
The urgent need for integrated and social healthcare in Europe

that enables individuals
and communities to take
a leading role in their
healthcare journey

The vision and call-to-
action from Ashoka Health
social entrepreneurs



Forward

November 15th, 2022 was marked as the **Day of 8 billion** by the United Nations. A milestone in human history in which “*unprecedented growth is due to the gradual increase in human lifespan owing to improvements in public health, nutrition, personal hygiene and medicine*” (www.un.org). Yet, despite these significant advancements in health, deep structural, social, and systemic inequalities embedded in our healthcare systems, continue to prevent large segments of the global community from realizing their own good health journey’s. There is no question that tomorrow’s health needs cannot be met by today’s health systems without new health approaches like integrated healthcare.

Ashoka Fellows and their solutions (such as the solutions highlighted in this paper) are one of the greatest resources for effective social innovation in healthcare. They provide a constellation of health approaches that support individuals, their families, and their communities to be: 1) Informed to seek out and take ownership of new health knowledge and skills sets 2) Empowered through inclusive and contextualized wellness support systems, 3) Empathic in building a *One-Health* identity, and 4) Connected to accessible care, with zero barriers. The holistic approaches of Ashoka Fellows are not in antithesis of allopathic health methods, but rather are a necessary and complementary addition to traditional health systems. Such solutions ensure that the best health outcomes for everyone, everywhere can and will be achieved. This, if nothing more, is the epitome of what integrated healthcare systems will accomplish with the solutions of Ashoka Fellows playing a key role in that achievement.

Yeleka Barrett
Ashoka Health Agency Lead



About Ashoka

For over forty years, Ashoka has identified and supported nearly 4000 of the world’s leading social entrepreneurs (Ashoka Fellows) – leaders with innovative new ideas that transform broken systems for the good of all, in fields from health to human rights, education to civic engagement, economic development to environment. Ashoka envisions a world where Everyone is a Changemaker and is equipped with the tools, mindsets and conditions to act for change. We work with businesses, foundations, medias, institutions and individuals to design innovative partnerships to accelerate changemaking.

Introduction

From sick care to integrated and social health care

In Europe, **our healthcare systems focus on disease treatment rather than prevention and healthy living**. Non-Communicable Diseases ('NCDs') are responsible for 87% of the disease burden in the European Member States and improved health promotion and disease prevention can reduce the prevalence of NCDs by as much as 70% (*EU4Health Program, European Commission, 2022*).

In the wake of the COVID-19 pandemic, we brought together leading Ashoka health social entrepreneurs in Europe to draw a collective picture of our healthcare systems in order to identify the root causes to what we believe to be one of the most pressing issue in the field: **the dominance and reliance of standard medical interventions when integrated and social care is more applicable in healthcare systems**.

For the purpose of paving the way towards integrated and social healthcare in Europe, this position paper identifies the key causes of the dominance of, and reliance on, standard medical interventions. This paper demonstrates the causality information asymmetry, lack of integrated care vision in training and education, power imbalances between patients and health practitioners - and more. This paper highlights key insights from social entrepreneurs and their organizations as well as the communities they represent as a way to advocate for and enable integrated and social healthcare in Europe.

With this position paper, **we promote the creation of more dynamic, integrated and equal partnerships between individuals, communities, and medical and social care stakeholders as a key pathway to enabling integrated and social healthcare for people in Europe**. This paper also aims to start a conversation in which social innovation and entrepreneurship meet policy to jointly design solutions that systemically address European health challenges.

Each social entrepreneur's case study in this paper ends with **key policy recommendations** and connections with current health plans and frameworks (when existing), highlighting important shifts that need to happen or confirming the direction of European healthcare.

Methodology

We conducted 6 Focus groups, of 2 hours each, with Ashoka fellows and staff in order to generate a consensus understanding regarding 1) the current gaps in the healthcare system (see appendix); 2) how an integrated, patient-centric approach can help generate these gaps; and 3) how the work of Ashoka social health entrepreneurs demonstrates the benefits of an integrated approach. We drafted this position paper based on this consensus understanding, using additional interviews between Ashoka Staff and Fellows to develop the case reports and policy recommendations. This initiative has been facilitated by Ashoka Staff and the final draft was approved by all involved Ashoka Staff and Fellows.

Definition of integrated healthcare

Integrated Health as defined by the WHO Regional Office for Europe and used by this Position Paper: “Integrated health services delivery is defined as an approach to strengthen people-centred health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions” .

