Inclusive Villages: The Future of Swiss Neurorehabilitation

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Inclusive Villages: The Future of Swiss Neurorehabilitation

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Report Submitted to :
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Abstract

The goal of our project was to compare how inclusive villages for neuro-lesioned people are implemented around the world, constructing a legal, ethical, and financial argument in favor of building them in Switzerland. Inclusive villages are a community-based neurorehabilitation solution proposed by Dr. Karin Diserens designed to replace outdated Swiss institutions that devalue privacy, independence, and dignity. We found that inclusive villages were ethically and financially superior to institutions and had legal precedents from many other countries. We recommend Switzerland take a policy-first approach to implementing inclusive villages, enforce a care pathway that covers everyone in the spectrum of disability, and safeguard disabled people's rights.

Executive Summary

Introduction

Neuro-lesions are a far-reaching condition that affects millions of people worldwide (Chua et al., 2007). The term neuro-lesion itself refers to a variety of brain injuries. While most neuro-lesions are not lethal, and most people recover fully, many are left disabled. These patients experience a plethora of issues, and no two cases are alike (Colantonio et al., 2010)

Due to the individualized nature of neurorehabilitation, comprehensive healthcare solutions in different countries' healthcare systems are few and far between. Many systems have gaps for certain patient groups that are not strictly covered, meaning they are pushed towards treatment options that don't meet their exact needs. In Switzerland, this gap is apparent for two specific types of patients (see Figure 1). The first group is younger adults who have aged out of their parents' insurance coverage, transitioning to their own. Due to the costs and nature of the treatment, they are forced to rely on their support system, if they even have one. The second group consists of older adults who don't have a support system at all. Both groups have one thing in common: even though they are mostly autonomous and require minimal medical care, they are sent to institutions that don't allow them the dignity and freedom of a life in Swiss society. Additionally, interactions between major stakeholders can slow changes in patient care (see Figure 2).

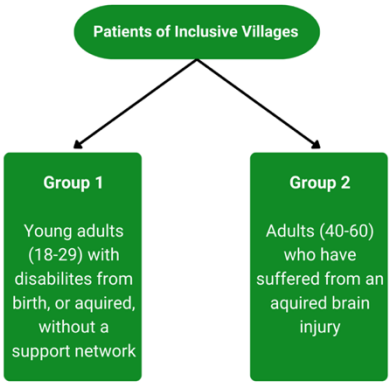

Figure 1. *Two target groups of individuals for Inclusive Villages*

The problem with institutionalization in Switzerland is that it is designed for the type of disabled person that require extensive care and strict medical supervision. Though institutions work for certain patients, they don't work for our target groups. What is needed is a more community-based option, where they can live with disabled and non-disabled people and are able to live independently while getting treatment as needed.

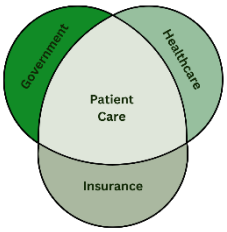

Figure 2. Interaction of key stakeholders in the inclusive villages project.

Approach

The solution to community-based living for disabled people is inclusive villages, a

form of housing for disabled people with a high level of autonomy. It typically takes the form of an independent or shared apartment. This allows life in the community with a mobile team of care providers that support people in their own accommodation. The result is more dignity and meaning in life. Inclusive villages must also be accepted by the surrounding community. Social and professional integration are key aspects of an inclusive village.

The goal of this project was to aid Prof. Karin Diserens of the Acute Neurorehabilitation Unit (ANU) at Centre Hospitalier Universitaire Vaudois (CHUV) by conducting research into existing inclusive villages, and creating a legal, ethical, and financial argument in favor of their implementation in Switzerland.

To achieve this goal, we set objectives to map our progress.

1. Identify existing inclusive villages.
2. Evaluate the success of inclusive villages compared to other forms of housing.
3. Generate an argument in their favor.

We achieved these objectives and the overarching project goal by employing two methods: content analysis and interviews. Content analysis refers to analyzing existing data and literature on inclusive villages. We also interviewed subject matter experts such as doctors and government officials to gain a more complete understanding of the current state of disability housing, and the solutions that inclusive villages provide.

Results

We conducted thorough research into several countries and their disability housing schemes. For clarity, we have organized our results by theme and a country-by-country comparison table can be found in Appendix J.

Ethical Argument

While researching the need for inclusive villages, we found that deinstitutionalization is ethical (Grunewald, 2003). The issue with institutionalization is that it marginalizes those with disabilities. As a result, nearly every country we researched is moving away from institutionalization and towards community-based living. Studies from the US found that institutions had minimal impact on patients' medical outcomes, showing that placing disabled people in institutions may hinder their ability to learn how to live independently (Figure 3), and that community-based living would promote independence (Figure 4).

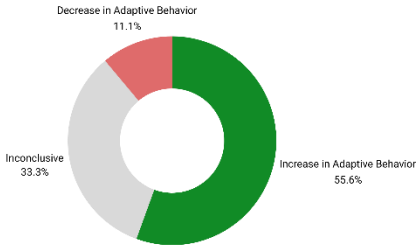

Figure 3. Behavioral outcomes.

Adaptive behavior is behavior that contributes to independent living skills. Gathered from Larson et al., 2012.

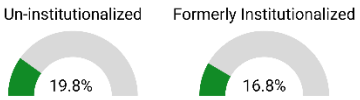

Figure 4. Home ownership for formerly institutionalized and non-institutionalized disabled people.

Gathered from Stancliffe et al., 2023.

Independence emerged as another theme throughout the research, especially from our interview with a colleague of Prof. Diserens' at CHUV. Her hope is that inclusive villages could allow teenagers and young adults with disabilities to have similar experiences as their non-disabled peers. Without community-based options, these people cannot leave home and become independent adults. Consequently, they feel that they are not progressing. However, the emergence of inclusive villages would allow them to gain independence and join the workforce or attend school.

Professional and social integration is an important benefit of inclusive villages as well. It allows for interaction between disabled people and their community, which can also open pathways to employment. Employment is neurologically beneficial as it stimulates the brain and leads to neuroplasticity, creating a sense of achievement (Loder, 2005). This contributes to happiness and satisfaction.

Finally, we've discovered an effort in many other countries to raise awareness of community-based housing. The best example comes from Ireland. Through our interview with the Director of Services and Inclusion at the Housing Agency, we learned about Ireland's awareness campaigns. Their purpose was to gather support and spread information regarding community-based options. These campaigns were necessary as they allowed disabled people to find the housing options available to them. An informed decision is important in housing for anyone, and easily accessible information is a must.

Legal Argument

In 2014, Switzerland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD clearly states the fundamental rights of disabled people. We focused on Article 19: living independently and being included in the community (UNCRPD, 2006). This article describes disabled people's right to choose where and how they live. By ratifying the UNCRPD, Switzerland has agreed to grant and uphold these rights. However, many reports argue that Switzerland is far from meeting the requirements laid out in the UNCRPD. In particular, the accessible living options provided to disabled people are extremely limited. Even with these glaring issues, there is not much the UN can do to enforce the UNCRPD, even in nations that have ratified it due to the nature of UN charters. The effort to enforce these rights must come from within Switzerland itself.

Financial Argument

Community-based neurorehabilitation systems, like inclusive villages, are cost-effective. When researching the annual expenses of neurorehabilitation in countries

around the world, the cost-per-patient value was significantly lower for non-institutional services than for institutionally based services, an example of which can be seen below in Figure 5.

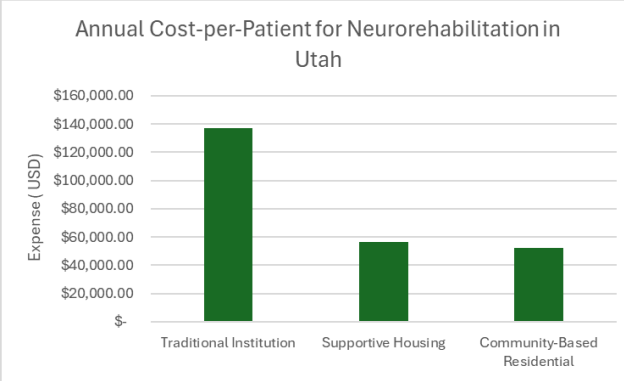

Figure 5. The annual cost-per-patient under state neurorehabilitation services in Utah. (USL, 2011)

While we found financial benefits from deinstitutionalizing, the level of cost-effectiveness depends on a variety of factors. The costs of staffing and the staff-to-resident ratio were the most profound of these factors as over 80% of the expenses for these systems stem from employee salaries, as seen below in Figure 6. Therefore, the structure of the service-providing organization, as well as the nation it is based in, is critical to achieving systemic success.

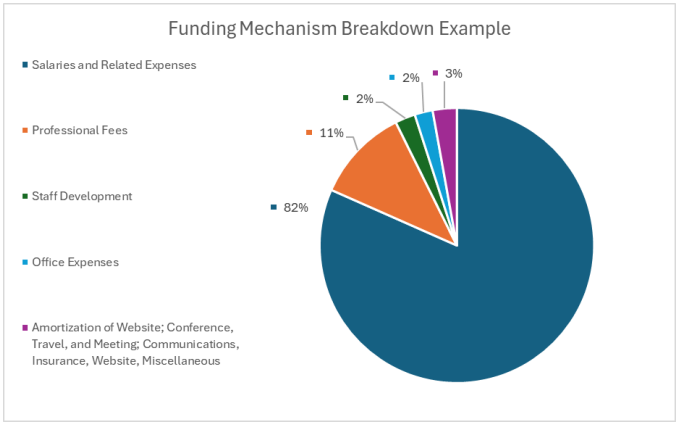

Figure 6. *Maryland Inclusive Housing Corporation Statement of Functional Expenses Year Ended June 30, 2023*

(MIH, 2023)

Our research highlighted the need for a well-supported and well-structured inclusive village system. A system with both characteristics would ensure that the residents have proper care options while also acting as a more cost-effective care option.

Recommendations

Develop Pilot Programs with Increased Community Involvement

We recommend that the Swiss government and the healthcare system work in collaboration to develop small-scale pilot inclusive village sites within communities. The pilot sites should improve the current situation by ensuring the presence of strong social integration as well as a more personalized and independent option for care. We recommend that periodic evaluations take place, focusing on the villages' impacts on the surrounding communities, the residents, and the healthcare workers. The knowledge learned

from these evaluations would allow for the development of an improved inclusive village system set up under a national creation and implementation strategy.

Use a Policy-First Approach

Through our research we have seen a policy first approach. Governments have created or assigned the task of implementing inclusive villages to government agencies, and then passed legislation that organizes these agencies, and directs funding. One potential agency in Switzerland could be the Federal Office for Equality of People with Disabilities (EBGB). This has been seen for Ireland, France, and Belgium. We also recommend contacting the Housing Agency of Ireland as they have a complex framework and plan for implementing community-based living options for disabled people. After pilot projects and a policy first approach, the movement towards inclusive villages can be strengthened by an awareness campaign from the federal government. This will ensure that citizens of Switzerland are aware of their housing options and rights.

Enforce the Neurorehabilitation Care Pathway

The neurorehabilitation care pathway describes the recovery process that neuro-lesioned patients take. The first step in the care pathway is hospitalization. This could be getting admitted to the Intensive Care Unit (ICU) or the ANU at CHUV. The second step in the care pathway is institutionalization, where they are offered more independence than they had in the hospital, while still being kept under strict medical supervision. The third step is a community-based rehabilitation model, which is much closer to the inclusive village model. The final step is full independence, meaning no medical attention is needed. This pathway should cover everyone within the disability spectrum and leave no gaps in the healthcare system. This pathway is not always followed stepwise, and many people do not fit well into any care option. More options are necessary to cover the full spectrum of disability.

Acknowledgments

We would like to thank Professors Christopher Brown and Laura Roberts for their continued guidance in our research and drafting process for this report. We would like to thank Professor Karin Diserens, our sponsor for this project, for giving us the opportunity to do this project and make a real difference in the Swiss healthcare system. We would like to thank Professor Nancy Burnham for making this project possible. Finally, we would like to thank everyone we interviewed and everyone we interacted with along the way; without your contributions, this project would not have been as educational and as impactful.

Authorship

Outlining, interviewing, editing, reviewing, and planning were all carried out as a team. Within our content analysis, we had two types of research: country-specific research and general research. For general research, we looked for examples of neurorehabilitation around the world and combined our findings. Once we identified countries that could be researched further, we divided up those countries between each team member and researched each one extensively. Once country-specific research was done, we identified common themes and criteria to evaluate neurorehabilitation solutions and distributed the themes to each team member to research even further. Finally, each team member was tasked with writing the section for the theme that they researched.

