current support structures in Albania and explain how our sponsor, the UNDP, fits into the broader picture.

2.1 The Effects of Disabilities

Throughout history, people with disabilities have faced prejudice. In a New York Times article, Solomon, a professor of clinical psychology at Columbia University (2019), considers how individuals are isolated from society due to disabilities. He describes how famous works of literature, like Shakespeare's *Richard III*, use disabilities to symbolize evil. The author asserts that the early 20th century eugenics movement led to the widespread vilification of disabled people. American court cases and medical practices, philosophers and ethicists, and genocidal dictators like Hitler all promote the removal of disabled people. Solomon argues that even today, doctors often tell parents about the issues they will face raising a disabled child, as opposed to the congratulations they would give to a non-disabled child's parents (Solomon, 2019).

The United States Center for Disease Control (CDC) groups disabilities into three categories: participation restrictions, activity limitations, and impairment. Examples of disabilities common in the world include attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy, fetal alcohol spectrum disorder, hearing loss, language disorder and speech disorder. These affect about one in four people in the United States (CDC, 2019). The World Health Center and The World Bank (2011) found that disabilities affect 15% of the global population. Over one billion people experience impairments in their daily life due to their disabilities.
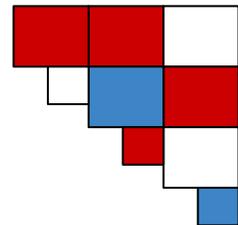
Intellectual disabilities (IDs) make up one category of disabilities. 200 million people worldwide have an ID (Special Olympics, n.d). The American Psychiatric Association (APA) defines an intellectual disability as causing impairments in mental abilities grouped by three domains: conceptual, social and practical (DSM-5, 2013). Reading, memory, knowledge, reasoning, math, language and writing comprise the conceptual domain while social judgement, having friends, empathy and interpersonal skills form the social domain. The practical domain includes independent living skills such as managing finances, vocational skills, personal hygiene and organization. Individuals with ID may also exhibit challenging behavior. Psychology researchers and social service professionals in the UK conducted a study which classifies challenging behaviors as self-injurious or aggressive-destructive. These behaviors may involve hair pulling, head hitting, or biting others (Bowring et al., 2017).

Intellectual disabilities range in severity from mild to profound. Individuals classified as having a mild intellectual disability have the ability to learn daily life skills, and can live life independently without significant support. Those who have a moderate disability can travel to familiar places by themselves, and can achieve personal care with some support. However, these individuals have developmental delays in speech that limit them to simple forms of communication, and can have difficulties in social settings. Individuals with severe intellectual disabilities need supervision in social situations, can learn self-care and daily routines that are simple, but cannot live independently without supervision. It is beneficial for individuals with a severe ID to live with family members or in a group home. Although those with severe ID have reduced communication skills, they still have the ability to understand speech. A profound intellectual disability includes physical limitations and significantly impaired communication. Individuals with a profound intellectual disability require close supervision and are unable to live independently without support. It is common for people with a profound ID to have a congenital disorder such as Down syndrome, cerebral palsy or a cleft lip (Sattler, 2002; DSM-5, 2013; Gluck, 2014; Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders, 2015; Sattler, 2002 and Bowring et al., 2017).

The following table describes the impairments that come with each severity of ID.
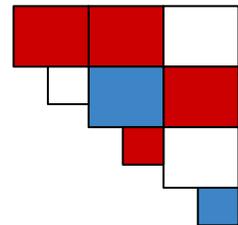
	Conceptual Domain	Social Domain	Practical Domain
Mild	In preschool children, there may be no obvious conceptual differences. For school-age children and adults, there are difficulties in learning academic skills needed to meet age-related expectations. In adults, abstract thinking, executive function (e.g., planning), and short-term memory, as well as functional use of academic skills are impaired.	Compared with typically developing age-mates, the individual is immature in social interactions. For example, there may be difficulty in accurately perceiving peers' social cues. Often noticed by peers, There may be difficulties regulating emotion and behavior in age-appropriate fashion.	Individuals need some support with complex daily living tasks in comparison to peers. In adulthood, supports typically involve grocery shopping, transportation, home and child-care organizing, nutritious food preparation, and banking and money management. Support is typically needed to raise a family.
Moderate	All through development, the individual's conceptual skills lag markedly behind those of peers. Ongoing assistance on a daily basis is needed to complete conceptual tasks of day-to-day life, and others may take over these responsibilities throughout the lifespan.	Friendships with typically developing peers are often affected by communication or social limitations. Significant social and communicative support is needed in work settings for success.	The individual can care for personal needs involving eating, dressing, elimination, and hygiene as an adult, although an extended period of teaching and time is needed for the individual to become independent in these areas, and reminders may be needed.
Severe	Attainment of concepts is limited (e.g., money, time, quantity). Caretakers provide extensive supports for problem solving throughout life.	Spoken language is quite limited in terms of vocabulary and grammar. Speech may be single words or phrases, and communication are focused on the here and now within everyday events. Relationships with family members and familiar others are a source of pleasure.	The individual requires support for all activities of daily living, including meals, dressing, bathing, and elimination. The individual requires supervision at all times. The individual cannot make responsible decisions regarding well-being of self or others.
Profound	Conceptual skills generally involve the physical world rather than symbolic processes. The individual may use objects in goal-directed fashion for self-care, work, and recreation. Motor and sensory impairments may prevent functional use of objects even if certain visuospatial skills are intact (e.g., can match objects based on physical characteristics seen visually, but cannot translate to appropriate use).	The individual has very limited understanding of speech or gesture. He or she may understand some simple instructions or gestures, and expresses his or her own desires and emotions largely through nonverbal, nonsymbolic communication. The individual enjoys relationships with well-known family members & caretakers primarily.	The individual is dependent on others for all aspects of daily living. Although, individuals without severe physical impairments may assist with some daily work tasks at home, like carrying dishes to the table. Simple actions with objects may be the basis of participation in some vocational activities with high levels of ongoing support.

Table 2.1: Table of Severities of Intellectual Disabilities (Medina, 2018)

Living independently with disabilities requires individuals to overcome or adapt to their limitations. Independent living may mean different things for individuals with different severities of ID. Regardless of an individual's specific impairments, adults need several things to live a successful independent life. Personal safety and hygiene skills such as bathing, grooming/shaving, or toileting are needed on a day-to-day basis. In addition, cleaning skills such as vacuuming, dusting, or folding laundry help to keep living areas clean. While hygiene is a priority, food is essential for survival. Individuals must have some way of consuming nutrients. Someone with mild intellectual disability may be working towards grocery shopping and cooking meals independently while someone with profound intellectual disability might need a caretaker to prepare meals and snacks throughout the day.

Another element of independent living is community involvement. This can take many forms. Individuals with a mild disability may be able to work towards community-based employment while someone with a profound disability may focus more on volunteer or recreational activities. If employment is a viable option, finance management skills will help people maintain a budget
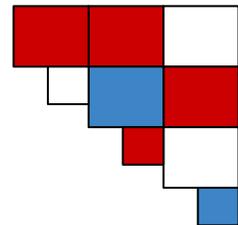
and pay bills. Individuals must be capable of using some form of transportation to navigate their communities. Whether walking, driving, public transit, or other arranged transportation, individuals will need a way to travel to and from their daily community activities. While in the community, individuals interact with other people throughout the day. Self-advocacy and social skills help individuals function in society. Communication skills allow people to express themselves and ask for help when needed. Good manners, patience, and sharing all help an individual form meaningful social connections and work well with other people. The impairments from ID can make the transition into independent living especially challenging due to limitations relating to independent living skills. There are several supports in place which assist intellectually disabled adults in the United States and other countries.