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The present state of healthcare

Our analysis of healthcare systems in Europe revealed that our systems are deeply impacted by the health industry and its profit mindset. This is a direct consequence of privatization that positions patients as a source of revenue. A recent UNDP study highlights causality between privatization “in order to boost efficiency or growth in the short-run” and higher COVID-19 mortality rates “as these reduce countries' long-term preparedness for dealing with pandemics” (Assa & Calderon, 2020).

Privatization contributes to treatments becoming unaffordable, and thus access to healthcare is positively linked to social inequality which impacts vulnerable populations. (Assa & Calderon, 2020).

Privatization also induces prioritization of services or health insurance for people with no pre-existing conditions, patients suffering from mild issues or who are younger (Cheng et al, 2015).

Individuals are, thus, not equipped to have a leading role in their own health journey as the system isn't built around a patient-centric approach to healthcare. While the patient-centric approach is recognized as a key enabler of a high quality healthcare system, our current systems lack essential elements required for implementation.

Healthcare systems suffer from information asymmetry, where health-practitioners don't have access to patient's health status and background, life circumstances, care preferences and values. Patients are also not owning their own health data and journey. This information asymmetry directly leads to

nonexistent diagnoses or misdiagnoses.

It also has a strong impact on trust and relationships between patients, citizens and health-practitioners, and reinforces imbalanced power dynamics where individuals aren't perceived – and often do not perceive themselves – as equal managers of their own health. In turn, communities aren't supported to promote healthcare and wellness.

The root causes of dominance and reliance of medical standard interventions

When identifying the dominance and reliance of medical standard interventions as one of the most pressing issue in Europe, we looked at its causes. We focused our analysis on three key causes and the multiple roots that keep this issue in place.

1. Patients/citizens do not have all of the information about their health situation. This is rooted in social inequality that reinforces the struggle of health literacy and information asymmetry.
1. Doctors/healthcare providers are not health creators but health managers. This is the result of a lack of holistic care and collaboration between healthcare providers and patients and community, reinforcing power imbalances between doctors and patients.

Healthcare systems are focused on curing illness rather than holistic care and wellness promotion. This is rooted in privatization, as no European definition or shared understanding of healthcare exists in the 21st century, and no policy framework around holistic care is implemented

Existing integrated health care actions in Europe

In 2016, the World Health Organization regional office for Europe inaugurated the ‘*European Framework for Action on Integrated Health Services Delivery*’. This framework aims to promote a shift towards people-centred health systems, and includes both recommendations and an ‘implementation package’ to facilitate effective actions in member states. This framework advocates broad transformations across multiple health sector domains to re-align services and incentives around the health needs of the populations and individuals it aims to serve. These broad transformations are grouped into four key domains: 1) populations and individuals - focused on identifying multidimensional health needs and empowering individuals to take control of their own health; 2) service delivery processes - focused on organizing health services around individual/population needs; 3) system enablers - focused on aligning health system functions to support conditions for service delivery (e.g. financial incentives, health tech innovations);

4) change management - focused on the strategic management of health system transformations. Further details on the Framework are available [here](#).

While stopping short of complete adoption of the WHO Framework, several EU public health topics and priorities have notably included integrated healthcare concepts within the past few years. These include the European Health Data Space slated for implementation across member states by 2025, which aims to empower individuals to take control of their own health data and, by association, care. Additionally, integrated models of care are emphasized as being ‘essential to delivering high quality health services’ in the recent *Pharmaceutical Strategy for Europe* and *Strengthening Europe in the Fight Against Cancer* EU resolutions.

Patients as assets not liabilities

The case of Patients Know Best (PKB)

Baby Mandy was only six months old when she was given prosthetic ‘dolly’ arms so that she ‘wouldn’t be unacceptable to look at’ when her mother took her out in the pram. Baby Mandy was a Thalidomide survivor, with physical impairments of her arm. Instead of creating a prosthetic which expanded her mobility and autonomy, she was assigned a prosthesis built for the purpose of appearance. She was treated as a liability in the healthcare system, without the power to express her needs as a patient.

In the last 100 years, developments in technology and a focus on specialization led to great advancements in medicine. Individual specializations in medicine led to innovation in each respective field but further siloed medical specialties, distancing medical professionals and patients from an integrated, socially-focused healthcare system and creating a fragmented one which saw patients as liabilities and as problems to be solved by highly skilled individuals. This also led to the widening of the power imbalance between the healthcare system and its patients, disregarding patients as providers of their own care.