Meet the Team

RYAN HSU - *Biomedical Engineering & Mechanical Engineering*

I have a passion for the life sciences, and this project allowed me to work at the interface of healthcare and social justice. I hope that our project makes a meaningful contribution to the Swiss neurorehabilitation landscape

BENJAMIN NYE - *Pre-Medical Track & Biomedical Engineering*

My parents introduced me to many different fields but the world of medicine always had my interest, and it is what drew me towards this project. I loved the work that we did, not only because of the environment but because of the impact that it could have on those in need.

HARSHITH IYER - *Computer Science*

I chose this project because it had the potential to have a real impact on patients in Switzerland, and change the healthcare system for the better.

Terminology

In our research, we have found similar resources referred to by vastly different names in different countries. Listed below are some of the names we have found for community-based neurorehabilitation solutions:

Inclusive village, integrative village, permanent supportive housing, assisted living, group housing, psychiatric work villages, supported independent living, supported/supportive housing, sheltered housing/hostels, and independent supportive housing.

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1 Introduction

Neuro-lesions are a far-reaching condition that affects millions of people worldwide; its impact has been compared to HIV/AIDS, and malaria (Chua et al., 2007). The term neuro-lesion itself refers to a variety of brain injuries. However, one commonality is the effect of these neuro-lesions on patients' lives. They can even be lethal, accounting for roughly 30% of all injury deaths in the United States (Faul et al., 2010). While most brain injuries are not lethal, and most people recover fully from brain injuries, many are left disabled. These people experience a plethora of issues, and no two brain-lesions are alike (Colantonio et al., 2010). This creates a need for comprehensive recovery programs, but in most countries, there are insufficient resources to provide adequate rehabilitation. Whether the problems result from the number of facilities, or the number of people that need rehabilitation, problems in rehabilitation persist.

An inclusive village is a form of neurorehabilitation designed for individuals looking to be included in society. It offers a more independent living arrangement with access to care, if necessary. It places an emphasis on community support and reintegration. Various forms of inclusive villages exist around the world. These villages will be best suited for neuro-lesioned people that do not require care from a dedicated rehabilitation facility and lack support networks such as family to take care of them.

Our sponsor is Professor Karin Diserens and her Acute Neurorehabilitation Unit in the Lausanne University Hospital (CHUV), who are leading the charge in researching, developing, and funding the first inclusive village. Prof. Karin Diserens is "a specialist in neurology and physical medicine and rehabilitation. She co-founded the Swiss Society for Neurorehabilitation and currently serves as the President of the Swiss Neurobehavior Society. Previously, she was the head of the post-acute neuro-rehabilitation clinic (1996-2005) and now leads a mobile transversal neurorehabilitation team at the Lausanne University Hospital (2006-2009) as head of the Acute Neuro-rehabilitation Unit of the Neurology service (NRA), Department of Clinical Neurosciences, Lausanne University Hospital" (Dobran, 2022).

1.1 Project Goal & Objectives

The goal of our project was to compare how inclusive villages are implemented around the world, equipping the Lausanne University Hospital with a legal, ethical, and financial argument in favor of inclusive villages in Switzerland. We accomplished this goal by achieving the following objectives:

1. Identify inclusive villages worldwide.
2. Explore the benefits and challenges of inclusive village versus other forms of neurorehabilitation.
3. Construct an argument in favor of inclusive villages.

1.2 Rationale

Due to the uniqueness of this problem to Switzerland, there are not many sources describing the specific problem that certain patients have with the Swiss healthcare system. As such, all the information in this section comes from our interviews and conversations with Prof. Karin Diserens, our sponsor, and her colleague, a doctor of pediatrics at CHUV.

In the spectrum of disability, the two ends of the spectrum as seen in Figure 1 below are covered by insurance and have straightforward treatment plans: people who are able to live independently do so while getting treatment only when they need it (for example, people who have fully recovered from a stroke but may need assistance in the future), and people who are unable to function without 24/7 supervision and care are taken to either inpatient facilities in hospitals (e.g. ICU) or have full-time at-home care. Insurance coverage varies depending on the specific treatment, but options exist and are clearly laid out. However, in the middle of the spectrum of disability, there is a lot of ambiguity. Nursing homes exist for older people and people with families or other support systems have people and resources that they can rely on, but for individuals who are independent enough to not need around-the-clock care but still need some level of medical supervision for rehabilitation, there is no option that allows them to live fulfilling and dignified lives. Their options are either to live in a nursing home with a much older population, which limits their independence greatly, or to stay in the hospital indefinitely, which takes resources away from other, more severe patients. As such, identifying a treatment option for this middle group of patients is pressing and needs an urgent solution. Furthermore,

interactions between major stakeholders in patient care can inhibit innovation in neurorehabilitation (see Figure 2).

Figure 1

Spectrum of Disability with Insurance and Healthcare Coverage in Switzerland

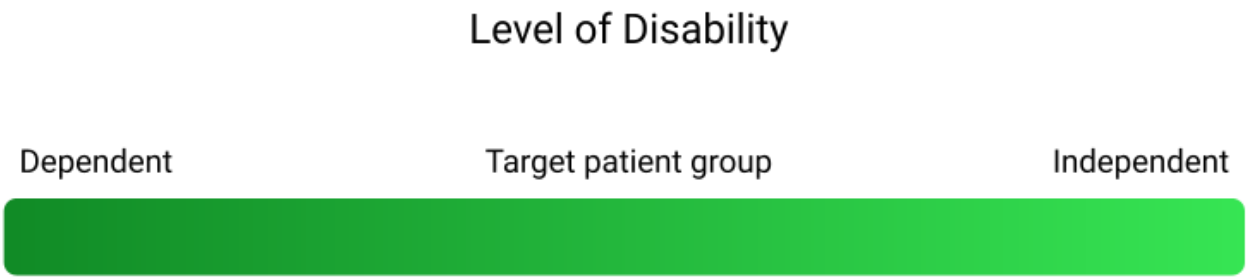
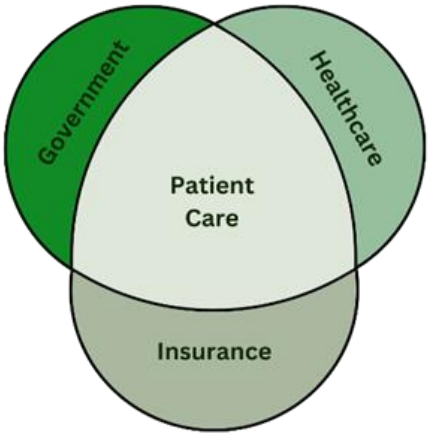


Figure 2

Interaction of Key Stakeholders in the Inclusive Villages Project.

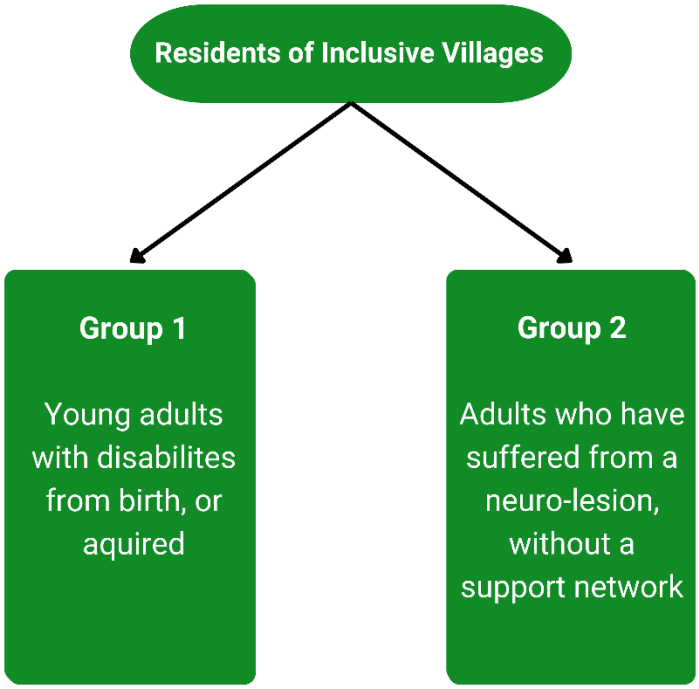


Our project is focused on two main groups that are currently overlooked by the Swiss healthcare system. As shown in Figure 3 below, the first group is young adults with neurological conditions who have aged out of children's health insurance. Until at least the age of 18, children's neurological treatments are covered by disability insurance, which covers much of the treatment a person might need. However, after the age of 20, these treatments fall under normal

medical insurance, which is not nearly as comprehensive and therefore does not have as much coverage. The second group is older individuals with brain injuries who don't have a support system to rely on to take care of them as they rehabilitate. This group is usually between 40-60 years old and are much younger than the average resident in a nursing home, but much older than anyone in the first group we discussed. Because they have no support system, there are no other options for supervised independent living.

Figure 3

Target Population



These individuals exhibit a variety of conditions. It can range from cerebral palsy all the way to strokes or other Acquired Brain Injuries (ABI's) or Traumatic Brain Injuries (TBI's). In either case, patients start out requiring full 24/7 in-patient care, for which there are many resources hospitals can provide, but later transition into semi-independence, being able to live and work on their own with some guidance and support from medical staff. Though this staff should always be available to them, they may not always need it. As the system currently exists, there is no solution that meets these requirements.

1.3 State of the Art

Current Forms of Neurorehabilitation in Switzerland

To realize the potential of inclusive villages, it was important to first understand how neurorehabilitation works in Switzerland, as well as its shortcomings. Existing research into neurorehabilitation has shown that many countries take very similar approaches to treating neuro-lesions. Due to the relatively few examples of neurorehabilitation for these patient groups in Switzerland specifically, we focused our preparatory research on other countries, primarily the United States. As more information was gathered, and we witnessed neurorehabilitation first-hand, it was confirmed that there are many similarities between Switzerland's approach, and that of many other countries.

The stage of treatment that follows the initial injury is called the acute care phase. Those whose injuries are not as severe initially may seek care from their primary care physician or no treatment. However, those who suffer more severe injuries receive emergency care, which may include surgery and stays in the ICU. The focus of this stage of care is simply to keep the patient alive and help them reach a stable condition. Typical surgical interventions may include removing clots or blood, repairing fractures, or relieving intracranial pressure (NIH, 2020). During the acute phase, the patient is diagnosed. Methods to determine a patient's condition vary between countries, but most use the Glasgow Coma Scale (GCS) (NIH, 2020). The higher a patient scores on the scale, the better their condition. A GCS score of 13-15 is typically diagnosed as mild, a GCS score of 9-12 is considered moderate, and 8-3 is considered severe. Imaging such as CT scans are also used in the diagnostic process (National Academies of Science, Engineering, and Medicine, 2022). The Barthel Index is also used as a measure of an individual's ability to function independently.

Once past the acute phase, patients who have recovered sufficiently are discharged to their homes where they may receive various forms of therapy. Common therapies include speech, physical, and occupational therapy. But those who are not able to care for themselves following acute care will be placed into a care facility that best fits their needs. It is at these types of rehabilitation that they receive therapy under round-the-clock supervision and care.

Neuro-rehabilitation facilities come in many different forms. The "gold standard" for neurorehabilitation is transitional rehabilitation which involves "...at least six hours of therapy per day" (BIA, n.d.). This is the service that the Acute Neurorehabilitation Unit (ANU) provides to its patients. Other forms include sub-acute rehabilitation, day treatment, or outpatient therapy (BIA, n.d.). The demand for beds in the acute care units often leads to patients being transferred as quickly as possible to further neurorehabilitation pathways.

Many patients require lifelong care. But, as previously discussed, there is a group of patients that fall into a gap when they do not have a family to support them or cannot afford to live at home. These patients are left to live in institutions. They cannot choose where they live. According to Peter Wehrli, the institutional network is well funded and capable, but they are called "golden cages" by members of the disabled population. He also notes that there is little effort made by the Swiss government because the current system is seen as flawless (Wehrli, 1999).

Switzerland and the UNCRPD

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted in 2006. It has two parts: the CRPD and the optional provision. Its purpose is to, "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UNCRPD, 2006). To date, there are 164 signatories to this convention (United Nations Treaty Collection, 2024), including Switzerland. However, our research has shown that Switzerland is lacking in its progress compared to its neighbors, and much of the European community. The Swiss government even admits, "Self-determination [for the disabled] in Switzerland is not yet as advanced as we would like" (Federal Department of the Interior, 2020). Self-determination is a cornerstone of the UNCRPD as outlined in Article 19 (see Appendix A), which includes, "Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and... have access to a range of in-home, residential, and other community support services" (UNCRPD, 2006). In response to this article, many European countries are moving away from institutionalization as housing for the disabled community. It has been realized that "Persons with disabilities who are placed in institutions are

deprived of their liberty for long periods of time, and in some cases even for a lifetime" (Bruijn-Wezeman, 2021). Switzerland still has a vast institutional network and is specifically lacking the variety of services necessary to give the disabled the ability to choose their residence.