2.2 The Role of Family, Governments, and NGOs in Supporting Intellectually Disabled Individuals Outside Albania

Role of Parents

Parents play a significant role in their children's lives and often influence their decisions on a daily basis. As primary caretakers, parents are likely to have intimate knowledge of disabled individuals. Researchers have argued that the perspective of parents should be considered when examining the quality of transition services. Disabled individual's desires may not align with their parents' wishes. In one study, psychiatric researcher Zoe Huntly compares the views of autistic individuals, their parents, and professionals researching ASD. Through interviews, the study found that people with ASD viewed their struggles and goals differently than their parents. Information in publications also conflicted with the views of autistic individuals (Huntley, 2013). While parents and their children disagree, parents of disabled children can be a large source of support.

Researchers Gauthier-Boudreault, Gallagher, and Couture from the Université de Sherbrooke in Quebec, Canada, conducted a study to determine if current disability services, in Canada, effectively help parents with the transition process. They conducted interviews with 14 parents of young adults with disabilities. Each parent participated in two interviews, separated by five

weeks. The first interview established the parents' situations. The second round of interviews further explored the topics found in participant responses from the first round of interviews. Both interviews involved open ended questions. Finally, researchers organized data thematically to see clear connections between emphasized issues. The graphic pictured below shows the information about problems faced by individuals and their families during the transition period. It shows that before the age of 21, the lack of programs primarily affect parents negatively. After a young adult turns 21, the lack of programs can negatively impact an individual and their family (Gauthier-Boudreault, 2017).
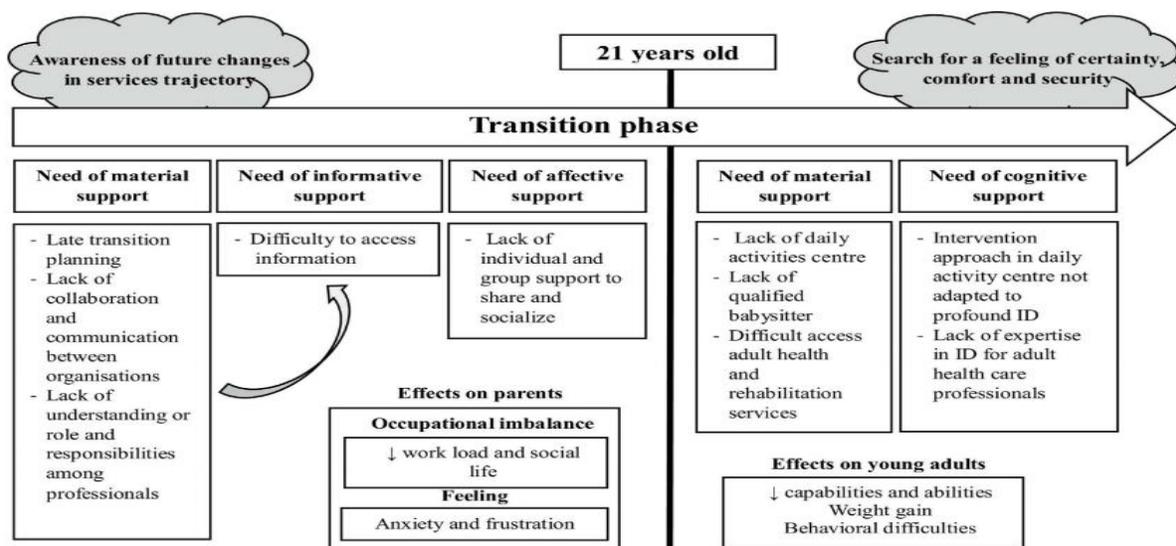
Figure 2.2: Transition diagram for young adults with disabilities

Gauthier-Boudreault, Gallagher, and Couture concluded that the needs of parents and their children are not being met by current services. The primary concerns raised by the study include a lack of services or programming for adults with disabilities, a lack of expertise in intellectual disabilities outside of pediatric care, and an absence of communication between existing programs. At the age of 21, students leave school and are no longer covered by education programs. The burden of the transition process fell largely on the parents unless they fought with services for assistance (Gauthier-Boudreault, 2017).
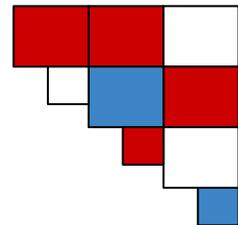
Role of government in US

Parents often turn to community programs and government supports for additional assistance once their child leaves the education system at the age of 21. In the United States, each state has a different department which assists intellectually disabled individuals. The implmentation of government services helps to counteract discrimination disabled individuals have faced in the past. In Massachusetts, intellectually disabled young adults who have aged out of the education system can receive services from the Department of Developmental Services (DDS). DDS serves both children and adults who have various disabilities including ID and ASD (Commonwealth of Massachusetts Department of Developmental Services, 2019). DDS matches each family with a service coordinator located at a nearby office. First, the service coordinator evaluates the individual's goals and preferences. The coordinator reviews the individual's history and compiles information from family members, healthcare providers, and educational records to identify the individual's current needs and determine the most beneficial services. If the initial evaluation deems the disabled individual eligible, the coordinator develops an Individual Service Plan (ISP) while considering the input of the disabled individual. ISPs are very similar to the IEPs used in educational programs for students under the age of 21 (Department of Developmental Services, 2017).

Each state's government uses some form of ISP to state the disabled individual's goals, the objectives set to achieve these goals, and the programs or services that will assist the individual in completing their objectives. A detailed description of each goal includes a method of evaluating the objective. This allows the service coordinator and the disabled individual's care team to measure the progress of goals. In Massachusetts, the DDS coordinator, the disabled individual, and their care team review the ISP annually to adjust content. For example, completed goals could be removed and replaced with new goals and new required services. Each state has their own policies for regulating the modification and creation of ISPs, but all care plans emphasize the input and preferences of the disabled individual (Department of Developmental Services, 2017). The ISP aims to improve disabled individual's quality of life. In Massachusetts, once the ISP has documented suggested programs, the service coordinator refers the disabled individual to local NGOs which provide the necessary services. NGOs and other community programs help individuals achieve their ISP goals in an effort to promote personal
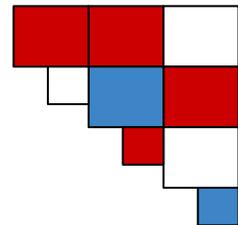
growth, community involvement, and self-determination (Massachusetts Department of Developmental Services, 2016).

Role of Community Programs

Many programs outside of Albania assist intellectually disabled adults by teaching independent living skills. Every program emphasizes person-centered planning within their course curriculums. One study suggests that residential programs monitor young adults with developmental disabilities and ensure they develop life skills properly with supervision. In this study, a month-long program with constant caretakers taught disabled young adults city safety and mobility skills. Occupational therapist Gillian King from the University of Toronto discusses how the residential program framework allows disabled individuals to feel more comfortable when learning. Disabled individuals scored higher on daily task assessments when they were on-site. Individual's scores increased after completing the program. The curriculum covered things such as cooking, shopping, and safety. After living with support for one month, these disabled young adults developed strategies to live independently (King, 2016). Two other residential programs through Bell Socialization Services and Stewart Home & Schools teach individuals hygiene and cleaning skills which may be a part of their ISP (ID Residential Services, 2019; Independent Living for Intellectual Disabilities, n.d.).

Several successful residential programs already provide quality service. Two social work professors from La Trobe University in Victoria, Australia evaluated a residential program for individuals with ID and challenging behavior (Clement, 2011). Professors Clement and Bigby (2011) described how the program utilized an overall *program theory* or practice framework. The framework outlined the specific expectations of program staff and included aspects such as active listening (including body language), positive language, choice and control (self-determination), plan of the day (routine), and active support (support level adjusted to meet the individuals need). The researchers modified the framework to fit specific situations the staff encountered. The program management team explained staff roles in detail with simple language. The clear documentation helped employees follow the program model (Clement and
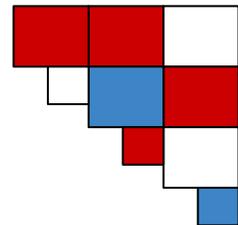
Bigby, 2011). This program's success highlights the importance of good management in the residential setting.