Founded by Mohammad Al-Buyadli, the organization Patients Know Best recognizes that all patients should have the tools to make a change for their health, no matter their circumstance.

“On the PKB platform, patients are given agency as the main actor in their own health to own their health data and be informed to act.”

In particular, Patients Know Best tackles power asymmetry to achieve integrated health benefits for both patients and the healthcare system in the long run. The Patients Know Best (PKB) social enterprise shifts the responsibility and power to the patients’ hands, knowing that patients are assets to their own care, not liabilities. The PKB technology platform champions data transparency, information accessibility, and safety through a system that is integrated around the patient, for the patient. Through this platform, patients are acknowledged as the main actor in their health and encouraged to own their health data and take informed action.

PKB is a health record system that is consolidated, up-to-date, and informative. The health data are always owned by the patient, not PKB.

PKB believes that when patients are aware and informed of their health status, patients will become the best advocates to communicate their own needs in the healthcare system. By providing access to information, PKB tackles the current fragmented healthcare system’s problem of information asymmetry through addressing health literacy, thereby disrupting the power imbalance between patients and providers. Through PKB’s online platform, patients have access to test results, care plans, messaging channels and educational information to make informed decisions about their own treatment.

Impact Stories from PKB

Re-defining relationships

Seventeen year old Sean Brown used PKB's messaging channel to contact his physician about his rare bowel disorder. By having a direct channel of communication, PKB has disrupted the hierarchy between Sean and his physician, so that Sean can take control of his own care.

"It has just really brought the talking with doctors into the 21st Century reality, it just makes living with a medical condition a lot easier, so it just feels like you have an equal say on your care"

PKB enabled Sean to take control of his condition, providing autonomy to attend university while maintaining his health.

North London, 2015

London faces the challenges of a fragmented healthcare system in their data sharing. A general practitioner in London faces 20% of patient changes every 12 months. In an area where so many people are moving in and out, having a consolidated data-sharing system has been a challenge. In 2015, PKB was used for 2.4 million people from 16 hospitals and 400 GP practices in North West London to encourage patients to take ownership of their own health data. This was the first time a population was trusted with their own health data. By having access to test results, sometimes as quick as 2 hours after testing, patients were empowered to take action as a member of the team in their own care.

Policy impact(s)

When elevators were first invented, a designated guide was in each elevator to press the buttons to function. Over time, a general consensus arose to change this, leading to the experience of elevators we have today without such guides. Similarly, there needs to be a shift in how we view and understand the status quo of information sharing and data in the healthcare system.

"Every single person with a body should have access to and own their health data, with PKB as its facilitating platform to enable informed and empowered care."

Key relevant impacts for policy change and work:

- 1) Patients Know Best provides a demonstrated solution which addresses EU aims to empower patients access to and control of their health data (*European Health Data Space; EU4Health*).
- 2) The data solutions provided by PKB enable improved performance and efficiency of multiple healthcare services, all while placing patients at the center of their own care.
- 3) PKB provides a ready-made solution to digital health data challenges that can be broadly scaled across EU member states.



PATIENTS KNOW BEST®
MANAGE YOUR HEALTH

Mohammad Al-Ubaydli



Community and data at the center of health journeys

The case of Fight The Stroke Foundation

Francesca Fedeli and Roberto D'Angelo are the co-founders of FightTheStroke.org, a foundation that supports the global cause of young stroke survivors and children with a disability of Cerebral Palsy, as their son Mario. Francesca and Roberto never knew strokes could happen to newborns and children. Despite there are 17 millions of people with Cerebral Palsy in the world, they were left alone as parents, helpless and hopeless about who to consult for support and care. In response, Francesca started a closed Facebook group for family and caregivers experiencing similar situations. To her surprise, people poured in to join the group, elated to connect for the first time with those with similar experiences with their own loved ones. From this experience, Fight The Stroke Foundation was created, to advocate for young stroke survivors and their families. For Fight the Stroke, integrated health means building a community that pushes towards new clinical research and policy. From day one of this movement, a sense of community was key to bringing people together in order to tackle the knowledge and care gap for kids who survived strokes. Everyday, 1000 survivors and their caregivers connected over similar experiences, solving problems together when no other resources were accessible for them. Fight The Stroke provided a new model of community-led healthcare

within a safe environment that had never existed before. This was created to be an inclusive environment built through the freedom to express thoughts about health and the desire to combine knowledge through connection and scientific data.