The Swiss Healthcare System

Switzerland is a stable, federal, democratic republic that is represented on three tiers, the Federal level, the Cantonal level, and the Communal/municipal level. Each tier of the government is responsible for various aspects of Swiss life. The Federal level primarily prioritizes national security, agriculture, and international trade and policy (and other nationally based systems). In terms of healthcare, the Federal government "regulates system financing, ensures the quality and safety of pharmaceuticals and medical devices, oversees public health initiatives, and promotes research and training" (Tikkanen et al., 2020).

On the Cantonal level, the twenty-six Cantons [states] each contain their own constitution, legislature, government, and court system. They are responsible for organizing and maintaining the education system, regional law enforcement, and the healthcare system. Their responsibilities within the healthcare system can be more specifically understood as; licensing health insurance providers, ensuring proper hospital services, subsidizing institutions and individual premiums, enforcing disease prevention methods, and ensuring that all its citizens are meeting the universal coverage standards.

The Communal tier of government reinforces regional and national policies through its local responsibilities, looking after school buildings, social affairs, and forms of public transportation. Its responsibilities relating to healthcare fall on the provision of long-term care, such as services for nursing homes and at-home care, as well as ensuring the "social support services for other vulnerable groups" (Tikkanen et al., 2020). Further insight into governmental healthcare management can be found below in Appendix B.

In 1994, Switzerland passed the *Health Insurance Law* that aimed to introduce a universal health insurance coverage system, requiring all Swiss citizens to have health insurance which could be through a public or private insurance company. As it is a requirement for all citizens to be always covered, health insurance is not sponsored by employers, which may present challenges for low-income households. Fortunately, both the federal government and the cantons provide income-based subsidies to some households to assist in mandatory health care coverage, however the subsidy amount varies by canton. In 2016, 27.3% of Swiss residents benefitted from subsidies (Tikkanen et al., 2020).

While opening insurance options up to public and private firms encouraged lower competitive rates across companies and various plan options, it also created a complex system of frequently overlapping plans and different regulation departments. All public health insurance groups are nonprofit insurers that exchange on a cantonal level but are supervised by the Federal Office of Public Health. Meanwhile, private insurance companies are regulated by the Swiss Financial Market Supervisory Authority and may also be for-profit. Swiss insurance options are vast, with over 56 insurance companies offering plans for three age groups (18 and below, 19 to 25, and 26 plus), they do tend to also be expensive. The average monthly premium for 2024 in Switzerland will be 360 CHF (~ 411 USD) per month, or around 4320 CHF annually (SWI, 2023). For reference, the United Kingdom projected 2024 monthly average will sit at about 90 euros (about 97 USD) (Steele, 2024). In 2016 54% of the publicly protected population selected an insurance model with the minimal deductible. (Tikkanen et al., 2020).

Challenges in the Swiss Neurorehabilitation Healthcare System

While the Swiss healthcare system can be considered one of the best systems in the world there are still areas in need of improvement, specifically when addressing mental health and neurorehabilitation. A partial-to-full restructuring of how the neurorehabilitation network operates would also improve the effectiveness of treatment. A study conducted by the Department of Health Sciences and Medicine at the University of Lucerne, headed by Adrian Andrea Falvio Speiss, aimed to identify and prioritize current challenges in the development and delivery of services in Switzerland. In 2018, the researchers conducted 13 interviews with Swiss healthcare professionals and identified 19 areas of challenge in the current system, most notably:

Poor integration of rehabilitation in primary care, a perceived lack of awareness for rehabilitation from both the public and policymakers (Spiess et al., 2022), and a lack of rehabilitation representation in medical studies. The full list of intermediate and final takeaways can be found in Appendix C and Table 1 respectively.

Table 1

Healthcare Professional Identified Challenges

Number	Challenge	Number	Challenge
1	Universal access to rehabilitation is not given	10	Lack of overall coordination
2	Strategic planning and preparation for the future of rehabulitation	11	Lack of interface management - rehabilitation is not sufficiently well networked
3	Rehabilitation financing models do not reflect current needs	12	Lack of discussion of ethics
4	Poor integration of rehabilitation in primary care	13	Health professionals are insufficiently recognized as equal partners in rehabilitation
5	Perceived lack of awareness for rehabilitation among policy-makers and public	14	Divergent perspectives and interests between PRM specialists and other medical specialists
6	No equal treatment - discrepancy between the Accident Insurance and the Health Insurance	15	Limited adoption of a multidisciplinary and interprofessional approach to rehabilitation
7	Limited adoption of functioning as a central concept in rehabilitation	16	Missing offspring
8	Lack of research and research funding	17	Pediatric rehabilitation and transition from youth setting to adult setting
9	Lack of rehabilitation-specific education and training	18	Psychological/psychiatric care of rehabilitation patients
		19	Unclear definition of terms

Note. The challenges are not listed in a ranked order. From. (Spiess et al., 2022)

As can be seen in Table 1, the study found that challenges arise from systematic design or systematic performance that inhibit the effectiveness of the available treatments. A lack of universal access and poor integration of rehabilitation in primary care results in rehabilitation treatment being a very limited option. This is then further limited by the “perceived lack of awareness for rehabilitation among policymakers and the public” and insufficient recognition of healthcare professionals within rehabilitation. The authors highlighted the overlap and unequal treatment occurring when rehabilitation is covered by accident insurance versus health insurance

as problematic, when mixed with the lack of universal access, the challenges only grow. (Spiess et al., 2022)

With the vast array of healthcare insurance plan options available for patients, along with the presence of other insurances -- like accident insurance which may sometimes be used to cover medical bills -- the patients and healthcare workers are forced to navigate the coverage options of their treatment. The authors noted that some treatments covered by health insurance are not covered through accident insurance, leading to either a lack of available treatments or a spike in medical bills charged at the patient's expense. They recognized that not only does each healthcare insurance model dictate which treatments are available and how much deductible they owe, but it also determines what percentage of the cost falls on their behalf. When intertwined with additional package offers on top of the basic coverage package, a severe lack of clarity emerges on which patient groups are being covered by insurance and what exactly is being covered. (Tikkanen et al., 2020)

With regards to the two target groups of patients: the young adults with a neurological condition who are transitioning out of children's health insurance, and older patients with a neurological condition who lack a family support network, this complex insurance coverage system only makes matters more challenging. As expressed in a study published by the *International Journal of Integrated Care*, young adults leaving the coverage of children's health insurance must find employment to help cover the deductible of adult insurance while also supporting their everyday lives financially. This is incredibly challenging for young adults who lack the residential, financial, and emotional support provided by their families. The authors acknowledge that the older group of patients are in a similar situation, where their employment must continue to cover their life-based expenses, but this now must be achieved while coping with their neurological development. While a fair number of these patients are covered through insurance-covered treatment options, for example: the 24/7 care found from a neurologic institution for fully dependent patients, or the at-home care services offered for mostly independent patients, there are a group of patients who are neither fully dependent nor independent that do not have a good system to progress with. The article concluded that while these patients may be suitable for some forms of work, they often require extensive and continuous treatment throughout their recovery. Hence, former forms of work are no longer viable options for these patients, and for the young adults lacking job experience and family

support, as they must learn new skills to be employed. While allowance programs do exist to assist in the financial expenses of living with a disability, they are simply not enough to allow this specific group of patients to thrive and reintegrate into society. The lack of treatment options for this group, and the lack of financial coverage for these treatment options leaves these adolescents and neurological impacted adults stranded with no clear path forwards. (Filliettaz et al., 2021)

1.4 Approach

An inclusive village is similar in principle to a rehabilitation home, although the residents are more likely to be permanent. They are designed for patients who are not fully dependent on the healthcare system, and therefore do not need 24/7 inpatient care, but are also not fully independent, and therefore cannot work and live on their own. Inclusive villages, and similar programs, allow these patients to live a dignified life slowly integrating back into society while still under the supervision of medical staff. Inclusive villages can be found throughout the world under different insurance and health circumstances. In some places, we see them implemented as rehabilitative communities, working villages, or as group homes. In others, they were only able to get as far as the planning stage. Some are targeted at neurological issues, while others are more focused on mental health issues.

Social interaction and community participation have great benefits for patients with neurological issues. Researchers went to Bandung, Indonesia to investigate how patients with severe mental health issues use social communication to learn to “recognize themselves, reconnect with others, and become overall mentally healthier” (Rosyad et al., 2021). This paper analyzes the case of Bandung within the context of the culture and expectations regarding mental health in Indonesia, and rather than discussing the effects of a rehabilitative village, it discusses how rehabilitation is done within this small village. It found that social communication provides great benefits to these patients, both socially and medically. Inclusive villages can bring these benefits to patients in Lausanne by allowing them to connect with each other and live as close to normal lives as they can.

In all research on this topic, great emphasis was placed on the importance of considering the unique, individualized nature of healthcare demanded by individuals with neuro-lesions.

Each person’s condition is unique based on the lesions they have, and therefore, their healthcare and treatment must be equally unique. The benefit of inclusive villages is that you get the individualized focus of at-home care with the social management of daily life with a regular community. Studies in Canada highlight the importance of individualized care: “Inappropriate placements were defined by the majority of providers as placements that do not meet or adapt to an individual client's ABI-specific needs” (Colantonio et al., 2010). This also highlights the importance of having several solutions to treating neuro-lesions at a healthcare provider’s disposal to offer to disabled people; the more treatment options they have, the higher their chance of receiving care catered to their specific condition.


Cust

2 Methods

To accomplish each objective towards our project goal, we used various data collection and analysis methods. The primary data collection methods we used were content analysis and interviews. Content analysis involved reviewing existing literature on the topics of supportive housing, neurorehabilitation, and other forms of treatment for brain injuries. Interviews were conducted with experts in the field, which included neurologists, researchers of neurorehabilitation, and directors of existing inclusive village sites worldwide. These methods allowed us to complete the objectives we outlined in Section 1.2 efficiently and knowledgeably. Below, we detail exactly how we used these data collection methods to accomplish our objectives, and the approaches we took in identifying useful data.

2.1 Identifying inclusive villages worldwide

To understand how to implement a successful inclusive village in Lausanne, we had to first see how it has been done successfully in other places. To that end, identifying the benefits and challenges of inclusive villages worldwide is critical. We did so by studying and analyzing existing literature on rehabilitative communities around the world.

Analyzing existing literature included case studies of existing inclusive villages and adjacent solutions, such as supportive housing or assisted living facilities. This also included other types of research, such as studies on the efficacy of such systems, articles detailing their benefits and challenges, and showcases of the effects of these systems on residents. Existing research on such systems already covers many of their benefits and challenges, so studying them was vital to understating how to successfully implement an inclusive village in Switzerland. We grouped our research by country to account for the political and healthcare landscapes of each region. To narrow down each solution, we used a checklist of criteria to ensure that each system had what we were looking for (see Table 2 below). If it met some or all these criteria, we recorded it in our findings.

Table 2

List of Criteria Used to Evaluate Similarity to the Model Inclusive Village System

Criteria
Target conditions
Community-based treatment
24/7 care
Professional integration
Social integration
Partially funded by non-patient groups
Resources for young adults

We took a systematic approach to finding these systems around the world. First, we identified synonyms and similar terms to "inclusive villages." Then, we started researching countries near and around Switzerland, using all the terms we identified before to search for government publications, public articles, medical journals and studies, and non-profit organizations. Finally, we collected data from each source, which usually consisted of the target population, outcomes, sources of funding, plans for expansion, and more.

2.2 Explore the benefits and challenges of inclusive village versus other forms of neurorehabilitation

With a clear understanding of Dr. Diserens' vision for the inclusive village project, and similar sites identified, we began to reach out to these sites. The rationale for reaching out to these sites was to collect information beyond what was published on their websites. We decided that a semi-structured interview through zoom, or over the phone was the best method of data collection (see Appendix D). We reached out to these sites by email first, and if there was no response within a few days, we called them on the phone. The organization of each inclusive village site was different, and we had to generate unique interview questions for each site to account for the differences. But, in general, the information that we wanted to obtain remained the same. From each site we asked questions about whether the inclusive village was cost effective compared to other forms of neurorehabilitation, whether the residents had greater

autonomy in this scheme, if there were any major pitfalls in the creation of the site, and if there were any other similar organizations, they were aware of. The purpose of the first three questions was to gain more information to help us from our argument in favor of inclusive villages. The purpose of the final question was an attempt to "snowball" and be referred to other applicable sites.