In addition to residential programs, there are many day programs in the United States which help adults with ID live more independently and teach disabled individuals various life skills. Most day programs offer habilitation which emphasizes community involvement. Two programs in the United States, Opportunities Unlimited of Niagara and Rising Ground, both offer volunteer experiences in daycares, nursing homes, and animal shelters which provide opportunities to gain vocational skills (Opportunities Unlimited, 2019; Helping children, adults, and families rise above their challenges, 2019). Additional field trips into the community allow individuals to work towards ISP goals while gaining social skills (Helping children, adults, and families rise above their challenges, 2019). The BUDD Day Treatment program also works to improve individuals' social skills such as anger management through walking and yoga therapy (Budd Day Treatment, 2018). Programs in the United States promote independent living among the intellectually disabled community by teaching vocational skills in various formats. Opportunities Unlimited of Niagara uses incentivized trainings in the food service and environmental service industries (Opportunities Unlimited, 2019). Rising Ground uses on-site job opportunities like delivering mail to staff so individuals gain experience in a familiar environment (Helping children, adults, and families rise above their challenges, 2019). Other programs use assistive technology or horticulture therapy to supplement their vocational skill curriculums (Charles River Center, 2019; Employment and Job Training for People with Disabilities, 2019).

American programs also support intellectually disabled adults with managing finances, preparing meals, and using public transportation. The staff at one Faith-Based-Organization, Mosaic, help individuals maintain a budget, assist individuals with grocery shopping, and teach individuals how to cook meals (Mosaic, 2019). Some services are better suited for individuals with mild intellectual disability. For example, at the Rising Ground program, staff accompany individuals on a subway to teach transportation skills while at Mosaic, staff members drive disabled adults to and from their medical appointments (Helping children, adults, and families rise above their challenges, 2019; Mosaic, 2019). Different severities of ID naturally require different levels of support.

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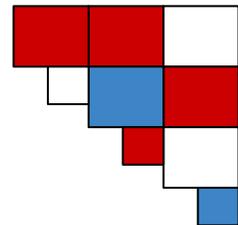
To assess the operations of American NGOs working with intellectually disabled individuals, we conducted an interview with Kristen Foley, the program manager of the Forsberg Independent Living Program (FILP). This program operates in Massachusetts and is part of the Ascentria Care Alliance (ACA). The ACA is a non-profit organization in New England offering a variety of services to vulnerable individuals. The FILP specifically serves intellectually and/or developmentally disabled adults over the age of 23. Individuals are referred to this program through the Department of Developmental Services (DDS). The FILP offers different forms of services which include in-home supports, residential programming, and community-based supports. Curriculums cover skills such as taking public transportation, brushing teeth, communicating with landlords, or shopping for groceries (K. Foley, personal communication, September 19, 2019).

Foley describes FILP's approach as person-centered, meaning program goals align with the desires of clients. All programming in the United States and most other countries follows this same approach. Foley acknowledges that desires of disabled individuals are important even if they differ from research findings. The FILP evaluates individuals and reviews their ISP upon intake to determine what specific services they will receive. (K. Foley, personal communication, September 19, 2019).
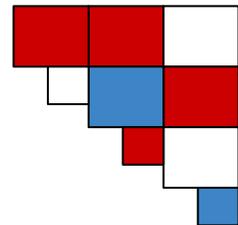
Foley also emphasizes the importance of staff training. Safety risks such as aggressive behavior from disabled individuals can be minimized with properly trained staff members (K. Foley, personal communication, September 19, 2019). The FILP utilizes a handbook similar to the program framework from the Australian residential program (Clement, 2011). Their mission statement is clearly communicated to all staff members and specific staff expectations are described in detail. This handbook is one of the many forms of documentation Foley described during our interview. She emphasizes the importance of organized documentation and continuous data collection. The FILP staff members input client data and field notes into a spreadsheet. Staff members compile data quarterly and annually. Program management can then measure progression towards ISP goals. Other forms of documentation help the ACA request additional funding. If program limitations are organized and easily accessible, donors understand
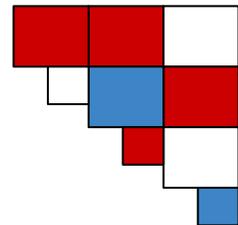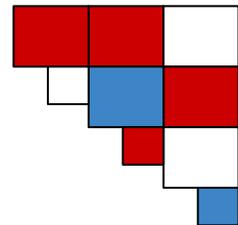
how their money is being used and which areas of the program need more support. Clear documentation, data collection, evidence-based curriculums, staff trainings, and person-centered planning are all important components of the Forsberg Independent Living Program (K. Foley, personal communication, September 19, 2019).

The following table summarizes some of the services provided by programs in the United States. The left column describes which area of independent living the described services assist with. The middle column summarizes the specific services in place. Numbered services from the middle column correspond with the numbered program names in the right column. For example, incentivized trainings for food service and environmental service industries are offered by Opportunities Unlimited of Niagara and aim to assist individuals with vocational skills.

Skill/Aspect of Independent Living	Services in US Assisting Intellectually Disabled Individuals with Specific Skill/Aspect of Independent Living	Name of Program(s) Offering Services
Vocational Skills/Employment	1. Incentivized trainings for food service and environment service industries 2. Person-centered employment services and assistive technology 3. Horticulture therapy which teaches gardening techniques 4. Job experiences such as mail delivery and cafe meal preparation on site. On-the-job mentoring.	1. Opportunities Unlimited of Niagara 2. Easterseals 100 3. Charles River Center 4. Rising Ground
Community Involvement	1. Volunteer opportunities in daycares and nursing homes. Individuals can also volunteer to	1. Opportunities Unlimited of Niagara 2. Rising Ground

|		
	deliver meals. 2. Volunteer opportunities at animal shelters. Hiking, museum trips, and zumba classes in the community.	
Social Skills/Communication	1. Course curriculum designed and taught by college students 2. Assistive technology to help with reading and writing 3. Yoga and walking therapies to teach individuals to cope with anger and transitions 4. Course curriculum which teaches individuals to communicate with landlords	1. Opportunities Unlimited of Niagara 2. Mosaic 3. BUDD Day Treatment 4. Forsberg Independent Living Program
Housing	1. Twenty-eight homes across MA with live-in program staff	1. Charles River Center
Food Prep/Cooking	1. Staff help individuals shop for groceries and teach individuals to cook meals	1. Mosaic
Finance Management	1. Staff help individuals maintain a budget	1. Mosaic
Transportation	1. Staff provide rides to and from medical appointments 2. Staff accompany individuals on subway to teach transportation skills	1. Mosaic 2. Rising ground

Hygiene/Cleaning	1. In-home lessons on brushing teeth 2. Residential program with 24/7 staff support and training on personal hygiene 3. Supervised independent living with routine which has built-in clean up days	1. Rising Ground 2. Bell Socialization Services 3. Stewart Home & Schools

Table 2.3: NGO Services in the United States

2.3 Disabilities in Albania

Albania, like many other parts of the world, is affected by disabilities. The Albanian central government collects national data to determine which types of disabilities are most prevalent. The government conducted the most recent national census in 2011, collecting information on the types of disability impairments. Documented impairments included cognition, self-care, communication, mobility, hearing and seeing. 1.5% of Albanians have impaired communication. Cognition and self-care impairments affect 3.6% of the Albanian population.