“Fight The Stroke works in the disciplines of disability, developmental medicine and digital health. A challenge in these intersections has been regaining trust in the relationship between the patient and the healthcare provider.”

An important issue of the current healthcare system is the lack of consolidated data on many conditions across Europe. This was the case for measuring the number of people with cerebral palsy in Italy. A bureaucratic problem occurred when the responsibility of providing data was left to each individual town, with only one town providing the information. Without agreeing to a national approach, this presented the false record of only three kids being diagnosed with cerebral palsy in all of Italy. In addition, the latest public available data were related to 2011, furthering the lack of accessibility and usability. Especially when monitoring trends in children, continuous updating of health data is crucial to understand and predict trends. Collecting and maintaining accurate and usable data on Cerebral Palsy as well as on People with Disabilities in Italy and Europe would allow people and patient associations to better frame the phenomenon, opening up new possibilities and perspectives to care for children, to rethink goods and services and to imagine a fairer and more inclusive society. Without a specific cure or treatment from the pharmaceutical field, cerebral palsy is a ‘forgotten disease’.

Although rehabilitation interventions are available, many of them are not scientifically validated and there is no current push for research because of the lack of data.

Impact Story: Rebuilding relationships between health practitioners and patients

Many patients feel inept at expressing their own health concerns, and the power imbalance between the healthcare provider and the patient creates an environment in which patients feel they are not allowed to ask questions. Proactive communication for treatment must occur on equal levels with mutual understanding and trust. Fight The Stroke approaches this hurdle with different solutions to facilitate communication. One way is through providing health literacy initiatives. When families of stroke survivors want to understand and manage their child's health, Fight The Stroke Foundation is the first landing place providing reliable resources and guidance on navigating the healthcare system experience. This includes guidance on how to read a scientific paper, explanations of certain drug information, members' sharing parts of their own data and generally providing validated information meant to assist people in making informed medical decisions. This aims to reestablish the information asymmetry between doctor and patient, between the medical system and people with disabilities: having beneficiaries sitting together at the same decisional table with other stakeholders would allow the whole civil society to find faster and better solution to care about over one billion people, the 15% of the world's population with a disability. When Fight The Stroke was elected as an Ashoka fellow in 2015, community-led healthcare was not part of the prevailing public discourse. Since then, Fight The Stroke Foundation has become a trailblazer.

Policy impact(s)

Key relevant impacts for policy change and work:

1. Fight The Stroke conducted extensive research and clinical trials, resulting in various scientific publication to address the gaps in the current healthcare system, as it happened for the inclusively designed services in the digital health system: concrete examples are the first tele-rehab platform [Mirrorable](#) and the epilepsy research kit [MirrorHR](#).
2. Fight The Stroke is a unique stakeholder for policy makers as they hold key insight and reputable information on the intersection of science, health technology and disability: with this aim they launched the [Disabled Data](#) platform, to open a window on the data associated with the phenomenon of disability and to support citizens and policy makers in researching and understanding the data currently available.
3. Fight The Stroke is proving that for patients and individuals to thrive, health practitioners and caregivers holding different expertise need to be connected and learn from one another, recognizing mutual knowledge: they opened up [the first Neonatal and Children Stroke Center in Italy in order to ease this process.](#)



Francesca Fedeli



How to be cared for without a diagnosis

The case of NoRo Center

An economics student in Cluj-Napoca, Romania in the 1980s, Dorica Dan's life changed completely with the birth of her daughter Oana. Realising immediately that there was a problem with Oana, who would not eat or cry, Dorica stopped her studies to fully focus on Oana's healthcare needs. Dorica suspected that her daughter may have a rare disease, but was unable to access the expertise necessary to properly diagnose Oana's Prader Willi Syndrome until after her daughter's 18th birthday.