When relevant inclusive village sites were identified, literature was conducted into the organization's finances. The goal was to collect quantitative data. The reason was that if costs of healthcare could be identified, they could be compared to other forms of neurorehabilitation. Finding this evidence would give us a very strong financial argument in favor of inclusive villages. This also provided a method of corroborating the answers given in our interviews. When financial information was found, we dove deeper into the insurance coverage, and government funding in country where the information was found. This measure was necessary as we had to determine whether this solution would be applicable to Switzerland. It is important to note, however, that this is a qualitative research project, and while quantitative evidence paints a clear picture, it is not entirely necessary to support our claims. The publication of financial information for non-profits and non-governmental organizations varies from country to country and in many cases, quantitative evidence was not found.

Without finding quantitative evidence for each country, we sought to find further qualitative evidence into the efficacy of the inclusive village model. We conducted literature reviews to find studies and testimonials regarding the experience of residents in inclusive villages. The motivation for the project was founded in Dr. Diserens' personal experience dealing with patients with no alternative to institutionalization. Part of our work was to create a legal and ethical argument in favor of her inclusive villages method. Resident experience is the cornerstone of our ethical argument, and without interviewing the residents themselves, our only way to understand the benefit of inclusive villages from the resident's experience was through literature review and testimonials. Again, finding evidence in a study that suggests that the inclusive villages are beneficial to disabled people was also a method to corroborate the information we received through interviews.

2.3 Construct an argument in favor of inclusive villages.

The team collected qualitative data from interviews and literature reviews and processed them using qualitative data analysis techniques. The recorded and transcribed interviews were broken down into themes and overarching ideas using a process known as coding. Coding helps pull major ideas or concepts out from qualitative data through a series of analyses. Each concept was categorized into general topics/themes before being further analyzed through the identification of reoccurring themes throughout the conversation. While individuals might have had varying forms of expressing their perspectives when asked a question, coding enabled comparison between interviewee responses.

We also performed this process during the analysis of the relevant literature to triangulate our conclusions. The takeaways from literature reviews regarding other inclusive village models were compared to the quantitative data from those sites and from the interviews to fully comprehend the effectiveness of certain systems. Triangulation through the usage of a mixed methods approach ensured stronger, more validated, multi-perspective-based conclusions.

We used comparative analysis between varying sources, methods, and locations of data (global or Swiss-based) to strengthen our knowledge of the differences between international inclusive village inner workings and the prospective Swiss inclusive network. We gained clarity on the challenges of the current Swiss system, while also advancing our understanding of how international village systems can be adapted to work within the Swiss healthcare, insurance, and socio-political landscape.

While the collection and analysis of the data certainly enhanced our ability to construct a strong argument for inclusive village implementation, the success of our report relies on obtaining increased support for inclusive village existence. The implementation of an effective and applicable system that drives neurorehabilitation forward through its usage of an inclusive village network remained the key driving factor for our research.

3 Results

Through the research we conducted while on-site in Lausanne, we aimed to achieve our goals of identifying inclusive villages worldwide and comparing the inclusive village model to other forms of neurorehabilitation. We were able to achieve these goals through content analysis and interviews. Since Switzerland formed the baseline against which we compared neurorehabilitation pathways in other countries, we continued our research into Swiss neurorehabilitation as well. The background research we conducted during the preparatory term was insufficient to gain a complex understanding. It was centered around understanding our target population. Also, we did not understand specifically what to research. Our project covers topics ranging from healthcare to policies, to insurance schemes. It was hard to nail down what exactly we were searching for. Through our interviews with both Prof. Diserens and her colleague, we were sent down a more targeted path and were thus able to generate findings. What we found was surprising. While we identified many issues with the current state of Swiss neurorehabilitation there were many positive findings. The themes that emerged from our research into both Switzerland and other countries will be summarized in the sections below.

Before these themes are summarized, it is important to note that a more developed understanding of the UNCRPD shaped our findings. What we came to understand is that the UNCRPD ensures equality for people with disabilities (UNCRPD, 2006). That means that people with disability must be afforded the right to choose "where, how, and with whom they live" (European Disability Forum, 2023) in the same way that a person without disability can choose their housing. Article 19, which deals with housing for the disabled has also been referred to as "...one of the most transversal articles of the [UNCRPD]. This means that if people cannot live independently, they are also unable to exercise many of their other rights (such as the right to education, work and employment and others)" (European Disability Forum, 2023). Thus, many of the models of inclusive villages we've identified as exemplary systems are in violation of the UNCRPD. They are seen as smaller forms of institutions because the residents remain segregated from the community. Even if there is a socio-educational aspect of the inclusive village, it is not

sufficient if the residents do not live in the community. The UN pushes for disabled people to be able to choose their accommodations, and then to adjust the accommodations to the needs of the person and bring care to them. After reconsidering the true meaning of the UNCRPD, we concluded that none of the countries we researched have satisfied the UNCRPD.

3.1 Housing Similar to Inclusive Villages Exists in Switzerland

Through our research we found that Switzerland is beginning to make steps to move away from the institutionalization of disabled people. One example of this is the presence of independent supported housing in Switzerland. Independent supported housing (ISH) is a form of housing that is like Prof. Diserens' inclusive village model. It is defined as a form of neurorehabilitation where "...individuals live in their own apartments and are supported by a mobile team for an indefinite period of time...and thus directly supports independent and autonomous living" (Adamus, 2022, p. 3). One study we found identifies five such ISH sites in Switzerland (Adamus, 2022, p. 3).

Stiftung Rheinleben is an ISH site located in Basel. Research into this site has revealed that it fits nearly all the criteria in our research. It is an institution in the traditional sense, but it offers an ISH program through the institution to disabled people who are autonomous enough to partake in independent living. It offers flexible care through a "residential support team". It also has partnerships with local organizations and employers, as well as professional training. This allows for professional integration for the people that participate in their ISH program. The organization is also funded mainly through the canton of Basel-Stadt disability assistance, not out of pocket payments. But it is unclear how the ISH program, specifically, is funded. It nearly perfectly fits the inclusive village model; however, the community-based approach is not sufficient to say that the people that live there are part of their community. Although this site is located within the city of Basel, the people remain in a clustered setting. In Ireland, the clustering approach is banned because it still leads to isolation. But these sites are similar to those found in other European countries (See Appendix L).

Despite the existence of ISH in Switzerland, there is still an overall lack of compliance with the UNCRPD, as previously discussed. As part of ratifying the UNCRPD, countries agree

to submit reports every four years to evaluate their fulfillment of the UNCRPD (IJRC, n.d.). The most recent report on Switzerland was delivered in 2022. In the report, the committee's concerns were twofold. The first was over "The institutionalization of adults and children with disabilities, including persons with intellectual or psychosocial disabilities and autistic persons, and reports of violence and abuse in these institutions" (CRPD, 2022). This is consistent with the concerns noted by both Prof. Diserens as well as her colleague. The report also mentions "abuse" which is a concerning characteristic of institutionalization (European Disability Forum, n.d.). It is compounded by the committee's second concern which was regarding "The lack of a comprehensive system to provide individualized support and personal assistance for living independently in the community, and the shortage of affordable and accessible housing in the community for persons with disabilities" (CRPD, 2022). Ultimately, the UN feels that there are not sufficient options available to people with disabilities in Switzerland. These concerns are supported by the number of institutions in Switzerland, and the Swiss population living in institutions. As of 2015 there were 527 institutions for people with physical disabilities (Federal Statistical Office, 2017). Additionally, as of 2022 there were 25,512 disabled people living in institutions (Federal Statistical Office, n.d.).

3.2 Ethical Argument

Independence

One of the biggest problems with the current Swiss neurorehabilitation system is a lack of independence for neuro-lesioned patients recovering from their conditions. As we discussed in the State of the Art, the only available option for our target population is institutionalization, which severely limits the independence of disabled people. However, as a representative from the Housing Agency of Ireland said in our interview, "[Disabled people are] born with an impairment, [but] it's [their] environment that disables [them]." As such, one of the major goals of many neurorehabilitation systems we've studied around the world is their focus on the disabled people's environment in enabling their independence.

In our interview with a colleague of Dr. Diserens' at CHUV, we discussed the current neurorehabilitation system in Switzerland. The main problem in Switzerland is that most

neurologically disabled people without support systems are sent to live in institutions indefinitely. These institutions are overcrowded and take up valuable space that could be used for more severe patients. Further, these institutions don't serve the needs of these disabled people well. Due to the sheer scale of these institutions, medical staff will never have enough resources to serve the unique needs of all the patients living there. According to the representative of the Housing Agency, patients get next to no privacy in their lives while living in these institutions, which doesn't allow them to live with much dignity. Adding onto the problem of institutionalization is the fact that this is the only option for people in our target population. A lack of choice further hinders the independence of this group.

In our interview, the representative from the Housing Agency discussed the issue of institutions (called "congregated housing" in Ireland) extensively, talking about the dire need for better living conditions for people living in these institutions. The solution that was found in Ireland was the "Time to Move On" movement, which was an effort taken up by the Irish government to transition as many people away from congregated housing into independent housing as possible. They did this by building more affordable housing for disabled people and giving disabled people more social welfare so they can pay for as much of the housing as they could. In the future, Ireland plans to build a more community-based living approach, especially for those with neurological conditions, as the inclusive village system is vastly preferable to the overcrowded congregated housing system. These goals are expanded upon in Ireland's National Housing Strategy for Disabled People. Importantly, these alternative solutions give disabled people the choice as to where they would like to live.

However, this problem is somewhat exacerbated for younger people. In our interview with the colleague at CHUV, we discussed the loss of independence due to disability, especially for adolescents. For disabled teenagers, they see their peers grow up and do many things that they are usually unable to, such as attending university or working certain jobs. Though these problems also exist for older people, the problem feels worse to younger people. Currently, the two options that these teenagers have are either to live with their parents indefinitely or to live in an institution. As such, it's important to give this group of neurologically disabled people opportunities to thrive on their own.

The argument in favor of independence is clear: disabled people should have the same rights to live independently and freely, while still being able to get the support they need at the level they need it.

Deinstitutionalization is necessary for fulfillment of the UNCRPD

When conducting the background research for the inclusive village project, we understood that institutions were contrary to the UNCRPD because they marginalize persons with disabilities. We also believed that the form of care known as supportive housing was the same as the inclusive village system of care. Our research in Switzerland revealed to us that supportive housing is seen as a form of micro-institution because they still separate persons with disabilities from society. We came to appreciate what it means to live in the community. We also came across in our research, the theory that institutions are put in place to "protect" disabled people. Many organizations, including the United Nations, argue that this "protectionist" point of view impedes the rights of persons with disabilities. Moreover, "There is evidence that no people with disabilities need to live in institutions, no matter how profound their disabilities are" (Grunewald, 2003).

The United States has been moving away from institutionalization since the 1980s. As such, there are many (mostly younger) individuals with disabilities that have never lived in an institution. One study we found analyzed outcomes for formerly institutionalized disabled people, and disabled people who had never been institutionalized. The data was collected in the form of a survey across several U.S. States. The results showed that 19.1% of un-institutionalized disabled people owned homes, and 16.8% (Figure 4) of formerly institutionalized people owned homes, despite being "…substantially older, much more likely have severe or profound intellectual disability…" (Stancliffe et al., 2023). This suggests that institutionalization plays no role in the success of disabled people in society. If institutionalization was protecting those with disabilities, then by releasing them into society it should follow that they would be unsuccessful without the institution. But the fact that home ownership is similar between the two groups shows that the formerly institutionalized are similarly successful to those who never experienced an institution. If institutionalization does not aid those with disabilities and hinders their ability to choose how to live, it is inherently unethical. Another study from the U.S. compared behavioral outcomes for disabled people

before and after leaving institutions. It suggested that community-based living led to disabled people increasing “adaptive behavior” which led to being able to live independently (Larson et al., 2012) (Figure 5). This is evidence that suggests that deinstitutionalization is necessary for people with disabilities to reach their full potential. And those who are willing and able to participate in society should be allowed to live in their communities.

Figure 4

Home Ownership Percentage for Formerly and Non -Institutionalized Disabled People

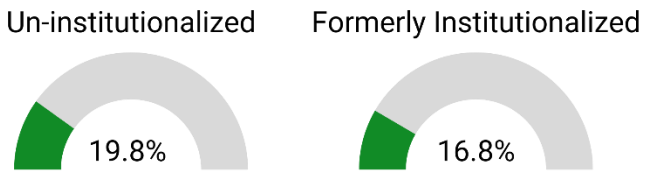
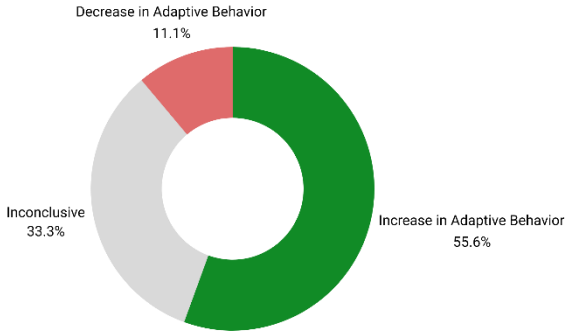


Figure 5

Change in Adaptive Behavior Before and After Leaving Institutions



Integration

While rehabilitation medically is critical to assisting the target population with recovering and living a more dignified life, our team has come across research that supports social and

professional integration as services that increase the quality of life of disabled people. For example, in the 2020 Article on the “Key Components of ICU Recovery Programs”, internal and external validation of progress was found to accelerate the recovery rates of people with disabilities. The achievement of personal goals, given goals, and noticeable physical or mental advancements in condition led to a more effective recovery (McPeake et al., 2020). Social and professional reintegration services assist disabled people in gaining a higher level of independence in their lives, while also providing structure, target objectives, and a distraction from their sole focus of recovery. However, the methods used to achieve social and professional reintegration can vary.