The following figure shows data from the 2011 national census in Albania (Ferré, 2015).
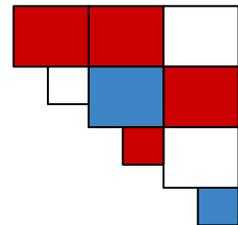
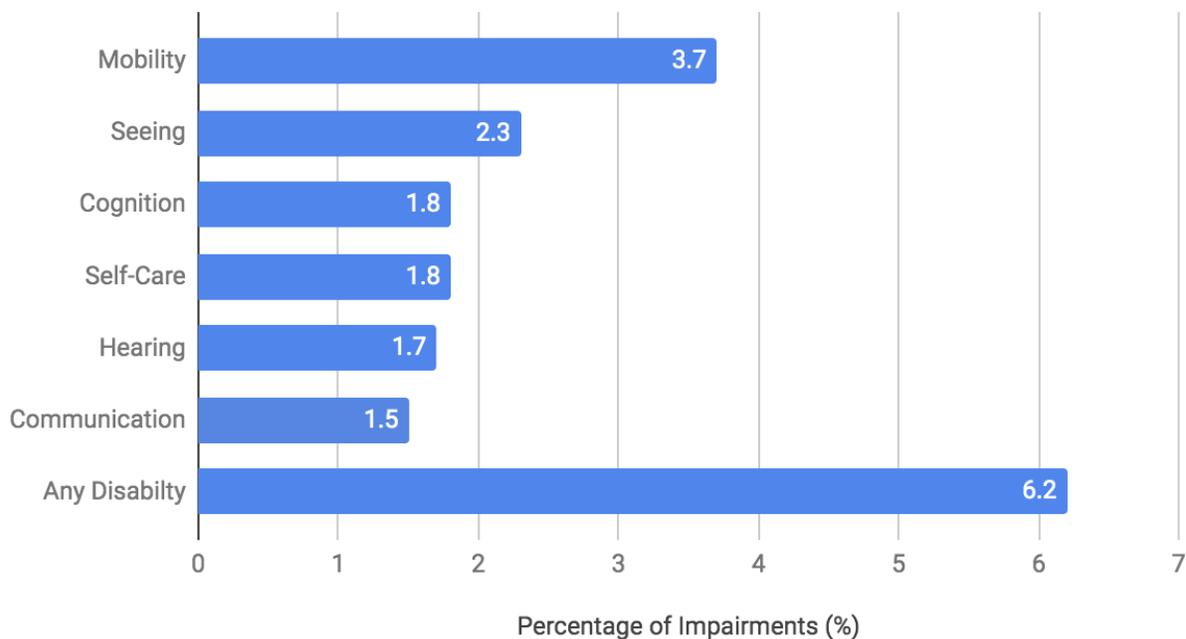## Impairments Related to Disabilities in Albania

Figure 2.4: Impairments related to in Albania

NGOs in Albania try to address the needs of the disabled community. The Albanian government proposed their first mental health policy in 1996, eventually leading to the Action Plan for the Development of Mental Health Sources in 2013. This plan remains in effect until 2022. The WHO (World Health Organization) and the MoH (Ministry of Health) help implement mental health laws and policies in Albania (Frasheri, 2016). In addition, the Global Autism Public Health (GAPH) initiative has also assisted Albania. GAPH is an international effort which develops policies and programs regarding individuals with ASD. GAPH utilizes one National Advisory Committee (NAC) per country which includes government officials, advocates, and other professionals. This team develops programs and laws that fit the priorities and limitations of their country's communities. Other components of GAPH include an awareness campaign, trainings, and data collection to assist public health services. GAPH has assisted Albania by bringing together the Albanian Children Foundation (ACF) and Autism Speaks in 2008. These
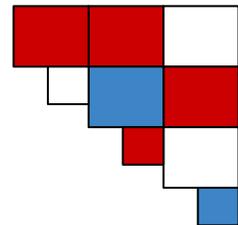
organizations met to prioritize goals such as translating available research into Albanian and establishing an ACF library on autism. ACF also opened the Fly for Life (FFL) Center in Tirana in 2009, which was the first early intervention center in Albania for children with ASD (Wallace, 2012). Albania has 6 special schools for children with disabilities (in Tirana, Durres, Elbasan, Vlora, and Korca). There are three daily centers and three residential centers mainly for those who suffer from intellectual disability. These centers are for adults and people who have difficulty living alone. There are also two national institutions in Albania: one for deaf people and one for blind people. These institutions assist and train the disabled to complete daily tasks (Balla, 2015).

Although there are programs and policies in place for disabled Albanians, Eneida Frasheri and Dr. Eris Dhamo (2016) from the University of Tirana, found that not all of them are effective in teaching independent living skills. Albania lacks the financial resources to improve mental health services (Frasheri & Dhamo, 2016). Laws to protect intellectually disabled individuals may be in place, however a lack of mental health facilities, epidemiological data on these people, and mental health services in rural areas was found due to a shortage of resources. In more wealthy areas, benevolent people provide donations. However, some areas lack funding because people are unwilling to help or are incapable of making donations. Frasheri mentions the need for more facilities and services which suggests that issues with existing structures persist (Frasheri, 2016).

In another Albanian study, 100 people with disabilities were surveyed in Tirana. The study consisted of 50 adults and 50 children, 55 of which were males and 45 of which were females. The data showed that people feel isolated from society, either due to physical barriers such as damaged sidewalks and inaccessible building entrances or psychological factors such as stigma. Individuals' responses also indicated a dissatisfaction with current disability services in place. Specifically, surveyed individuals feel there is a lack of communication between state and individual health services, and most participants stated "the medical services are minimal and often corrupt" (Kllogjri, 2017). Individuals felt that communities lacked awareness of disabilities. Sixty-five percent of people felt that public health services do not benefit them. This suggests that current resources and government policies are not successfully accommodating disabled individuals' needs. Seventy-five percent of surveyed individuals had a physical disability (Kllogjri, 2017). While the most common disability may involve physical limitations,
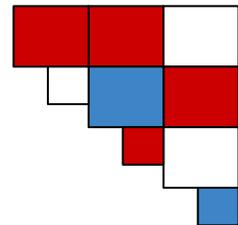
there are no fully formed community programs which assist intellectually disabled young adults in Albania (A. Bregu, personal communication, September 12, 2019). The lack of community programming has motivated our focus on intellectual disabilities.

Currently, Albania lacks a complete program which can provide support to intellectually disabled individuals over the age of 21. There are several small organizations which assist children with disabilities. A group of parents of disabled children started MEDPAK, an organization which lobbies for disability rights in Albania, in 1993. MEDPAK worked with an organization called Save the Children to lobby for inclusive schools. The Jonathan Center and Down Syndrome Albania are two NGOs that work with children who have Down syndrome. The programs help children gain necessary life and social skills relating to personal care, hygiene, communication, and socialization. The Albanian Children Foundation (Fondacioni Femiojet Shqipetare) is the largest organization helping disabled children in Albania. Some of their programs provide assistance to children with developmental disabilities. Another Albanian NGO, The Help the Life association (HTL), has a wide array of goals focused on improving the lives of disabled individuals in Albania. HTL lobbies for disability rights and focuses on political advocacy for disabled children. HTL has also worked with disabled young adults aged 21-30. They have recently worked with disabled young adults to provide vocational training. Additionally, The Albanian Disability Rights Foundation promotes and protects the rights of disabled individuals of all ages in Albania. This provides disabled people with more opportunities and allows them to become more involved in the country's social and economic life. Although many organizations seek to help disabled individuals, there is still much to be done in Albania concerning disabilities.

2.4 The United Nations Development Program: Leave No One Behind

The UNDP's Leave No One Behind Program (LNB) is sponsoring our project. LNB empowers vulnerable individuals in Albania (UNDP, 2019). Its goal is to bring systematic change in the field of social protection and to bring change to social services that will gradually ensure basic human rights to all Albanians. LNB works closely with central and local governments to implement social policies that assist vulnerable individuals.


Figure 2.3: Leave No One Behind Logo

LNB receives funds from the Swiss Government and UN agencies in Albania such as UNDP, United Nations International Children's Emergency Fund (UNICEF), United Nations Fund for Population Activities (UNFPA), and UN Women. LNB uses the approach of UN Delivering as One (DaO), which brings together the expertise of multiple UN agencies (UNDP, n.d.).