However, as Dorica would soon discover, accessing the correct diagnosis for Oana was only half the battle – the growth hormone treatment for her daughter was not available for adults. Alone and with little information about Oana's rare condition, Dorica founded the Prader Willi Association in 2003 to map patients with the condition and to provide essential information and guidelines. Dorica soon realized that her struggles accessing diagnosis and care for Oana's Prader Willi Syndrome were common across all rare disease patients. Soon she broadened her focus towards restructuring healthcare for rare disease patients based on a collaborative, patient-centric approach. The manifestation of Dorica's focused efforts is the NoRo Center, founded in 2010 to provide comprehensive,

integrated care for rare disease patients and their families in Romania. An estimated 6-8% of the world's population suffers from one of over 8,000 rare diseases, defined as a condition affecting less than 1 in 2,000 people. Because of their infrequency, pharmaceutical research into rare disease treatments is typically not cost-effective due to low demand – less than 5% of rare diseases have pharmaceutical treatment options, which are often very expensive and sparsely covered by insurance. Rare diseases are often not adequately addressed by the national health system due to their small and disconnected patient populations, the lack of knowledge about services for rare diseases patients, not enough experts in the field, no communication between medical, social and educational services, rarity of those conditions and the lack of financial resources allocated for care services. This leads to fragmented medical and care services for patients with rare diseases and their families.

“The NoRo Center cooperates with nongovernmental organizations, health care providers, social workers, teachers, employers, and several institutes with expertise in rare diseases to provide a patient-centric ‘one-stop shop’ integrating medical, social and educational services to patients and their families”.

To this end, the Center has set up a network of video conference facilities with seven medical universities across Romania, allowing patients to access required expertise while avoiding travel costs. A help line is also available for patients or professionals looking for information and support. Additionally, the Center organizes a range of direct support services for

patients and their families (group therapy, education and rehabilitation, daycare center, etc.).

Impact Story: *Community nurses as rare disease case managers*

A key ingredient of the success of the NoRo Center is its training of public social workers and community nurses as ‘rare disease case managers’ to coordinate patient care. These case managers provide a streamlined central contact point between patients and their families and available medical, supportive, and educational services both in Romania and abroad. Accordingly, these case managers personify integrated care for patients at the NoRo Center, facilitating a patient-centred approach to accessing the disparate resources needed to comprehensively care for rare disease patients.

The NoRo Center is recognized as a European model for rare disease care and identified by the Romanian Ministry of Health as a health care provider and specialized social service with research capacity, that receives annual funding from local and national government sources. Every year, more than 200 people register for its therapies and therapeutic education services, and many other beneficiaries take part in information and training services. The sustainable success of the NoRo Center not only provides proof that rare disease care can be effectively delivered in low-income countries, but also demonstrates the potential for local/national social health entrepreneurship to inspire EU-wide changes. The NoRo Center is designated as a Center of Expertise in Rare Diseases, is part of the European Network of

Resource Centers for Rare Diseases, and contributed to the European INNOVCare project aiming to facilitate integrated pathways to rare disease care across Europe. In partnership with the Romanian National Alliance for Rare Diseases and with experts in the field of rare diseases, The NoRo Center has integrated all of their proposals into the new National Plan for Rare Diseases and is advocating to integrate their proposal in the National Strategy for Health (which is under public debate now).

Policy impact(s)

At a European level, Dorica and the NoRo Center continue to push for increased integration of rare disease expertise and social and medical services across country borders to improve the future of rare disease care for all EU citizens.

Key relevant impacts for policy change and work:

1. During the COVID-19 pandemic, NoRo Center has developed a Risk Alert platform for patients in need of emergency services: www.riskalert.ro, created with the support of the SmartHealthClusterOrganization. In response to the war in Ukraine, the platform has been adapted to coordinate the care for refugee patients with rare diseases. The platform will serve as a space for emergency/crisis situations.



The human touch for care and cure

The case of discovering hands®

Dr. Frank Hoffmann is a gynecologist with a longstanding socially entrepreneurial spirit based in Duisburg, Germany. In 2001, Dr. Hoffmann founded the Quality Circle of Gynecologists, a round table of Duisburg gynecologists aiming to guarantee standardized quality control of care in the region. Four years later, new German healthcare legislation significantly limited reimbursements for breast cancer screenings, particularly for women under 50. Suddenly, Dr. Hoffmann was unable to provide the high-quality care to his patients that he had worked to promote, leading to his development of an innovative solution enabling high-quality breast examinations to be broadly delivered within new legislative constraints: discovering hands®.