Through our research into the Ovelgönne site in Germany, social and professional reintegration occurs through real-life exposure to non-disabled individuals. Residents of the Ovelgönne Inclusive Village can work in local town establishments like a local pub and function room, hotel, bowling alley, and village shop, or through assisting in services like delivery, caretaking, and laundry. Not only does this method allow for the village residents to return to a more structured life while earning an income, but also allows for interpersonal interactions in everyday-normal life environments. (SLOM, n.d.)

Other community-based models, such as those seen from SLS services in Belgium act less as the employer and more as the preparer for the residents. While each community-site takes a different approach, depending on the residents, they all are focused more on preparing them before returning to work. For instance, La Passerelle in Hannut provides their residents with long- and short-term projects to work on throughout their recovery. Meanwhile, Cote-a-Cote and Notre Maison offer an employment assistance service and have work integration programs for their residents. However, these services are a separate program from the social integration services. Le Ressort is an alternative site that places more emphasis on social reintegration than professional reintegration. (AVIQ, n.d)

Like that seen in Belgium, the Don Carlo Gnocchi Foundation (DCGF) primarily based out of Italy also has a variety of services at each rehabilitation site. It must be acknowledged that this is also due to the overall size of the DCGF which takes on people with physical, mental, or

intellectual disabilities at all ages (DCGF, n.d.) The broadness of their coverage is part of the reason for their large spread of available integration services.

The availability of such services is highly dependent on the coordinating organization. In the United States, some State programs offer social and professional reintegration at their residential sites, while other States require eligible members to apply and then commute to obtain such services. This causes challenges and significantly limits the availability of social and professional reintegration care, which can slow the emotional and financial recovery process of the residents (see Appendix J).

Raising Awareness on a National Level is a Necessity

Giving disabled people the options to choose how they live will not be successful without an awareness campaign to make sure that everyone, especially those with disabilities, understands the options available to them. This has been a common theme in our findings from other countries. Not every country has accessible forms of information. The approach we took when researching disability and care pathways in other countries was by researching on a national level. The countries where it was most difficult to find information were those with strong states, provinces, or cantonal structures. We found a model of neurorehabilitation (SLS) that met all of our research criteria in Belgium, but only on a regional basis. The Agency for Quality Life (AVIQ) is a governmental health agency for the Walloon Region. The Walloon Region is the French speaking, southern part of Belgium. It is comprised of five provinces (Encyclopaedia Britannica, 2024). In the Dutch-speaking region of Belgium, there is an entirely different agency to aid persons with disabilities. They are called the Flemish Agency for Persons with Disabilities (VAPH). The situation is similar for the Swiss Federation. The way that disability is handled varies from Canton to Canton. We've also found that the services provided and the accessibility of information regarding these services ranges vastly between the Cantons. This is supported by the UNCRPD review committee concern 9c which notes, "The lack of accessibility of information about public policy and decision-making processes, and limited opportunities to participate at all stages of these processes" (CRPD, 2022).

Conversely, the countries with the most accessible information organize their disability schemes on a national level. For example, France has the Caisse Nationale de Solidarité pour

l'Autonomie (CNSA) which includes information on the legal basis and funding information for its disability insurance and neurorehabilitation schemes. This site allowed us to find crucial information regarding the legal and financial basis for inclusive villages. It outlines the laws that were put in place to support inclusive villages, as well as the amount that is covered on a per capita basis. For example, the Law on the Evolution of Housing, Planning, and Digital Technology (ELAN) of 2018 established the basis for creating inclusive housing sites. It stipulates that while governmental funds cannot be used to build the sites themselves, the government will finance the operation of these sites (CNSA, 2023).

Perhaps the best example of a national awareness campaign is the effort made in Ireland. The Housing Agency of Ireland is the government organization responsible for providing housing to disabled people. They have a page titled "Housing for People with a Disability". This page was instrumental in our research as they include many documents including their National Housing Strategy for Disabled People, and a summary of the background research they conducted when making their strategy. Using the information provided on this page, we were able to identify several other countries that have inclusive housing models. We were able to interview a representative of the Housing Agency of Ireland. During this interview, she expressed the value of awareness saying, "We've had a really big awareness campaign, and we're about to embark on another one now around independent living, and... trying to get people... [not] wait until it's a crisis". Ireland is the only country we've researched that has a coordinated national strategy to address housing for the disabled and fulfillment of the UNCRPD.

Another issue that falls under awareness is the terminology used when discussing people with disabilities. Across all our research, Switzerland is the only country that uses the term "invalidity" when talking about disabled people. It is used in the context of "invalidity insurance", the social security scheme designed to support people with long term disabilities in Switzerland (Swiss Confederation, n.d.). We've found that the term should not be used when referring to people with disabilities because it portrays them as "lacking" (ADA, n.d.). Research into the proper terminology is conflicting because there are two approaches, the person-first approach (persons with disabilities), and the identity-first approach (disabled people) (University of Wisconsin Madison, 2019).

3.3 Legal Argument

Policy-First Approach

A common theme that we found in our research of neurorehabilitation systems around the world is that the most successful ones took a top-down approach to planning and implementing new systems of neurorehabilitation, like inclusive village-adjacent solutions. This means a higher body, such as a local or federal government, would research and write an implementation strategy and plan for a new system, then slowly implement it over time through strict and achievable action items.

A great example of this is Ireland. In 2011, the Housing Agency of Ireland decided to write a Housing Strategy for Disabled People. In 2016, they ratified the UNCRPD, at which point they rewrote the strategy to be more modern. Finally, in 2022, they rewrote the strategy once again, adding more modern aspects to the strategy (O'Brien et al., 2022). With each subsequent rewrite of the strategy came a new set of goals, an honest evaluation of progress achieved thus far, and additional collaboration with disability advocates and disabled people directly affected by these policies. According to the representative from the Housing Agency, writing this strategy and the implementation plan for the strategy was vital to the rapid progression of accessible housing policy in Ireland, and allowed many disabled people in the country to live more independent, more dignified lives. There was also a focus on transitioning away from traditional, congregated housing schemes for disabled individuals, as they found it to be borderline inhumane. Without a top-down planning and implementation approach for housing disabled people, along with direct support from other federal agencies, building such housing would be much more difficult.

The National Solidarity Fund for Autonomy (CNSA) from France also exemplifies this policy-first approach. This fund finances two schemes for inclusive housing: an inclusive housing package and shared living assistance. The CNSA is also backed by the ELAN law of 2018, which was a law regarding the future development of housing. Though it does not cover any building or operations costs, it does subsidize non-profit organizations to build their sites as they see fit and partially pay for residents' healthcare, depending on the services required for

each person (which could be between €3k - €8k) (CNSA, 2023). Here, we see a law from the national government of a country that not only aims to provide housing for disabled people, but also enables its financing.

Another example of a policy first approach is Belgium. A plan for building inclusive housing in Belgium was created by the Agency for Quality Life (AVIQ) called Services de Logement Supervisé (SLS), which funds NGO's that provides housing, social & professional integration services, and medical rehabilitation for disabled people, particularly those with cerebral palsy (AVIQ, n.d.). SLS allows sites around Belgium to be built while having the funding to have the exact resources they need to rehabilitate their residents, allow them to live independently, and transition towards integrating into society as much as possible. Though the sites under SLS are not ideal sites for the model we are looking for in inclusive villages, as they are more segregated from the non-disabled community, it shows how such a system could be used to build model sites.

A commonality between these two systems is that cooperation between multiple parties is essential to the success of any implementation approach. Plans for housing, medical rehabilitation, disability advocacy, and funding for everything must each come from different departments of a government, meaning they must work together to build a strong foundation upon which supportive housing schemes can be built. Additionally, pressure must come from outside the government as well as from inside to force change to happen. In Ireland, for example, it wasn't until disability advocacy NGOs were fighting the Irish government to fund more affordable, accessible housing that they started to write their housing strategy in 2011.

To create an effective rehabilitation system that also enables accessible housing, policies and frameworks should be researched, written, and ratified before many sites are built in the country. This is to ensure that sites can be funded properly, residents are well taken care of (both financially and medically), and no gaps are left in the system during the transition from institutionalization towards community-based rehabilitation.

3.4 Financial Argument

Our team found throughout our research evidence that supports the idea that community-based neurorehabilitation systems are more cost-effective than institution-based services. One example of this can be seen in the United States, specifically in Utah. There are three types of facilities for neurorehabilitation in Utah: the Intermediate Care Facilities (ICFs), the Utah State Developmental Center (USDC), and the Residential Services offered through the Division of Services for People with Disabilities (DSPD). Each form offers sustained support care options and residential living accommodations, however, the style of care and living differs greatly.

ICFs are privately owned facilities managed by the Division of Medicaid and Health Financing in the Department of Health in communities across the state. There are 14 total facilities (USL, 2011) varying in size between 12 and 85 beds. The ICFs stem from the introduction of the Medicaid State Plan and therefore are offered as "an entitlement" to those who meet the necessary eligibility requirements. These ICFs operate as a middle ground between full institutional care, and the inclusive village concept, as there is less independence for the residents in this model and not integrating the residents into the community. However, it is still a step towards deinstitutionalization.

The USDC is owned by the DSPD (part of the Department of Human Services) and differs in that it targets patients with a severe disability. The patients admitted to the USDC must "require either continuous medical care or interventions for behaviors that present a danger to themselves or to others" (USL, 2011). With this understanding, the USDC acts more as a typical institution rather than a truly community-based form of rehabilitation. While the USDC does serve as a permanent place of living for 80% of its population (about 165 patients), the other 20% (41 patients) use the USDC as a temporary form of treatment immediately following an intellectual development (USL, 2011).

The DSPD residential services allow patients a wider range of more community-based treatment options across 270 different provider sites. The styles of living using these services drive the concept of deinstitutionalization, with less densely populated community-living options

being available. For example: group homes with up to five patients in apartment-style living, supervised apartments with up to three patients, professional parent homes, supported living arrangements, and host homes are all offered through the DSPD services.

The 2011 Interim Report on the "Costs of Residential Care for Individuals with Intellectual Disabilities" highlights the cost-effectiveness of community-based neurorehabilitation and can be found below in Table 3 and Figure 6.

Table 3

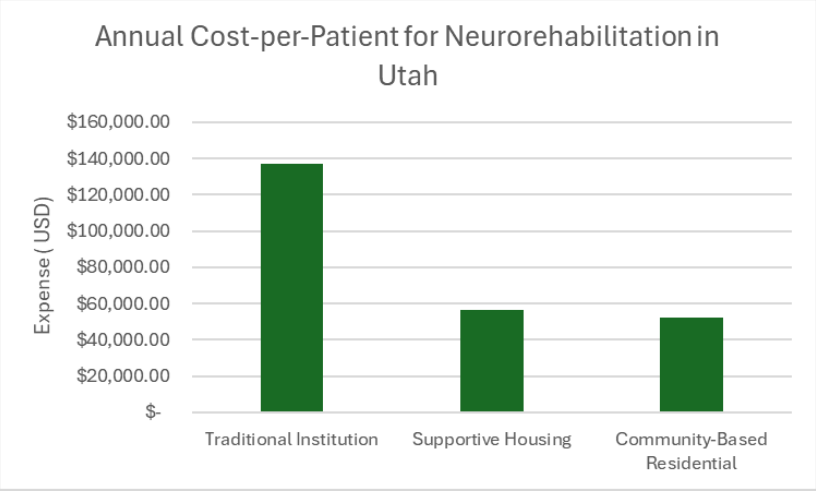
Utah Intellectual Disability Financial Breakdown

2010 Financial Breakdown	Number of Patients	Number of Facilities	Expenditure (2010 USD)	Cost per Facility (Average)	Cost per Patient (Average)
ICF/ID	557	14	31531000	$ 2,252,214.29	$ 56,608.62
USDC	206	1	28215900	$ 28,215,900.00	$ 136,970.39
Comm. Res.	2215	270	114995800	$ 425,910.37	$ 51,916.84
Total	2978	285	174742700	-	-

Note. The table was created following the Utah State Legislature 2011 Interim report on the "Costs of Residential Care for Individuals with Intellectual Disabilities" https://le.utah.gov/interim/2011/pdf/00001394.pdf

Figure 6

The Annual Cost-per-patient Under State Neurorehabilitation Services in Utah.