LNB is committed to improving capacities of national institutions that implement their program framework. In 2019, LNB is prioritizing the improvement of social services. This goal will be accomplished through local interventions where most individuals access services. LNB's framework involves educating NGO employees on best practices when working with intellectually disabled young adults, providing effective curriculum for these disabled individuals, and generating new knowledge about useful practices for programs. LNB is not yet implementing NGOs, but theoretically will be within a few years (UNDP, n.d.).

To assist LNB with their framework, our group will be working to find best practices and useful curriculums that we can apply to local NGOs that would like to assist intellectually disabled young adults.
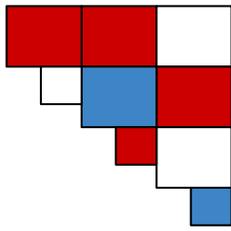
Chapter 3: Methods

Our goal for this project is to work with Leave No One Behind (LNB) under the United Nations Development Program (UNDP) to propose programs which foster independence for young adults with intellectual disabilities (IDs) in Albania. Our program suggestions will assist LNB with its goal of including vulnerable individuals in society. We have identified four objectives to fulfill our goal:

- Assess the desires and concerns of intellectually disabled young adults' family members and caregivers.
- Assess the desires and concerns of intellectually disabled young adults.
- Determine the skills acquired by intellectually disabled individuals during childhood and adolescence.
- Determine the supports and limitations of local NGOs and the local government in Tirana.

These objectives will enable us to consider the perspective of each stakeholder when suggesting programs to LNB.
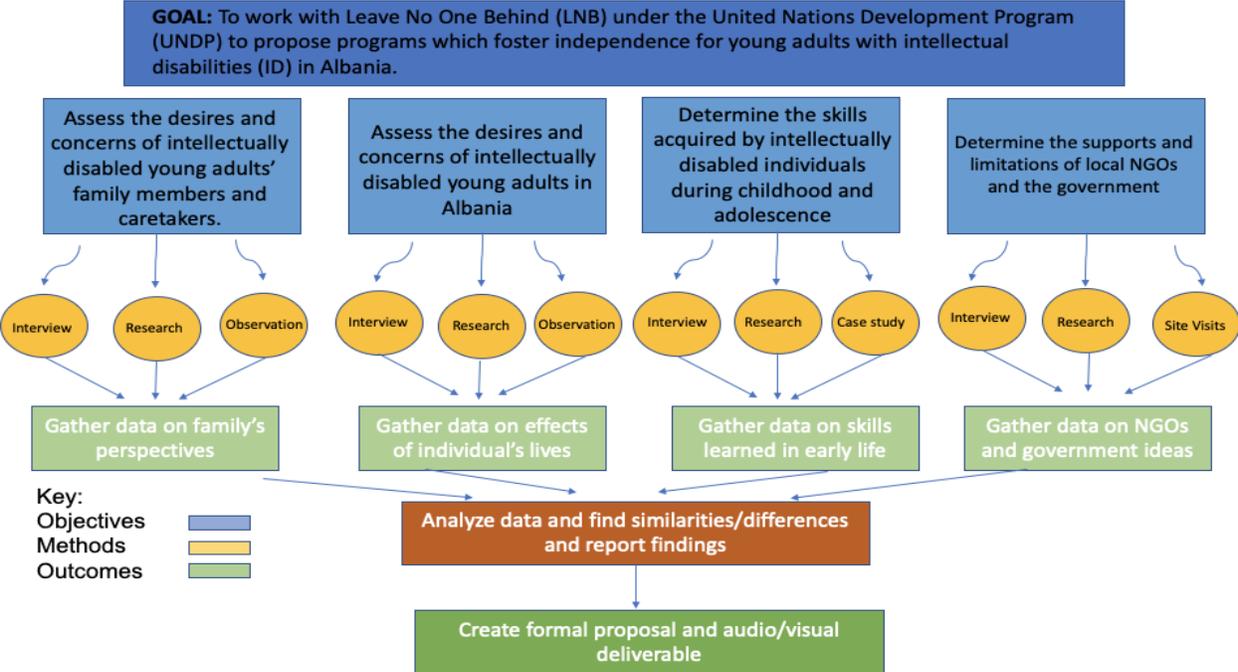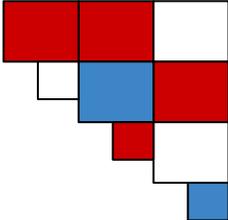

Figure 3.1: Methods Overview

3.1 Objective One: Assess the Desires and Concerns of Disabled Young Adults' Family Members and Caregivers

Pilnick (2011) and Gauthier-Boudreault (2017) argue for the importance of families in the lives of disabled individuals. By interacting with the education system and various community programs, family members can provide insight into their positive experiences and talk about their struggles with these support structures. We plan to ask parents of intellectually disabled children about the programs they have accessed, the NGOs that have helped their children, and their knowledge of available services. Additionally, the parent interviews will prepare us for interviews with their children. The families will explain how the young adult's disability may affect the interview. After the interviews, We will assess the biggest challenges faced by families, as well as what services, if any, have been the most helpful. Interview questions include:

- How do you help your child throughout the course of the day?
- How does your child's disability impact the completion of daily tasks?
- Which community programs are most helpful to you and your child?
- What type of support could your child benefit from?

A full list of interview questions can be found in Appendix C.

We will use LNB contacts to locate our interview sample which will include at least five families in Tirana. Interviews with families of disabled individuals will address the research questions of objectives one, two, and three. We will stratify our sample by the severity of the young adults' disabilities A detailed sampling strategy is described in Section 3.2, Assessing the Perspective of Intellectually Disabled Individuals.

Two team members will meet with each family. One student will interview while the other takes notes. We plan to interview parents before their children. The team will conduct the interviews in the homes of families, or in another place the family feels comfortable. These semi-structured
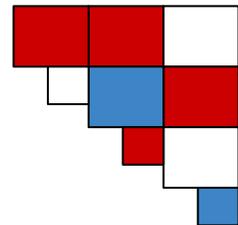
interviews will be based on the questions listed in Appendix C. An analysis of the interview responses will help us suggest programs to the UNDP as described in Section 3.5 Data Analysis.

3.2 Objective Two: Assess the Perspective of Intellectually Disabled Young Adults in Albania

As noted in the previous chapter, program goals for the UNDP should align with the views of individuals with ID. Many successful community programs use person-centered planning (K. Foley, personal communication, September 19, 2019). We plan to conduct in-depth interviews with at least five intellectually disabled young adults, aged 21-30. The team will assess their needs, desires, and struggles related to independent living. We hope five sets of interviews will allow us to accurately represent the demographics of the Tirana disabled community. NGOs will reach out to their beneficiaries and ask if anyone is willing to participate in our study. These initial interviews may connect us with other interviewees via the snowball effect (Gauthier-Boudreault, 2017). Our sample aims to include individuals with varying degrees of ID in order to consider a range of needs in our programming suggestions. Independent living may look different for each individual in our sample. For example, at least one person will require in home support while others may be successful with only minimal support in community settings. Given the seven-week time frame, our sample will be limited to people residing in Tirana. We hope the sample will include at least two individuals of each gender and reflect a range of economic statuses to consider a spectrum of needs in Tirana. Interviewee availability and time constraints will determine the exact number of interviews and specific demographics of participants. Interview responses will be one component of a comparative case study, fully described in Section 3.5 Data Analysis.