Prevention and effective treatment of breast cancer depends on early diagnosis of potential cancers through regular screening. Since 2005 mammography screening examinations have been offered in Germany, a high-tech, expensive diagnostic tool typically only reimbursed for women from 50 to 69 or a superficial manual breast examination available to women of all ages. No standardized techniques for manual examinations are taught to doctors, and these examinations are typically 3 minutes.

Due in large part to the impersonal, stressful, and often ineffective experience of manual breast examinations, German women tend not to participate in preventive diagnostic procedures in Europe.

Discovering Hands® engages and leverages the heightened sense of touch of blind and visually impaired persons, a generally neglected cohort of the German labor market, to provide cost-effective preventive breast care diagnoses.

Using a standardized system of 'tactilography' using braille strips, discovering hands® trains blind women as Medical Tactile Examiners (MTEs), a new, specialized type of medical assistant. Given their lower labor costs compared to doctors, breast examinations conducted by MTEs last 30 to 60 minutes, allowing for both a comprehensive breast examination and a relaxed atmosphere for patients to ask questions and receive reassurance of their good health. Further, research has demonstrated that manual breast examinations from MTEs resulted in the identification of additional, and in particular smaller, tumors as compared to doctors, all for 25% of the cost of mammography.

Impact Story: Medical Tactile Examiners (MTEs): Disability as an asset for improved diagnoses and patient empowerment

In addition to delivering better diagnostic outcomes in comparison to brief physician manual exams, tactilography done by MREs provides an opportunity for patients to receive valuable care for their emotional needs in an often stressful healthcare situation. Beyond simply answering patient questions,

the humanizing care experience provided by MTEs build bonds between patients and the often cold, hierarchical healthcare system. 97% of patients are satisfied with breast cancer screening provided by MTEs, with these patients also more likely to participate in other essential screening and care procedures. Additionally, the MTE role empowers blind women by providing both specialized employment opportunities and a context in which their disability is an asset, rather than a limitation.

Impact Story: *Empowering, cost-saving diagnoses*

Research demonstrates that over 5 years, 10 MTEs would identify an additional 125 cases of early-stage breast cancer that would have been otherwise diagnosed in a much larger stage. Catching these cancers early would save the health system 1.1 million EUR in therapy-related costs, preventing productivity losses of 6 million EUR. Additionally, the gainful employment of MTEs would save 750,000 EUR in disability support payments. The improved emotional connections between patients and the health system are likely to also yield further quantifiable benefits. Accordingly, *discovering hands*® provides a framework which both improves health outcomes and reduces health system expenditures, rapidly repaying initial investments in MTE training. Social Impact Bonds could help train a larger number of MTEs; they are unfortunately not available in Germany to this date.

Policy impact(s)

Key relevant impacts for policy change and work:

1. *discovering hands*® is a demonstrated tool for improving preventive cancer practices by integrating more sensitive diagnostics with superior care for patients' emotional needs.
2. The use of MTEs for manual breast cancer examinations provides an approach to incorporating integrated care principles in diagnoses of breast cancers and beyond.



Frank Hoffmann



From patients with a diagnosis to resourceful individuals

The case of The Human Aspect

At the age of 13, Jimmy was sitting in a tree planning how to take his own life. He had ADHD, was navigating a complicated family situation with an alcoholic father and a sick mother, and suffered from being bullied as a result of being a sensitive child living in the country, where masculinity took a particular form. Wanting to protect his loved ones from another “burden” and in fear of being even more rejected by his peers due to the stigma attached to ADHD and suicide, Jimmy decided to stay silent and was left without any support.

The latest student survey in Norway from 2021 revealed that the number of students that self-reported having severe challenges with their mental health increased from every 6th student to close to every 2nd student (45%) from 2010 to 2021. Every 5th student reports having hurt themselves on purpose to regulate emotions and the same amount of students report having experienced suicidal thoughts like little Jimmy, within the last year. The survey consists of students between the age of 18-34 and 62.000 students responded. The trend has been declining from the first survey in 2010, and the pandemic only seemed

to reinforce that decline. The pandemic pushed mental health further up on the list of global priorities, but still only 2% of the total health budget is spent on M.H. on a global scale.

The most alarming data from the student survey in Norway was that the number of students seeking help for their struggles decreased. **The burden of challenges increased, while the number of students seeking help decreased.** Similar to Norway, the other European countries struggle with long queues, an efficiency-focused systems approach, an increase in drug treatments and reported failures. In addition, psychology is an academic sector that is largely unchallenged and uncriticized, sitting on top of the hierarchy within mental health and having limited focus on preventive and proactive approaches. Treatment impact research recognizes the importance of warmth, empathy, time to create trust, custom treatment plans, and space for usage of lived experience in the treatment rooms, none of which are enabled by the system.