Note. The graph was created focusing on the final column of the Utah State Legislature 2011 Interim Report found in Table 3.

As can be seen in Table 3, the community residential services department had the largest expenditure by far, with an operating cost of almost 115 million USD, while the ICF and USDC had a combined expenditure of less than 60 million USD. However, the community residential services also served the most patients at 2215. This resulted in the lowest cost per facility, and more significantly, the lowest cost per patient for treatment, as seen in Figure 6. The ICFs also had a relatively low cost per patient, however, the cost per facility was much greater as each facility cares for a larger number of patients. Similarly, the institutional USDC is the outlier for the cost per patient, as well as the cost per facility with a cost per patient value over 250% that is expressed from the community residential services (see Appendix K for additional examples).

While our research indicated that it is possible to develop a cost-effective neurorehabilitation system, it also revealed that the country and organization operating these systems can influence how cost-effective the system can be due to structural differences. When comparing the results, more specifically the cost-per-patient values, of Utah residential services and France, some of that influence became more evident.

The Paris Project from the Simone de Cyrene Foundation (SCF) is the addition of three community-based residential facilities for neuro-lesioned patients in France. The overall structure and provided services are very similar to Utah, with a more independent and integrated environment being provided than that seen from an institution. However, the most relevant difference between the two services is the average cost per patient annually. The average cost in Utah is over twice as expensive as the costs seen in France despite offering similar services, as can be seen below in Table 4.

Table 4

Simone de Cyrene Foundation Paris Project

Year of the USD	Number of Patients	Number of Facilities	Anticipated Expenditure	Cost per Facility (average)	Cost per Patient (average)
2024	42	3	$1,493,513.00	$497,837.67	$35,559.83
2010	42	3	$1,042,702.86	$347,567.62	$24,826.26

Note. https://www.simondecyrene.org/2018/06/25/quel-financement-pour-le-projet-de-paris/

The SCF anticipates spending about 25,000 USD (using an adjusted amount for inflation) on average per patient across the upcoming year which is significantly less than that spent per patient in Utah for community residential living (SCF, 2023). The SCF cost per patient would be roughly 48% of the lowest average seen in Utah for any neurorehabilitation. In addition, the cost per facility is also significantly less. These differences may be due to a more updated community-based approach, as the system from SCF has had the resources and time to improve its performance as the Utah system is from 2010, and the SCF is from 2024.

When analyzing these two examples, the SCF system is much more cost-effective than the system used in Utah, however, a more recent system model is not the only influential factor in cost-effective evaluations. The costs of staffing and staff and patient density serve as major factors in producing a cost-effective system.

Staff and patient density refer to the geographic spacing of residents within a community as well as the ratio of staff to residents impacts the cost-effectiveness and overall effectiveness of that particular system. Our team found that high amounts of resident spacing result in the need for additional staff to be able to offer immediate care when needed, however, this drives the expenditure on salaries to increase. Meanwhile, centering the residents around a core of staff results in poor integration and a limited amount of independence within the resident community. This density factors into the costs of staffing and the ability to care for the residents.

As seen below in Table 5 and in Figure 7, the costs of staffing is one of the leading expense sources for community-based rehabilitation.

Table 5

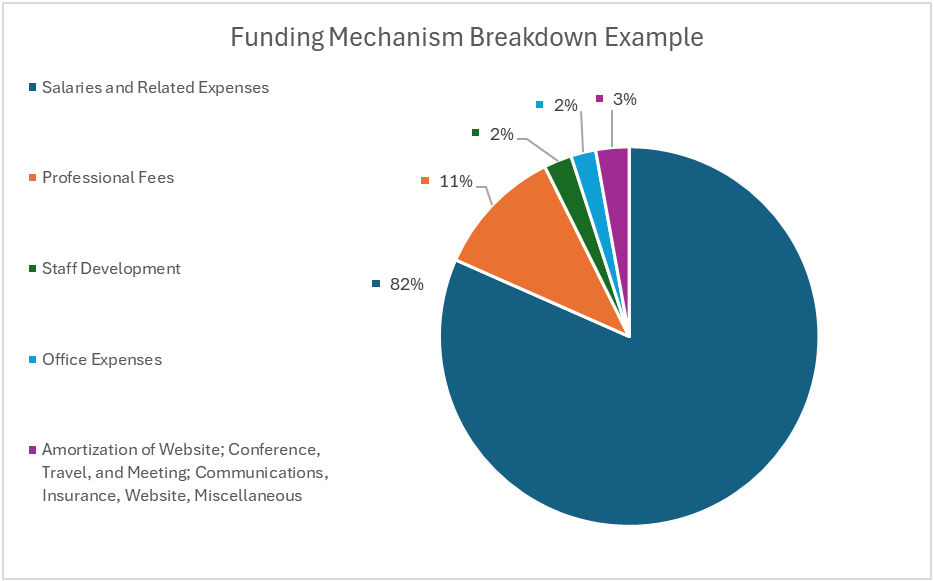
Maryland Inclusive Housing Corporation Statement of Functional Expenses

	Program Expenses	Management and General	Total
Salaries and Related Expenses	$ 436,871	$ 74,688	$ 511,559
Professional Fees	42,905	26,301	69,206
Staff Development	12,518	2,384	14,902
Office Expenses	3,645	9,666	13,311
Amortization of Website	-	5,627	5,627
Conference, Travel and Meeting	4,801	305	5,106
Communications	-	2,544	2,544
Miscellaneous	-	2,229	2,229
Insurance	-	1,781	1,781
Website	-	512	512
Total Expenses	$ 500,740	$ 126,037	$ 626,777

Note. Year Ended June 30, 2023 https://mih-inc.org/wp-content/uploads/2023/11/MIH-FY23-Audited-Financial-Statements.pdf

Figure 7

Maryland Inclusive Housing Corporation Statement of Functional Expenses Year Ended June 30, 2023



Note. The graph was created focusing on the functional expenses expressed in Table 4.

The salaries of the healthcare workers made up over 80% of the annual expense (MIH, 2023). Hence, a balance of treatment demand and treatment availability is needed to be most cost-effective. Relating to the patient-staff density, a lower patient-to-staff population would decrease the cost-effectiveness of a particular system; however, overpopulating a facility would result in a return to institutionalization and therefore a failure to serve the individual needs of each patient which is also ineffective. The structure of the system on an organizational, regional, and national level is crucial to the success of the care provided to the patients, and the level of financial benefit from deinstitutionalizing.

4 Recommendations

The evidence in favor of the inclusive village model exists in other countries from a legal, ethical, and financial standpoint. However, the question of how this will be brought to Switzerland remains. Below are some of our recommendations for the steps that Switzerland needs to take to have the smoothest, most successful transition towards a community-based rehabilitation solution for our target populations, based on our research.

4.1 Start small-scale pilot programs

This recommendation stems from our understanding of the current care options in Switzerland and the analysis of characteristics of successful systems worldwide. We recommend that representatives of the Swiss government work in collaboration with the Acute Neurorehabilitation Unit at the Lausanne University Hospital (CHUV) to design and implement small-scale pilot village sites in existing communities.

While there are current projects that achieve some of the criteria for an inclusive village, there are no existing sites that meet all the expectations for providing the best personalized care for these neuro-lesioned individuals. One of the largest differences between the current situation and the ideal is the level of community integration. The pilot sites should not be smaller institutions with disabled individuals living only with other disabled individuals but rather spread throughout the community with a built-in care and support network. Not only has our research indicated that this would accelerate their social integration, but also improve the quality of life of the residents by allowing them to live in greater independence.

These pilot program sites should be studied over an extended period of time to identify areas of improvement more accurately within this style of system, specifically within the healthcare structure of Switzerland. Analyzing the effects of the inclusive village on the lives and progress of the residents, the healthcare workers, and the surrounding community would all serve to implement a better system.

4.2 Rewrite policy to make inclusive villages possible

As with any large undertaking, the implementation of the inclusive village housing model will undoubtedly take careful planning. As our research has shown, this can take years or even decades to carry out. Therefore, it is important that Switzerland acts now to avoid falling further behind in its treatment of disabled people and fulfillment of the UNCRPD. While Switzerland has invested heavily in its institutions, it is simply not in the best interest of any stakeholders to continue to invest in institutions. From a financial standpoint, the amount of money that a country has already invested in its institutions plays a large role in how cost effective the inclusive village model would be in that country. In that regard, any further investment in institutions will only make it harder for inclusive villages to succeed and expand in Switzerland, which they should as previously stated.

For the inclusive villages to reach their full potential, the first step in planning is to conduct a policy rewrite. In countries where there are inclusive villages, or at least a framework in place, there is typically a governmental organization responsible for its oversight. For example, in France it is the CNSA. As in France, policies could be rewritten to direct funding towards this office for the purpose of building or staffing inclusive villages. The Federal Office for Equality of People with Disabilities (EBGB) could be a potential suitor.

For further planning, Ireland has a framework in place for community-based housing for the disabled. This framework should be carefully studied, and connections should be made between the housing agency of Ireland and the Swiss Confederation to understand what it would take to bring inclusive villages to Switzerland on a national level. Ireland's framework is one of, if not the most advanced plan for housing for the disabled. Learning from Ireland and following the UNDIS accountability guidelines would ensure the fastest progress towards not only the inclusive village project, but also fulfillment of the UNCRPD.

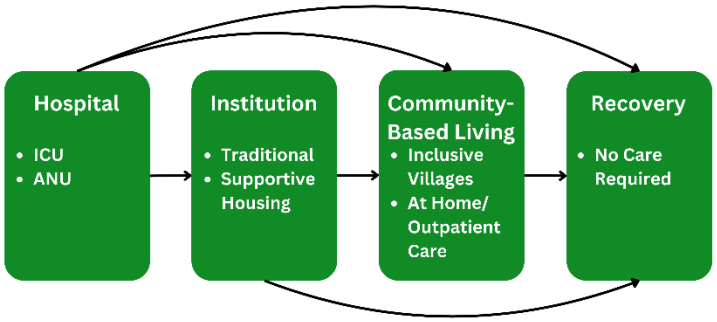
Another change that could be made to streamline progress towards inclusive villages is beginning a national awareness campaign. If inclusive villages are going to succeed, people must be made aware of their existence. Taking this information and organizing it through a national office would further increase the likelihood of this form of care being pursued.

4.3 Enforce the neurorehabilitation care pathway

The care pathway is a framework describing the recovery progression for someone who has recently acquired a neuro-lesion. As seen in Figure 8 below, there are 4 main steps, where someone at any step can jump to any step later in the pathway regardless of progression depending on their condition and recovery. This pathway exists in a small way in Switzerland, but the goal should be to make this pathway the forefront of neurorehabilitation and fully enable every step in the pathway so that there are no gaps in neurological healthcare. Regardless of disability, there should be a treatment that fits your needs.

Figure 8

The Neurorehabilitation Care Pathway



The first step in the care pathway is hospitalization. This could be getting admitted to the Intensive Care Unit (ICU) or going through rehabilitation in the Acute Neurorehabilitation Unit (ANU) at CHUV. This is a vital part of the pathway that serves recently lesioned patients, unconscious patients, and patients who need 24/7 medical care and attention. The second step in the care pathway is institutionalization. Once someone has recovered enough that they are conscious but still need lots of medical support, they have reached a level of independence that

allows them to leave the hospital and move into an institution, where they are always under medical supervision and are afforded more independence than they had in the hospital. The third step is a community-based rehabilitation model, which is much closer to the inclusive village model we described throughout this report. Finally, the last step is full independence. Though this is not common, there are cases of neuro-lesioned people that have fully recovered to where they need next to no medical attention at all and are able to live on their own.

5 Limitations

This section will discuss areas of limitations and potential biases throughout the creation of the report but is more specifically focused on the data collection period.

While attempting to schedule interviews with subject matter experts, we struggled with getting responses. This may have been due to a few reasons. First, our interview request email may have been too long, making potential interviewees less likely to read and process the whole email. Second, most of our interviewees were doctors or medical researchers, who are extremely busy people and have much bigger priorities than responding to students' interview requests. Third, because we are only junior undergraduate students, potential interviewees may not have taken us as seriously as they would have if we were more experienced. Fourth, some interviewees we contacted did respond to our request, but upon follow-up, they would go unresponsive. Of the 14 parties that we contacted (see Appendix E), 2 outright rejected us, 6 didn't respond, 4 responded but weren't interviewed, and only 2 were interviewed (see Appendices F-I).