Before meeting with the individuals, our team will speak with family members to understand how the ID may impact the interview. The team will ask family members to describe their child's disability. We will use this information to determine appropriate interview techniques such as using pictorialized questions, reading questions aloud, or inviting personal questions to make participants feel more comfortable. The team will conduct interviews in an environment
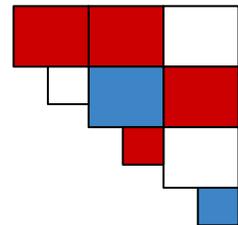
familiar to the individual, although it is expected that most will take place in the participant's home. Interviews with disabled individuals may be challenging due to communication barriers and/or memory impairments. Intellectually disabled individuals may feel uncomfortable or have difficulties verbalizing thoughts (Corby et al., 2015). Our team will adapt to challenging situations and listen to family members and caregivers suggestions when considering the best form of communication.

The interviewee may feel more comfortable if their family members are present during interviews. Parents may be asked to read the interview questions, however the team will attempt to prevent parents from guiding our conversations. Intellectually disabled individuals can be easily swayed by external influences and may give biased responses when asked directional questions. The interviews will contain open-ended questions with simple language to minimize response bias (Corby et al., 2015). If possible, we will meet with participants at least three times within a three-week period. The first meeting will run for one hour, focusing on introductions and explaining the goal of our project. Subsequent meetings will allow the team to develop a rapport with the interviewee as they become more comfortable. The second and third interviews will include a topic-based guideline, however specific questions will stem from interviewee responses (Corby et al., 2015). Two team members, and a translator will conduct the interviews. If needed we will explain interview questions to the translator provided by LNB. The translator will speak in Albanian to the interviewee and the team will observe the participant's body language to pick up on possible misinterpretations. We plan to speak with our translator ahead of time to ensure he or she uses simple language. The team will initiate interview breaks if participants show signs of stress or discomfort (Corby et al., 2015). Throughout the interview, one team member will serve as the primary interviewer and give their undivided attention to the interviewee and any family members present. Another team member will observe the interviewee 's body language, take notes, and communicate with the translator.

Prior to the interview, we will request permission from families to use any quotes, drawings, pictures, or audio recordings produced during the interview process. If the interviewee gives consent, we will record the second and third interviews to transcribe and analyze responses later on. The full consent script can be found in Appendix A.
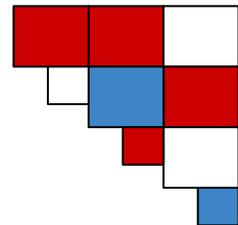
Interviews with intellectually disabled young adults will assess the needs, desires, perceived challenges, and goals of each participant. A detailed interview protocol and full list of interview questions can be found in Appendix D.

Some sample interview questions are listed below:

- What do you do during the day?
- What do you like to do for fun?
- Do you need help doing anything?
- Who do you like to spend time with?

Interviews may include a variety of exercises which actively engage families. Participants could be asked to draw a picture of their ideal future (Chevalier & Buckles, 2013). Individuals with disabilities and their families may be asked to take part in photo elicitation. This interview technique uses photography as a form of data collection (Rose, 2016). If this method is deemed appropriate, disabled individuals will take photographs of their favorite places or objects while family members will take photographs of their daily activities. We will ask participants about the pictures they have taken during the second and third interviews. Photo elicitation will serve as a talking point which encourages open conversation and allows family members to observe their own reality from a distance, bringing new awareness to seemingly mundane scenarios (Rose, 2016). In addition, family members may be asked to keep a journal which documents their daily experiences. These activities will allow us to form meaningful connections with our interviewees and perceive their reality as accurately as possible (Seidman, 1991).

In addition to program suggestions, our team plans to produce an audio-visual deliverable which communicates the daily life stories of disabled young adults, family members, and caregivers. This deliverable may include images of drawings, sculptures, and/or photographs produced by the interviewees. With the interviewees' permission, we will combine their artistic creations with interview audio recordings to communicate their hardships and hopes for the future. English subtitles may be added for non-Albanian viewers. We will prioritize anonymity and individuals
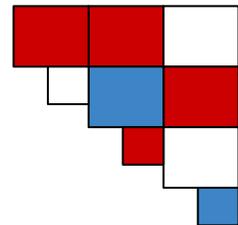
will be asked multiple times if they are still comfortable with their personal content being used. This additional deliverable could tell a powerful emotional story which raises awareness for the disabled community of Albania. The presentation aims to empower vulnerable individuals and encourages the inclusion of all people, supporting LNB's ultimate mission.

3.3 Objective Three: Determine the Skills Acquired by Intellectually Disabled Individuals During Childhood and Adolescence

We hope to identify the skills learned by disabled individuals throughout their lives to determine the most beneficial program curriculums. Schools, community programs, peers, family members and health care professionals all may have taught these skills. Our research will focus on life skills needed to live independently. Our project fosters independent living, however the severity of an individual's ID will determine the degree to which an individual can live independently. For example, a person with stronger vocational skills and weaker hygiene skills may work independently while living at home with family members. Someone with a mild intellectual disability may be able to learn the skills to live on their own without in home support. In addition, family members and disabled individuals will evaluate the education system so we can avoid problems they identify in our proposal. Interviews will explore the questions below. The full set of interview questions can be found in Appendix E.

- Do you think the education system prepared your child for life after school? Why or why not?
- Which skills were the most difficult for your child to learn?
- Which skills were the easiest for your child to learn?
- What qualities do you value most in a teacher?

We will interview at least five sets of parents of children with a variety of intellectual disabilities. The team will use the sampling strategy described in Section 3.2 to determine our parent sample. Semi-structured interviews with open-ended questions will allow individuals to elaborate on important topics. We will ask permission from families to record audio during
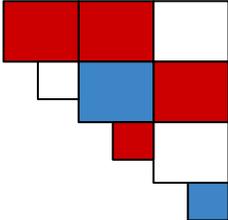
interviews and maintain confidentiality with all interview materials in accordance with our consent script shown in Appendix A.

3.4 Objective Four: Determine the Support Local NGOs and the Government Provide to Intellectually Disabled Young Adults and Assess their Limitations

NGOs are currently assisting intellectually disabled individuals in Albania. We plan to determine the supports provided by NGOs and the local Tirana government while identifying the areas they believe need more assistance. We will focus on organizations in Tirana. The UNDP and LNB will provide us with interview contacts. NGO administrators and staff will be interviewed because they can share insights into community programs from a different perspective than families. We will use open-ended questions, avoid confrontational probing and be flexible when using an interview guide. Open-ended questions will allow us to explore a variety of topics (Seidman, 1991).

We will reach out to Albanian government officials and several NGOs working with disabled youth such as Help the Life and the Albanian Disability Rights Foundation. Several interview questions are listed below:

- Can you tell us about what your organization does?
- What services, if any, do you provide to adults with ID aged 21-30?
- Is there a cost associated with your services?
- What services do disabled individuals and their families typically request?
- How do individuals learn about your services?
- How are disability rights protected in Albania?

The full set of interview questions can be found in Appendix F.
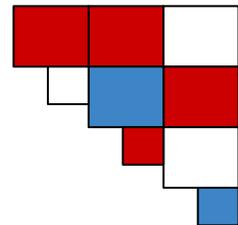
Analyzing local programs through interviews and archival research allows us to compare the available services to what disabled individuals and their families feel they need and want. In addition, successful strategies of current programs could be integrated into our recommendations. We will determine the operating costs of Albanian NGOs to ensure reasonable program expenses in our suggestions. The team will determine the resources NGOs need to implement programs by assessing the current resources used by Albanian organizations on a daily basis.

3.5 Case Study and Data Analysis

Each objective's methods include interviews with stakeholders. As part of a comparative case study, the team will analyze interview responses from intellectually disabled young adults, parents, caregivers, NGO staff, and government officials. This study's main research questions explore the following:

- What do disabled individuals and their families need and want?
- What are the current community supports available to these families?
- What are the current government policies aimed at helping these disabled individuals?
- What are the current supports that these families find helpful?
- Why is the current support system not sufficient?