The Human Aspect wants to move beyond seeing people as patients organized in different diagnostic groups, to seeing people as individuals with different personal challenges and resources, that are tackled and leveraged with the help of the health system.

Since its creation 6 years ago, The Human Aspect (THA) digitized the lived experiences of more than 750 people. Through in-depth video interviews, THA captured the essence of individuals’ mental health journeys, sharing these videos for free across the world on their website database. THA recognizes that people need

agile, customized care and support, to help them access their own resources and take an active part in their healing journey.

For THA, integrated health is when the system evolves and adapts around a person. Where the analysis of the person includes their holistic self, such as their life goals, current consequential challenges, life-context, current health burden (physical, social, practical, relational, emotional and psychological), and their motivation and ability to recover. This approach considers all aspects of a person, not just the symptoms, acute consequences and diagnosis. With this foundation, THA can build a custom health package that aims to create an intersectional response involving the whole health and social support system. A package that encourages collaboration not only between the person and the system, but is inclusive of their social support network. This approach utilizes the full power of the health systems we have created in Europe, including specialization, diversity in services, and the soft skills of professionals and their expertise.

Impact Story: Health coordinators at the center of recovery journeys and holistic health

The key for such a system is a health coordinator who collaborates closely with the person, and through a close and personal connection supports them in executing and following-up on their holistic recovery plan (including physical, emotional and psychological recovery). Different to a traditional treatment plan, which implies power imbalances between the person offering the treatment and the person receiving it, a recovery plan focuses on the recovery journey, leaving the roles

more open. In the professional sphere, the health coordinator and the recovery plan positively contribute to the fulfillment of motivated employees, hence supporting cost-effective recoveries for people in the system. To succeed in offering this health system, the system needs to consider all aspects of health and approach recovery holistically. Most European countries are working on a universal health system to ensure a smooth transition of not only health data, but also lessons, new research, standards and regulations.

Policy impact(s)

Key relevant impacts for policy change and work:

THA is working closely with different partner organizations and layers of the health system to develop a log-in platform for health workers and coordinators that allows them to:

1. Utilize THA's free resources in their psychoeducation and as part of their recovery plans
2. Share insights with other healthcare workers, particularly those internal to the partner organization
3. Customize and easily transfer programs to their users in a fully digital format.

THA is also working preventively with schools and companies to increase general psychosocial knowledge and to lower stigma. In the education system, THA has created a platform for teachers in Norway with classroom-ready educational schemes and additional resources to support vulnerable students.

 THE Human ASPECT
Jimmy Westerheim



European Policy Recommendations for Integrated Health

- **Europe needs a platform for integrated health.** This space would enable the coordination of integrated health initiatives, connecting experts and providers in order to weave their approaches and build the vision and implementation of integrated health.
- Current GDPR policy is heavily regulated. While keeping data private and safe is crucial, we shouldn't forget about the need for individuals to access data. The sicker you are the more crucial it is to access your data. **New legislation should include a component to reduce the burden on small sorganization** trying to leverage health for the good of individuals and patients.
- **All health data should be digitized by 2025 and be the property of the patients,** becoming consistent and accessible across Europe.
- There should be European legislation to address the gap of data sharing and access across members' countries and within countries. **Innovation in healthcare should be financially supported beyond considerations of drug development.**
- **Community nurses are important human resources who can support the coordination of care for patients with rare diseases.** Their training as care managers is crucial and should be at the heart of rare disease strategies and well connected to countries' healthcare plans.
- **Every person should be given the right to a holistic assessment and a custom recovery plan. New professional roles as health coordinators should be created** as positions integrated with current General Practitioners.
- **Broader availability of 'Social Impact Bond' schemes would ease start-up funding constraints** for sustainable healthcare solutions capable of rapidly reimbursing initial investments through system-wide cost savings.
- Disability is a source of innovation. **All healthcare plans, ventures, and businesses should be built with an inclusive design** because when you build a health solution for individuals with disabilities, you build a health solution for everyone.

This Position Paper is in constant evolution and its implementation needs you!

Do you want to **contribute?** Are you interested in supporting the application of **Policy Recommendations?**

Reach out to us:
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