Financial information regarding annual expenses, funding mechanisms, and multi-year analyses were often unobtainable within the framework of our project. While some financial information was able to be collected, the lack of financial transparency for most of the studied models created the possibility of skewed or inaccurate financial representation in our report. All of the collected financial information pointed towards Inclusive Villages being a more cost-effective model than institutional-based care; however, the low number of financial cases analyzed cannot be expected to represent all existing global Inclusive Village models.

6 Conclusion

Researching various neurorehabilitation solutions around the world revealed the depth and complexity involved with improving an inequitable system. Each model we investigated worked towards the same goals as the others and shared many similarities; however, the inner workings of each system were unique and intertwined with other care systems.

Throughout our content analysis and interview phase, it became evident that the systems we were studying were also incomplete. The characteristics and approach of one organization/state would differ from those of another, but none would meet all of the needs of a perfect system. Our research enabled us to learn not only why a more effective care system is needed, but also the attributes that one would need to offer its residents to truly improve the current conditions. We found that independence and integration were at the forefront of priorities for improving neuro-lesioned individuals' conditions, while financial benefits, awareness campaigns, and ethical responsibility aided in the success of these Inclusive Village systems.

Our team feels that Switzerland has the obligation to better serve its disabled population and has directed our recommendations for neurorehabilitation toward the Swiss government. Our initial recommendation is to begin designing and implementing small-scale inclusive village pilot programs. This should be done in collaboration with healthcare representatives to ensure high levels of care and community integration. Studying the pilot program sites would assist in the second recommendation for developing a national framework and rewriting related policies in Switzerland. These policy and framework adaptations would clear the path for the third and final recommendation in enforcing the neurorehabilitation care pathway. These recommendations will ensure a full spectrum of care options for the full spectrum of patient conditions, improving the conditions and lives of the currently underserved community.

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Appendix

Appendix A

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006)

Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

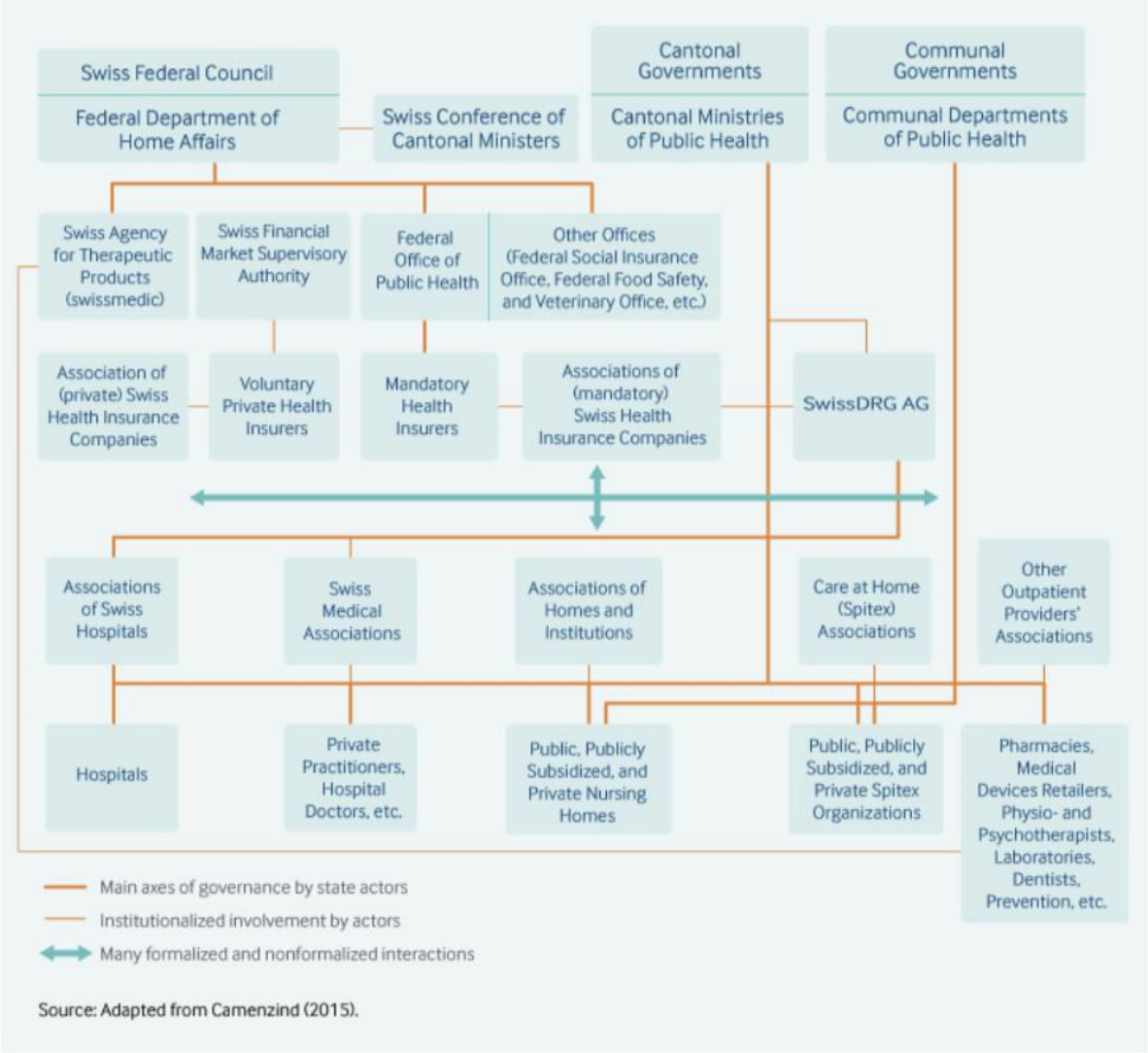
c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The entire UNCRPD can be found here.

Appendix B

Figure B

Organization of the Healthcare System in Switzerland



Note. Swiss Healthcare Administrative Control Flowchart. From. (Tikkanen et al., 2020).

Appendix C

Table C

Intermediate Results from Healthcare Professional Identified Challenges

Numbe	Challenge	Priorit	Numbe	Challenge	Priority
1	Insufficient rehabilitation-specific education and training		17	Divergent perspectives and interests between PRM specialists and other medical specialists	Clinician
2	Increasing difficulties to finance rehabilitation		18	Effectiveness and economic benefit of rehabilitation must be proved	Clinician
3	Lack of overall coordination		19	Lack of specific research funding instruments for the integration of rehabilitation and acute medicine	
4	Poor integration of rehabilitation in primary care	Therapist	20	Insufficiently large patient cohorts	
5	No equal treatment - discrepancy between the Accident Insurance and the Health Insurance		21	Lack of representation of rehabilitation in medical studies	Clinician
6	Lack of research		22	More in-depth integration of specific rehabilitation into acute medical treatment concepts	
7	Perceived lack of awareness for rehabilitation among policy-makers	Clinician	23	Health professionals are insufficiently recognised as equal partners in rehabilitation	Therapist
8	Perceived lack of awareness for rehabilitation among the public	Therapist	24	Technology-supported rehabilitation	
9	Lack of interface management - rehabilitation is not sufficiently well networked		25	Advanced practice nurse as a future model	Therapist
10	Non-hospitalised patients have almost no access to inpatient rehabilitation		26	Rehabilitation presents itself too little and too little positively	
11	Unclear positioning of rehabilitation within the medical specialties		27	Psychological/psychiatric care of rehabilitation patients	
12	Rehabilitation financing models do not reflect current needs	Therapist	28	Limited adoption of a multidisciplinary and interprofessional approach to rehabilitation	Clinician
13	Lack of discussion of ethical issues		29	Pediatric Rehabilitation and Transition from Youth Setting to Adult Setting	
14	Universal access to rehabilitation is not given		30	Financing	
15	Missing offspring		31	Limited adoption of functioning as a central concept in rehabilitation	
16	Unclear definition of terms		32	Dealing with digitalisation	

Note. The priority column indicates the crucial areas in need of improvement indicated by the profession in the column. Spiess et al. 2022

Appendix D

Informed Consent for Interviews

Hello, we are the inclusive villages research team from WPI. Our names are Benjamin Nye, Ryan Hsu, and Harshith Iyer. We are a group of students conducting research on the potential for inclusive villages as a form of neurorehabilitation in Lausanne, Switzerland. We are collecting information on the existing state of neurorehabilitation systems internationally. This interview will be part of the data that is collected.

Prior to the start of the interview, you should know that this interview is completely voluntary and while we appreciate your participation, you may stop the interview at any point, or choose not to answer any questions. To secure the information that you provide us with, we will be recording (either audio or video) and taking notes; assuming we have obtained your approval to do so. The information collected in our interviews will be used in a report. If we wish to use a direct quote, we will reach out to obtain further consent, otherwise your answers will remain anonymous. If you are directly quoted, we will send you a copy of the report before publication.

Note: If you wish to have your responses removed from our study after you have been interviewed, email gr-d24-lausanne-villages@wpi.edu.

Appendix E

Table E

Interviewee Contact List

Name	Location	Contact Name	Method	Info	Bio	Article/Website Link	Response
Ovelgoenner	Germany	Julia Morr	Email Phone	julia.morr@ovelgoenner-muehle.de +49(04401/7062026)	Site that formed inspiration for the inclusive village project.	https://ovelgoenner-muehle.de/	Made successful contact. Did not receive an interview
	Israel	Efrat Keidar	Email	keidar.efrat@gmail.com	Wrote relevant paper	https://journals.sagepub.com/doi/10.1177/0957154X231193078	No Response
Cape Cod Village	Massachusetts		Email	info@capecodvillage.org	Supportive housing site in MA	https://www.capecodvillage.org/	Made successful contact. Declined Interview
The Housing Agency	Ireland	Claire Feeny	Email Phone	research@housingagency.ie	Established National Housing Strategy for Disabled People	https://www.housingagency.ie/taxonomy/term/39	Made successful contact. Interviewed.
Seven Hills Foundation	Massachusetts		Email Phone	508.755.2340	Supportive housing site in MA	https://www.sevenhills.org/	Made successful contact. Did not receive an interview
Incare Health	Australia		Email	admin@incarehealth.com.au	SIL site in Australia	https://incarehealth.com.au/	No Response
NDIS	Australia		Email Phone	enquiries@ndis.gov.au 1800 800 110	Governmental agency responsible for SIL	https://www.ndis.gov.au/	Made successful contact. Did not receive an interview
Don Carlo Gnocchi	Italy	Andrea Labruto	Email Phone		Italian NGO with supportive housing sites	https://www.dongnocchi.it/	Made successful contact. Did not receive an interview
Cote-a-Cote	Belgium	Emmanuelle Dedriche	Email Phone	0485/84 18 28 coordinatrice@coteacote.info	SLS site in Belgium	https://www.coteacote.info/	Made successful contact. Did not receive an interview
	Switzerland	Cecile Holenweg-Gros	Email	cecile.holenweg-gross@fondationcombe.ch	Pediatrician and colleague of Prof. Diserens		Made successful contact. Interviewed.
InclusioPlus	Switzerland		Email	info@inclusioplus.ch	ISH site in Switzerland	https://inclusioplus.ch/	No Response
Stiftung Rheinleben	Switzerland		Email	info@rheinleben.ch <info@rheinleben.ch>	ISH site in Switzerland	https://www.rheinleben.ch/	No Response
	U.S.	Pamela Klonoff	Email	pamela.klonoff@dignityhealth.org	Asked by Prof. Diserens to contact	https://www.barrowneuro.org/person/pamela-klonoff-phd/	Made successful contact. Declined Interview
World Health Organization	U.S.		Email Phone		Asked by Prof. Diserens to contact		Made successful contact. Declined Interview

Appendix F

Agenda for the Interview with a Colleague of Prof. Diserens' at CHUV

1) **Disclosure/Privacy Statement**
2) **Student introductions**
3) **Consider the agenda**
4) **Interviewee introduction**
5) **Review the two groups of patients**
    a) Older patients who are recovering from neurological conditions
    b) Younger patients with neurological conditions who have aged out of the insurance system
6) **Discuss the details of an inclusive village**
7) **Cost of inclusive village vs. Current forms of rehabilitation**
8) **Prof. Diserens' conference in June**
9) **Research done thus far**

Appendix G

Agenda for the Interview with a Representative of the Housing Agency of Ireland

1) **Disclosure/privacy statement**
2) **Student introductions**
3) **Consider the agenda**
4) **Interviewee Introduction**
5) **Focus of our project**
    a) Inclusive villages, supportive housing, etc.
    b) Target group of patients
6) **Origin and development of the NHSDP**
    a) Why did it need to exist?
    b) How did you convince people it needed to exist?
    c) What did the research behind this strategy include?
        i) Disability and Housing: Approaches in Other Jurisdictions
    d) Fulfilment of UNCRPD?
7) **Community-based residential care for people of all disabilities**
    a) What is the ideal community-based residential care model that is being strived for?
    b) How is it funded?
    c) How do you plan to measure success?
8) **Gaps in the Strategy**
    a) What would you change/add/remove?
9) **Current State of the Strategy**
    a) How far along are you in accomplishing the goals?
    b) What is there left to do?

