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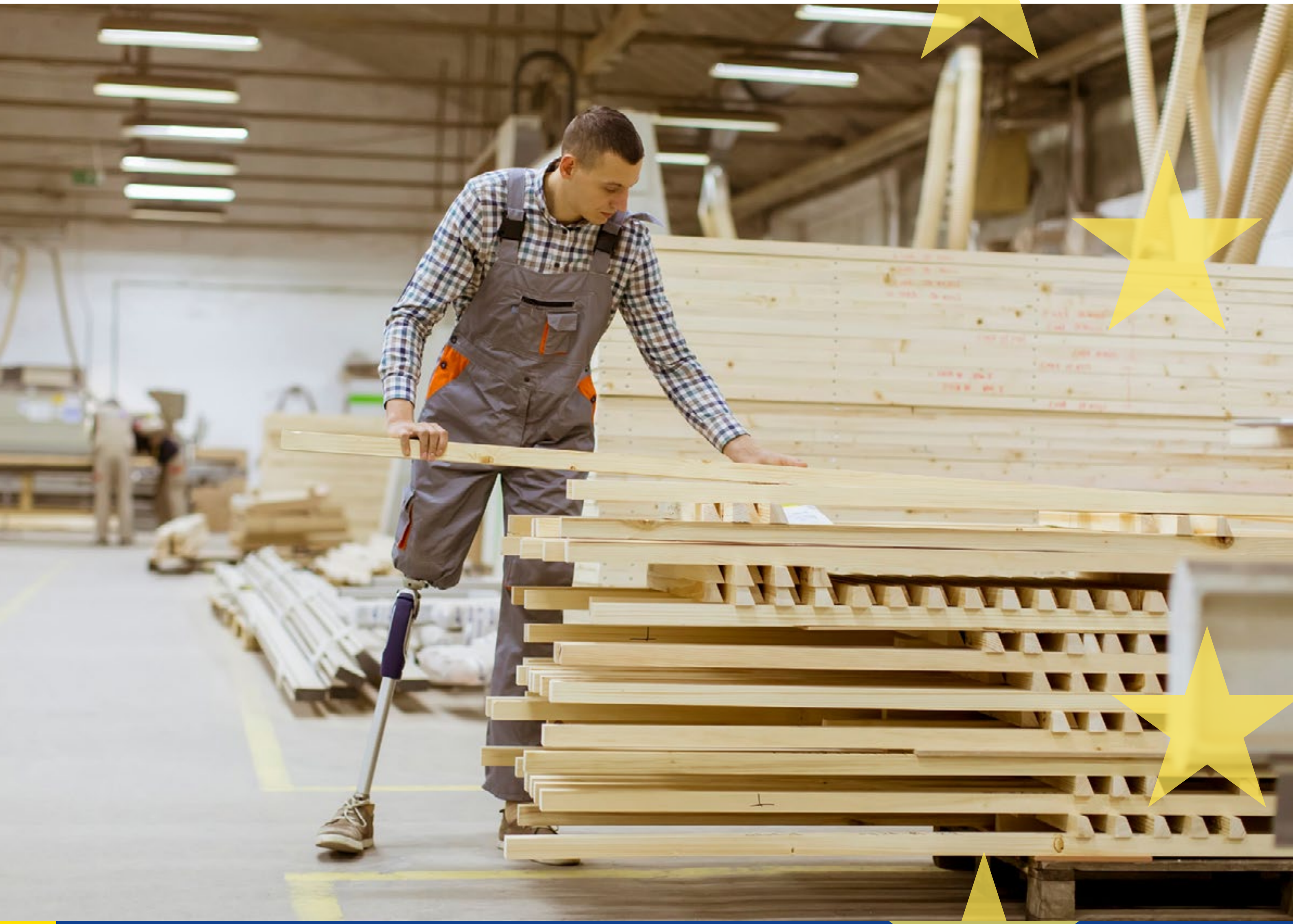

FROM INSTITUTION TO COMMUNITY LIVING

Collection of Models of Good Practice in deinstitutionalisation for people with high support needs/multiple disabilities, including practices on how assistive technology can support inclusive living

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This is a report of the European Association of Service providers for Persons with Disabilities (EASPD) subcontracted to Professor Anne Rosken, Nic Crosby, Dr Peter Fuzesi

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We thank EASPD for funding this work and for enabling this collection of practice to be put together. We hope it will be useful to many people across Europe and more widely and assist the transformation of support services towards a community-based model for people with disabilities of all ages.