Each case will analyze one disabled individual's specific circumstances and consider their current support system which may include parents, siblings, grandparents, caregivers, peers, and healthcare professionals. As mentioned in Section 3.2, the sample will consider each individual's socioeconomic status, gender, and disability severity. We hope the stratified sample will enable our proposal to reflect the disabled community's most prevalent concerns.

The team will apply supplemental information from NGO and government interviews to each case as deemed appropriate. Our program suggestions will consider disabled individuals' needs while keeping in mind the limitations of NGOs. In addition, the proposal will reflect best practices of successful community programs in other countries. LNB will provide an intern who will translate Albanian responses into English. Once data has been collected, we will reread field
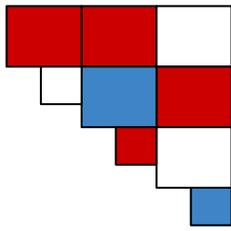
notes and listen to the audio recordings from interviews. The team will label interview responses with the data collection method, date, and stakeholder name. We will then categorize the data based on themes which emerge from our analyses of interview content (Renner & Taylor-Powell, 2003).

Information gathered throughout the course of this project will help the UNDP develop future programs for young adults with intellectual disabilities. We will create summaries of our interview transcriptions to clearly document important information. Documenting the perspectives of disabled young adults and their families will help the UNDP tailor their programs and future research to disabled individuals' needs and desires. Determining the skills disabled young adults learn during childhood and adolescence will help NGOs develop new curriculums and other educational programs. Our audio-visual deliverable may help the UNDP spread awareness of the intellectually disabled community in Albania.

3.6 Schedule

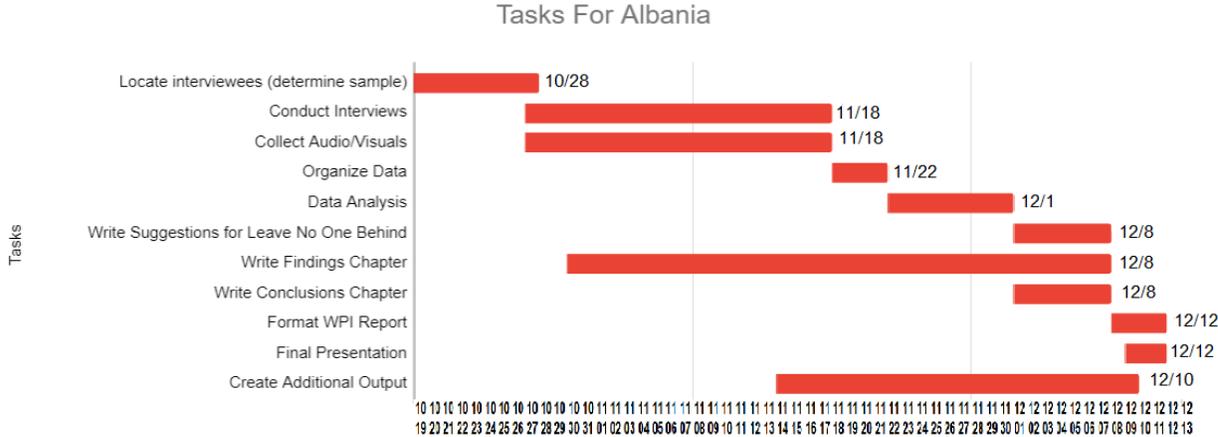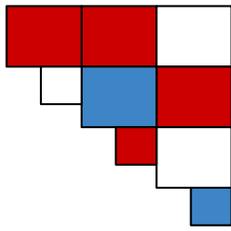The graphic below depicts an estimate of how the team will spend our time in Albania.

Figure 3.2: Gantt Chart for Albania

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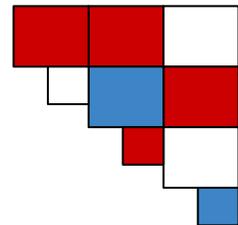
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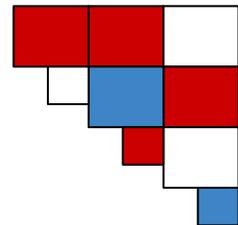
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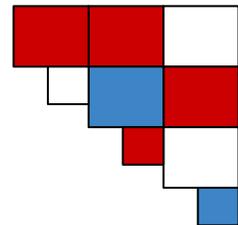
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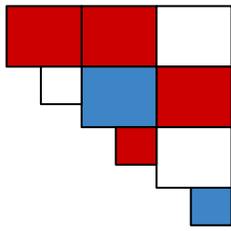
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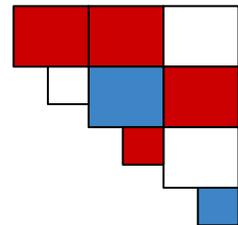
Appendices

Appendix A: Consent Script

Do you consent to us using quotes, audio recordings, photos, drawings, and/or other media produced during this interview?

I, _____, consent to the above being used in UNDP documents and projects completed by students at Worcester Polytechnic Institute.

Consent Script (Custom Alternate)

Please clearly mark which of the following you consent to being used outside of this interview:
- ❏ Quotes
- ❏ Audio Recordings
- ❏ Photographs
- ❏ Drawings
- ❏ Other media

I, _____, consent to the content marked above being used in UNDP documents and projects by students at Worcester Polytechnic Institute.

Consent Script (For Disabled individual and parent)

Do you consent to us using quotes, audio recordings, photos, drawings, and/or other media produced during this interview?

I, _____, consent to the above being used in UNDP documents and projects by students at Worcester Polytechnic Institute.
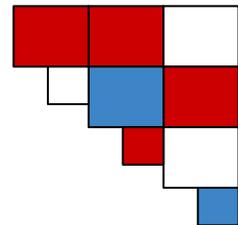
I, _____, as the parent/guardian of the above signed, give consent to students at Worcester Polytechnic Institute using quotes, audio recordings, photos, drawings, and/or other media produced during this interview.

Appendix B: Interview Considerations

Individuals:
- Interviews will take place in the individual's home, or another place the individual and their family are comfortable
- Preliminary interviews with parents will ensure we know the type of disabilities the young adults have and allow us to plan out special considerations for future interviews with the young adults
- Due to potential communication restraints the interview may include visual information
- Family members may assist the individual if needed
- The interviewee will take breaks as needed

Families:
- Interviews will take place in a location of the family's choosing

NGOs:
- Interviews will likely take place in the office of the NGO or online through Skype, unless otherwise specified by the organization

All Groups:
- Interviews will run for approximately 45 minutes

Appendix C: Sample Interview Format for Families

All of the questions below are an outline for a semi-structured interview. The tables represent a preliminary list of questions that are subject to change and reordering once on site. The team will phrase questions more conversationally during interviews.

Introduction for Families:
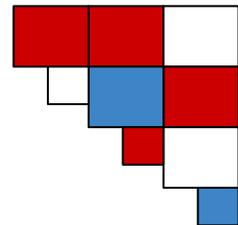
Hello ___,

Thank you for taking the time to meet with us. We are university students from Worcester Polytechnic Institute working on a project with the UNDP Leave No One Behind Program. Our goal is to propose ideas for programs which can assist in fostering independence for young adults with intellectual disabilities in Tirana. We believe that families and caregivers play a big role in the lives of these individuals. We have been researching information about the difficulties in the daily lives of people with disabilities along with the role families play in their lives and would like to know more about your child's experiences living with a disability.