Appendix H

Questions for the Interview with a Colleague of Prof. Diserens' at CHUV

1) Could you talk about the insurance system, and what happens to young adults once they turn 21, and they don't have support anymore?
2) What happens to the majority of patients today? What option do they choose?
3) These youth programs that you mentioned. Are these common programs that these children will take advantage of?
4) Could you describe some other similar types of programs that you've seen?
5) Are there programs for employment for these children once they grow up?
6) How much do you know about Dr. Diserens' plans and vision for an inclusive village?
7) Do you think that the cost of an inclusive village versus the cost of treating children the current way is better for them? Do you think it will be a lower cost than the current treatment?
8) For children who don't have the option to stay with their parents, do you think this is a better solution for them than what they have now?
9) Do you find that there's a social benefit? Do you think that there will be a social benefit to having many patients living together?
10) Are you aware of, and will you be attending, the conferences in June and July where Dr. Diserens will discuss inclusive villages?
11) Have you seen examples of inclusive villages and similar forms of treatment for this group of patients around the world?
12) Do you want to talk about anything else before we finish the interview?

Appendix I

Questions for the Interview with a Representative of the Housing Agency of Ireland

1) Could you talk about why the Housing Strategy for Disabled People needed to exist initially back in 2011, and why it needed to get revised in 2022?
2) How did you manage to convince people that this framework needed to exist?
3) Could you talk a bit about the research needed to write the strategy?
4) I noticed in "Approaches in Other Jurisdictions," you chose countries that had ratified the UNCRPD. But the United States, even though they didn't ratify the UNCRPD, had already fulfilled a lot of the conditions that you were looking for. Was that taken into account when you were doing your research?
5) Ireland first ratified the UNCRPD in 2016. However, the first Housing Strategy was written in 2011. Did you consider the UNCRPD when writing that first strategy?
6) Could you talk about what congregated housing is, and what the problems are with it?
7) You mentioned rent for patients. How do they pay for that if they can't work in a professional setting?
8) Does the social housing for disabled people have accessibility as part of it?
9) Is there an ideal community-based residential care model in Ireland that is being strived for?
10) A short discussion on terminology relating to disabled people.
11) As we've conducted our research, we've come across different ways that they measure success, whether that's through a quality-of-life index, or quality of care. Is there a plan to evaluate how well your strategy is being implemented?
12) Are there any gaps in the current strategy that you're looking to fill in the future?
13) How is progress on the strategy looking?
14) Do you have recommendations for anyone else we can talk to

Appendix J

Research Summary Table

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Iceland (ISL)	Housing for a wide range of disabilities and conditions	Group homes for 4-6 disabled residents	Further research necessary	Further research necessary	Further research necessary	Further research necessary	Services for adults of all ages	Relatively little information on this type of housing in Iceland. Iceland still has a large institution network

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Ireland (IRE)	Nearly all disabilities covered in housing plan.	Temporary and limited permanent housing provided, but their plan to expand is ambitious.	Currently only 24/7 in-patient care, no integration with society. Once fully independent, accessible, affordable housing is built, community integration	Provided through social welfare programs.	Not provided yet.	Almost completely government funded.	Further research necessary.	Housing Agency of Ireland research on other countries' implementations of accessible housing.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
			will be considered.					
United Kingdom (GBR)	Supports those with brain injuries and similar conditions	Either individual or shared apartments	Yes	Further research necessary	There is an effort for social integration	The patient's needs are assessed, and a funding package is approved by a local council. There are personal expenses for patients, however	Supports adults of all ages	Run by various non-governmental agencies who receive payments from patients through the patients' funding allowances

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Portugal (PRT)	Intellectual and neurological conditions.	Temporary and permanent housing provided based on patient need.	Yes	Limited.	Limited.	Almost completely government funded but further research necessary.	Evidence found, but further research necessary.	Acts like small scale institutions, not substantial community integration
Spain (ESP)	Intellectual Disabilities	Temporary and permanent supportive living homes	Yes	Limited (further research required)	Limited (future research required)	Mixed (Future Research is Required)	No	NOT A MODEL SYSTEM - Not servicing community well

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
France (FRA)	Brain injuries and associated conditions	Considered a micro-institution because caretaker live in the same facility, and patients are clustered.	Yes	There is a focus on professional re-integration based on patient condition	Disabled patients also have non-disabled roommates	Funded by a disability allowance (3-8k Euros) from the CNSA	Not targeted towards young adults, but adults of all ages	The foundation that was researched was the Simon de Cyrene Foundation. It has 25 shared houses and 20 in development

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Belgium (BEL)	Various neurological conditions	Some locations are, but some are considered micro-institutions	Yes	Yes, many sites provide professional training and help in finding a job	There are sports clubs and day workshops that promote social integration at these sites	Funding provided through a government agency called AVIQ	Targeted towards those who are 16+	The type of housing is called Service de Logements Supervises (SLS) and is supported by the Agency for Quality Life (AVIQ) in Wallonia, Belgium

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Netherlands (NLD)	Various disabilities, however, some services are centered towards intellectual disabilities.	Yes, in the form of sheltered housing (long-term facility) with 11-30 individuals in each facility.	Yes	Limited professional training options	Yes (following in accordance with Netherlands' Social Support Act (2015)	Mix of government, municipality, and private funding. Funding figures can be found under the Exceptional Medical Expenses Act	Yes, sheltered housing and family housing services for children/adolescents.	All housing options are through not-for-profit/volunteer organizations.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Luxembourg (LUX)	Adults, children, and older individuals with intellectual disabilities	Small group housing services (6-10 places)	24-hour support is available if patient conditions require them	Further research necessary.	Trained services are available to assist patients in overcoming isolation; it is aimed at encouraging full involvement in social and community activities.	Mixed source of funding, mainly through government funding and private donations	Yes (some external educational services are available)	Provider: Voluntary/Not-for-profit organizations Other: The Ministry of Family and Integration contracted 11 institutions that have provided 41 residential services

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Germany (DEU)	Intellectual and neurological disabilities.	Group and individual housing available	Yes	Professional integration available based on patient condition.	Social integration available based on patient condition.	Mostly government funding via allowance and social security benefits, with additional private funding.	Yes.	Ovelgönne: prime example of inclusive housing, model for Switzerland.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Switzerland (CHE)	Severe neurological disabilities.	Limited, private housing. Shared housing is available, but no integration with society.	Yes, in institutions.	None.	None.	Critical patients covered by public and private insurance; less critical patients covered partially by insurance.	Limited.	

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Italy (ITA)	Various types of disabilities (including intellectual)	Residential structures for persons with disabilities with social assistance services; group apartment styles living; boarding schools for children/adolescents	Yes, depending on patient needs	Yes Future research is required for additional details. Each site at Don Carlo Gnocchi Foundation offers varying services	Yes Each site at Don Carlo Gnocchi Foundation offers varying services	All community-based services are funded by the regional and local authorities with some patient costs (as per 2015)	Yes	Youth-based services are nationally provided; adult-based services are through voluntary/non-for-profit organizations.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Austria (AUT)	Intellectual, neurological, and mental disabilities	Small group housing, training apartments, and individual housing.	Yes	Professional integration and training available based on patient condition.	Social integration and training available based on patient condition.	Mixed source of funding, mainly through government funding and private donations	Yes.	Most of these resources and housing opportunities are provided through NGOs, but the Austrian government funds them through allowances and subsidies.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Sweden (SWE)	Various types of disabilities	Individual apartments within a larger apartment complex for the disabled	Further research required	Further research required	The large group-based setting promotes social integration between patients, but not with the community	Specific details are unknown, but seems to be covered by the government	Supports adults of all ages	Information on this form of housing has been difficult to find. In Sweden, this form of housing is called fokus housing, or boendeservice.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Lithuania (LTU)	Mixed forms of impairment (although most services are provided to individuals with intellectual disabilities or mental health problems)	Yes, permanent social care homes and group-based options are available.	Yes, all forms of residential services have 24-hour support provided	Future research is required	Yes (Future research is required)	Funded through national funding and municipality funding.	Yes	National, local authority, and private/NGO service providers

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Latvia (LVA)	Mixed forms of impairment	Group house apartments are available for individuals with intellectual disabilities returning from a long-term care and social rehabilitation institution. Eligibility for persons with mental disabilities	Yes, is provided at all community-based treatment options.	Future research is required	Yes, although initiated while in an institution (prior to community-based living)	Through a mixture of government and private funds (typically 50/50 funding)	Yes	Group-style living is provided by the municipality, or an institution funded by the municipality.

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Greece (GRC)	Intellectual disabilities, physical disabilities, mental health problems	Apartments for supported living for individuals with disabilities (maximum of 6 guests per apartment); communities are separated by age group (19-30, 31-55, & 56+)	24/7 care is available; however, support options are based on the need presented in each apartment complex.	Future research is required	Psychosocial care aimed to achieve independence autonomy and effectiveness to function in the community and achieve independent living.	Mixed funding between government, local authority, and private funds	Yes	Mixed service providers: not-for-profit, for-profit, & state-based

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
Australia (AUS)	Individuals with more severe disabilities and "complex" needs	Individual or shared living arrangements	Yes	Nothing for job training. The goal is to build independent living skills	Yes, houses are placed in the community	Funded by the National Disability Insurance Scheme (NDIS) which gives an allowance to cover rent	Yes	

Country	Neurological Conditions	Community-Based Treatment	24/7 Care	Professional Integration	Social Integration	Partially Funded by Non-Patient Groups	Resources for Young Adults	Other
New Zealand (NZL)	Individuals with more severe disabilities and "complex" needs	Individual or shared living arrangements	Yes	Some employment counseling is available, but it is very limited	More research is required	Funded by through governmental services More information is required	Yes	Mostly run through NGO's and non-for-profits
United States of America (USA)	Individuals with disabilities (all) as well as the homeless	Individual, shared and/or group living arrangements.	Yes, it is available at site/state specific instances (dependent on patients' conditions)	Yes Organization /State Dependent Contact for additional information	Yes Organization /State Dependent Contact for additional information	Yes Mixed/State dependent Contact for additional information	Yes Resources vary between states however	Mixed service providers: not-for-profit, for-profit, & state-based

Appendix K

Louisiana

In 2005, following the destruction of hurricanes Rita and Katrina, a series of stakeholders came together to create the Permanent Supportive Housing Program (PSH). This program aims to "link affordable housing with voluntary, flexible, and individualized services to people with severe and complex disabilities, enabling them to live successfully in the community" (LDH), leading to the creation of over 3000 homes targeted for those with disabilities and a low income. While the program is directed at adults with physical and mental disabilities, the data does not represent any of the younger population. However, the takeaways from Table K below are still valuable to analyzing the cost-effectiveness of a community-based rehabilitation system.

Table K

Louisiana Medicaid Cost Savings for all PSH Household Members

Diagnosis	N	Pre	Post	% Decrease
DD	244	$1,927	$1,497	22%
MH	1,185	$1,190	$939	21%
SA	44	$2,289	$2,206	4%
PH	717	$791	$513	35%
Overall	**2,402**	**$1,088**	**$828**	**24%**

N → Number of Patients

DD → Developmental Disability
MH → Mental Health
SA → Substance Abuse
PH → Physical Health

Note. https://ldh.la.gov/page/permanent-supportive-housing psh#:~:text=Preliminary%20data%20indicates%20a%2025,people%20in%20the%20PSH%20program.

While the above table and statistics do not directly cover our target population, and the cost decrease represents the patients, not the operating costs, it was deduced that the effects of such a program still display the effectiveness of an inclusive village program. To start, all patient groups represented in the study experienced a reduction in Medicaid costs regardless of

diagnosis following their enrollment in the PSH program. The physical health patients witnessed the largest decrease, with about a 35% reduction, while the substance abuse patients only had a 4% reduction. However, it must be noted that the substance abuse population was minimal in size, at only 44 patients while the other three diagnoses had well over 200 patients.

While the magnitude of difference between the pre-and post-PSH operating costs will likely differ from those seen by the patients, there is no data to suggest that the provider is paying for the reduction in patient costs nor are they paying the same value as pre-PSH operations. Hence, our team inferred that such a large reduction, on average 24%, in patient costs stems from a reduction in overall operating costs, therefore emphasizing PSH as a more cost-effective system than the pre-PSH institutional system.

Appendix L

Final Presentation Deliverable to our Sponsor

Inclusive Villages Final Presentation.pptx

Note: If this link doesn't work (if you are not a WPI student, it probably won't), please contact us at gr-d24-lausanne-villages@wpi.edu .