Anne, Nic, Peter

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Contents

Executive Summary

The work centres on identifying five case studies from across the European region where an institution for people with disabilities including those with high/complex support needs, has been completely closed.

The work was commissioned in September 2020, the first version of the report was completed in December 2020.

The Five Case Studies

The case studies span almost fifty years of time and work; in the view of the project team this provides a useful timeline that identifies how each has learned from the experience of the previous work and built an ever stronger and evidence informed approach to complete closure. From the radicals setting out to close the institution in Trieste, led by Franco Basaglia, to the detailed and strategic approach in Moldova, each case study provides a good sense of the work needed and what it takes to succeed in completely closing an institution for people with disabilities. The five case studies are:

★ Trieste / Italy

The Mental Health Department in Trieste, accredited as a collaboration centre of the World Health Organization (WHO), is considered a sustainable model for the proven effectiveness of service development in Europe and worldwide. As a first closure the work in Trieste has continued with developments in support, community inclusion and the use of personalised funding meant that this case study is not simply an explanation of a time-limited closure but of an ongoing programme of learning development and action. The work to close the institution began 1971 with the appointment of a new Director Franco Basaglia and ended as a programme in 1980 when the hospital was declared closed.

★ Stockholm City Region, Sweden

This case study examines institution closures in the Stockholm City region. The process of building a system of community-based support aided by the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), 1993[1] took many years. People moved out if the institutions in Stockholm in different waves: the last resident left Carlslund in 1988 and Bjornkulla in 2000.

★ Lennox Castle, Scotland UK

The closure of Lennox Castle was part of a national closure programme between 1995 - 2003. The bridge funding was provided by the Secretary of State for Scotland via the health authority to take forward the Greater Glasgow closure programme (Lennox castle). They create the 'HomeLink' team to identify and provide housing for people moving out of the institution using a personalised plan for all. The support was for people with high/complex support needs.

★ Kilcornan House, Brothers of Charity / Ireland

Residents moved to community-based settings through a in long and gradual process. Developing and trialling pilot projects served both as a learning process and demonstrated that those with high/complex support needs can live more independently, within community-based support. The process was based on seeking consensus and partnership between management, families and labour unions.

★ Marculesti, Moldova

A complete closure of a residential educational institution for children and young people with disabilities. The programme of work led by Lumos in partnership with local and national government delivered a highly-organised and structured closure programme that included the development of a completely new 'foster care' provision alongside new family support services within social care departments.

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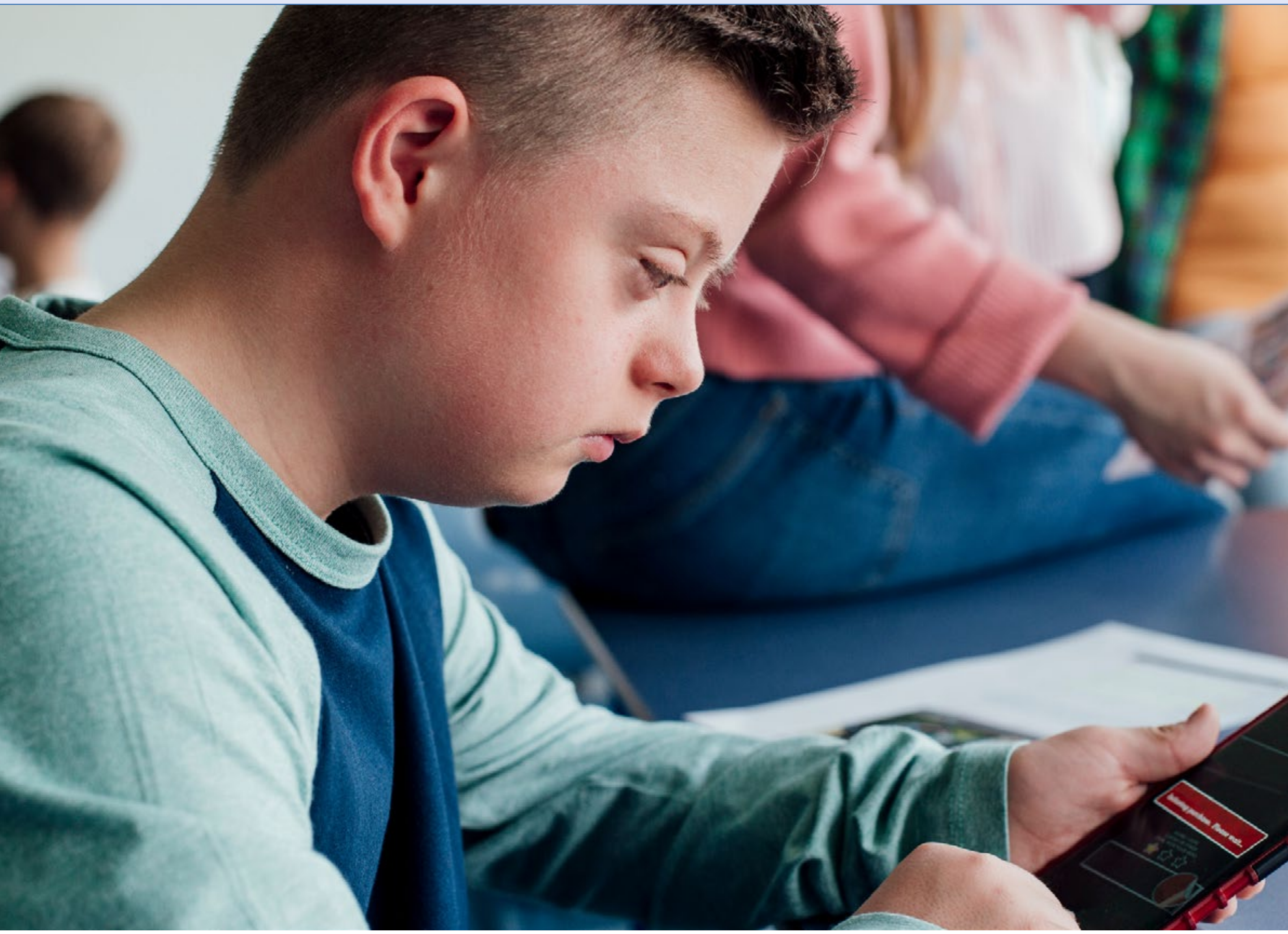
[1] Kingdom of Sweden., 1993. Act concerning Support and Service for Persons with Certain Functional Impairments. SFS 1993:387