Questions for Families:

Interview Questions
What is your child's disability?
How old is your child?
Who lives in your household?
Can you tell us about [child's name]?
How do you help your child throughout the course of the day?
How does your child's disability impact the completion of daily tasks?
What activities does your child enjoy?
What tasks does your child struggle with? (This question will be used to guide discussion around basic life skills mentioned in section 3.3)
What challenges have you faced in raising a child with an intellectual disability?
Who else works with your child on a daily/weekly basis?
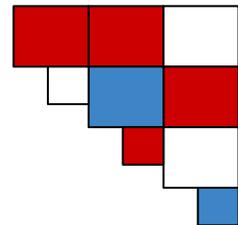
Have you and your child used any services offered by NGOs or charities?
Are healthcare professionals working with your child? If yes, how so?
Which community programs are most helpful to you and your child?
What type of support could your child benefit from?
Do you face any difficulties requesting support for your child? What type of difficulties?
Do you think schools have prepared your child for life after school? Why or why not?
What goals do you have for your child?
How have your child's needs changed in the last few years?
Which skills were the most difficult for your child to learn?
Which skills were the easiest for your child to learn?
What social, vocational, or life skills would you like your child to learn?
What qualities do you value most in a teacher?
On a scale of 1-5, with 1 being least helpful and 5 being most helpful, how beneficial are the available community services ?
On a scale of 1-5, with 1 being least helpful and 5 being most helpful, how helpful are the available healthcare services?
On a scale of 1-5, with 1 being least helpful and 5 being most helpful, how helpful is the government in supporting your child?
On a scale of 1-5 how familiar are you with the Leave No One Behind Program? (LNB could be replaced with any NGO that we are interested in)
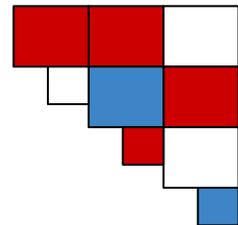
When interviewing your child are there any special considerations we should make?
Please rate your child's skill level relating to ___ on a scale of 1-10. (skills may cover personal hygiene, cooking, cleaning, transportation use, or vocational abilities)
Please draw a picture of a possible future you envision for yourself.
Please document your experiences everyday in the provided journal.
Please take pictures of your daily activities throughout the week.

Table A1: Interview questions for parents of disabled individuals

Conclusion for Families:

Thank you for being willing to share your experiences with us! Your input is helping us to understand the role of families and the effects that current programs have had on your children's lives in order to propose a new program that fulfills your needs. Is there anything more you want to share about your experiences? Are there any questions that you have for us? [Insert a suggestion for a follow-up in here if necessary]

Appendix D: Sample Interview Format for Disabled Individuals

All of the questions below are an outline for a semi-structured interview. We will ask questions in a more conversational, less direct way. The tables represent a preliminary list of questions that are subject to change and reordering once on site.
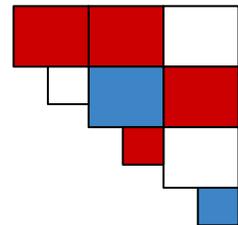
Introduction for Disabled Individuals:

Hello ___,
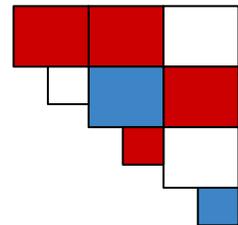
Thank you for taking the time to meet with us, we look forward to getting to know you more during this interview! We are university students from Worcester Polytechnic Institute doing a project for the UNDP Leave No One Behind Program. Our goal is to develop ideas for programs that help young adults with disabilities to live more independently. We have been researching information about the daily lives of people with disabilities and want to give a chance for you to share your own experiences about what life is like for you every day.

Questions for Disabled Individuals:

Interview Questions
What do you do during the day?
What do you like to do for fun?
Do you need help doing anything?
Who helps you complete tasks?
What do you do in the community?
Who was your favorite teacher?
Do you want to live on your own?
Do you like living with your parents? (Only asked if parents aren't there)
Who do you like to spend time with?
What does independent living mean to you?
What career do you think you would like?
Can you draw a picture of what you like to do during the day?

Can you draw a picture of what you'd like to do in the future?
Can you sculpt your favorite place to visit during the week?
Can you take pictures of your morning routine during the next week?

Table A2: Interview questions for disabled individuals

* Questions will be phrased in a way that reflects the individual's comprehension level

** We may also ask bucket questions regarding skill competency. For example, how hard is it for you to brush your teeth? The interviewee can choose between very easy, easy, hard, and very hard. Similar questions may be used to determine the abilities of individuals.

Conclusion for Disabled Individuals:

Thank you for sharing your experiences with us! Your input helps us understand what programs might help you. Is there anything more you want to share about your experiences? Are there any questions that you have for us? [Insert a suggestion for a follow-up in here if necessary]

Appendix E: Sample Interview Format for NGOs

All of the questions below are an outline for a semi-structured interview. We will ask questions in a more conversational, less direct way. The tables represent a preliminary list of questions that are subject to change and reordering once on site.

Introduction for NGOs:

Hello ___,
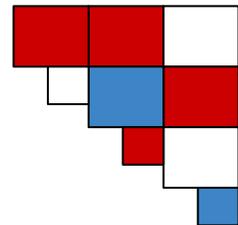
Thank you for taking the time to meet with us, we look forward to getting to know more about your organization through this interview! We are university students from Worcester Polytechnic Institute doing a project for the UNDP Leave No One Behind Program. Our goal is to propose ideas for programs which can assist in fostering independence for young adults with intellectual disabilities. We have been researching strategies and organizations outside of Albania and would like to speak with you to find out more about your organization.

Questions for NGOs:

Interview Questions
Can you tell us about what your organization does?
Can you tell us about the history of your organization?
What would you say is your organization's mission statement or overall goal?
Can you tell me about the services you provide?
What services, if any, do you provide to adults with ID aged 21-30?
What are some of your most used services?
Is there a cost associated with your services?
How do individuals learn about your services?
What are some services you would like to see added to your program?
How many people are involved with your organization?
Where do you offer services? Do you feel that your programs have adequate building space?
What services do disabled individuals and their families typically request?
Would you like more assistance from the Albanian government in implementing your
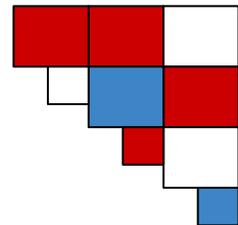
programs?
How do you raise money for your programs?

Table A3: Interview questions for NGOs

Conclusion for NGOs:

Thank you for taking the time to speak with us today! This experience was beneficial to our understanding of what currently exists in Tirana for disabled individuals. Is there anything else that you feel you would like us to know about your program? Anything you want to add or any questions that you have for us about how the information gathered from this interview will be used in our project? [Insert a suggestion for a follow up interview here if necessary]

Appendix F: Sample Interview Format for Government Officials

All of the questions below are an outline for a semi-structured interview. We will ask questions in a more conversational, less direct way. The tables represent a preliminary list of questions that are subject to change and reordering once on site.

Introduction for Tirana Government Official:

Hello ___,

Thank you for taking the time to meet with us, we look forward to getting to know more about your policies concerning disabled individuals through this interview! We are university students
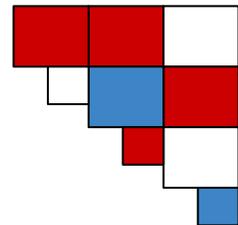
from Worcester Polytechnic Institute doing a project for the UNDP Leave No One Behind Program. Our goal is to propose ideas for programs which can assist in fostering independence for young adults with intellectual disabilities in Tirana. We have been researching policies and laws in place outside of Albania as well as within Albania for disabled individuals and would like to speak with you to find out more information about policies in Albania.

Questions for Tirana Government Official:

Interview Questions
Do you feel that more could be done for intellectually disabled individuals in society?
How are disability rights protected in Albania?
Can you tell me about the demographics of disabled individuals in Albania?
Are you aware of any programs that assist intellectually disabled young adults with their transition into adulthood? If yes, which programs do you know of?
What laws are currently in place to protect disabled young adults?

Table A4: Interview questions for government officials

Conclusion for Tirana Government Official:

Thank you for taking the time to speak with us today! This experience was beneficial to our understanding of government policies and laws in place for disable individuals in Albania. Is there anything that you want to add? Any questions that you have for us about how the information gathered from this interview will be used in our project? [Insert a suggestion for a follow up interview here if necessary]