Person-centred / Assistive technology

In the five deinstitutionalisation cases examined, we found that the most common technologies were simple tools and adaptations to one's home, for example handle-bars or stepping out of the bathtub or accessibility or care related technologies like hoists or alarm systems. While accessibility can be planned on an organisational level, the implementation and use of many assistive technologies has to be person-centred and planned according to the needs, abilities and preferences of the single individuals.

Framework of recommended activity:

A consistent set of themes are highlighted across the examples, along with innovations or approaches that clearly contributed to the successful closure of each of the institutions. The project team have gathered these activities together under three titles as a timeline: foundation, implementation and legacy to illustrate what the case studies tell us about the work and activity needed to successfully close an institution.

Glossary/Main Abbreviation

Assistive technology (AT): The WHO defines Assistive technology as the application of organised knowledge and skills related to assistive products, including systems and services. Assistive technology is a subset of health technology (WHO, 2016)[2].

Assistive products: The WHO defines Assistive technology as any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual's functioning and independence, and thereby promote their well-being. Assistive products are also used to prevent impairments and secondary health conditions (WHO, 2016).

Co-production: An inclusive working practice between experts by experience (users), organisations being of support, public authorities and, if relevant, families and other stakeholders. The ultimate goal is the delivery of a service, policy or activity that is responsive to the user's needs and preferences in line with the principles of the UN CRPD. Through co-production all stakeholders are empowered and are empowering as they are continuously involved in the design, development and delivery of the service, policy or activity.

Community-based services: Enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to an institution. It encompasses mainstream services, such as housing, healthcare, education, employment, culture and leisure. It also refers to specialised services, such as personal assistance for persons with disabilities, short break care and others.

CRPD: Convention on the Rights of Persons with Disabilities.

Group home: A home where a small number of unrelated people in need of care, support, or supervision can live together. The home and the support are provided by the same organisation/service. A 'Small Group Home' is defined as one for between 4 and 6 people.

Inclusion: Being included as fully participating citizens in society; within local communities, in mainstream schools, having access to the same opportunities as all other citizens with the support you may/may not need.

Independent living: Persons with disabilities have the right to choose their place of residence and the right to live in the community. This includes not obliging them to live in a particular living arrangement and the obligation to provide people with disabilities with access to a range of in-home, residential and other community support services, including personal assistance.

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[2] World Health Organisation., USAID, Alliance, I.D., 2016. Priority assistive products list: improving access to assistive technology for everyone, everywhere.

Individualised funding: Often referred to as an ‘individual’ or ‘personal’ budget. Funding allocated on an individual basis to meet an individual’s support needs in flexible ways. The most common form is as a ‘direct payment’ where the funding is passed on to the individual or their nominee and managed by themselves to purchase support and other services.

Information and communications technology (ICT): is an umbrella term that includes any communication device or application, encompassing: radio, television, cellular phones, computer and network hardware and software, satellite systems, and so on, as well as the various services and applications associated with them, such as videoconferencing and distance learning (Huth et al., 2017)[3].

Information technology (IT): covers any form of technology, that is, any equipment or technique used by a company, institution, or any other organisation which handles information. It incorporates computing, telecommunication technologies, and includes consumer electronics and broadcasting as it is getting more and more digitised (Grauer, 2001)[4].

LSS: The Act concerning Support and Service for Persons with Certain Functional Impairments. 1993:387. Kingdom of Sweden

MHD: Mental Health Department

Public procurement (Commissioning): The purchase by governments of goods, services and works. An efficient and effective public procurement system should ensure the delivery of quality services to the public.

Persons with disabilities: People with Disability.

Stakeholders: A stakeholder is anybody who can affect or is affected by an organisation, strategy or project. They can be internal or external and they can be at senior or junior levels. The process of institution closure will impact not only on the lives of the people moving out and the workforce but on local communities and services; all are stakeholders to some degree.

Supported Living: A service designed to help people with a wide range of support needs retain their independence by being supported in their own home. People in supported living have their own tenancy and are responsible for their own bills and cost of living.

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[3] Huth, M., Vishik, C., Masucci, R., 2017. 8 - From Risk Management to Risk Engineering: Challenges in Future ICT Systems, in: Griffor, E. (Ed.), Handbook of System Safety and Security. Syngress, Boston, pp. 131–174.

[4] Grauer M. in Smelser, N.J., Baltes, P.B. (Eds.), 2001. International Encyclopedia of Social & Behavioral Sciences. Pergamon, Amsterdam; New York.

1. Introduction

‘From Institution to Community Living’ sets out to develop a clear framework of activities and work that will provide better chances of successfully closing institution for people with disabilities in the future. This framework is based on evidence gathered from five case studies where the closure of an institution has been completed. The closure of institutions for people with disabilities has not moved forward at the expected speed, as evidenced in the report submitted to the European Commission in January 2020, or as swiftly as would be hoped by the many lobbyists, activists and persons with disabilities campaigning for change. All parties agree that more needs to be done and with this in mind EASPD commissioned this research. This work is centred on the practical steps needing attention when working to close an institution; today there is consensus about the need for closing institutions, there is also a recognition that to date limited progress has been made and the process should speed up.

The case studies collected span fifty years of work; from the closure of the institution for people with psycho-social disabilities (mental health support needs) in Trieste in the 1970’s to the closure of the residential institution for children with a range of support needs in Moldova in 2014. Together these case studies identify the key factors leading to complete closure; they also tell a story of the ongoing work that these closures set in motion. Whether it be the work to further early family intervention in Moldova, or the development of personal health budgets to facilitate access to housing in Trieste; the impact of the closure means a change in societal appreciation persons with disabilities’ inclusion, is not simply a time limited process but the start of a much larger transformation. We see great value in highlighting this, and the span of time by the case studies as vitally important for understanding what closure entails and what work can be undertaken early in the process to pre-empt some of the challenges that have been encountered.

The Framework that this report sets out covers essential areas of work and activity which,

with commitment, can deliver complete closure of an institution. The voices of people who moved to community-based support evidence clearly what it means to them and many other residents, for those in new work roles the change has been similarly transformative, and for the local community and wider society the closure has changed, and continues to change, people’s attitudes and appreciation of being more welcoming and inclusive.

We greatly appreciate this opportunity to delve into these case studies, to learn about people’s experiences and the impact of closure on people and communities across Europe. Many people have freely given their time and energy to supporting this work, and we would like to reiterate their thanks for all the support from many people across Europe that this report has benefitted from.

2. The purpose of this study

The project has developed a rich understanding of how the deinstitutionalisation process worked in different national contexts, organisations, legislative frameworks and funding arrangements. This was achieved by examining five closure programmes where persons with high support needs/multiple disabilities and/or psychosocial disabilities were supported to move on, and who are now living in local communities receiving the support including from assistive/person centred technology they need, with freedom to make choices about their lives.

The specific objectives of the study were to:

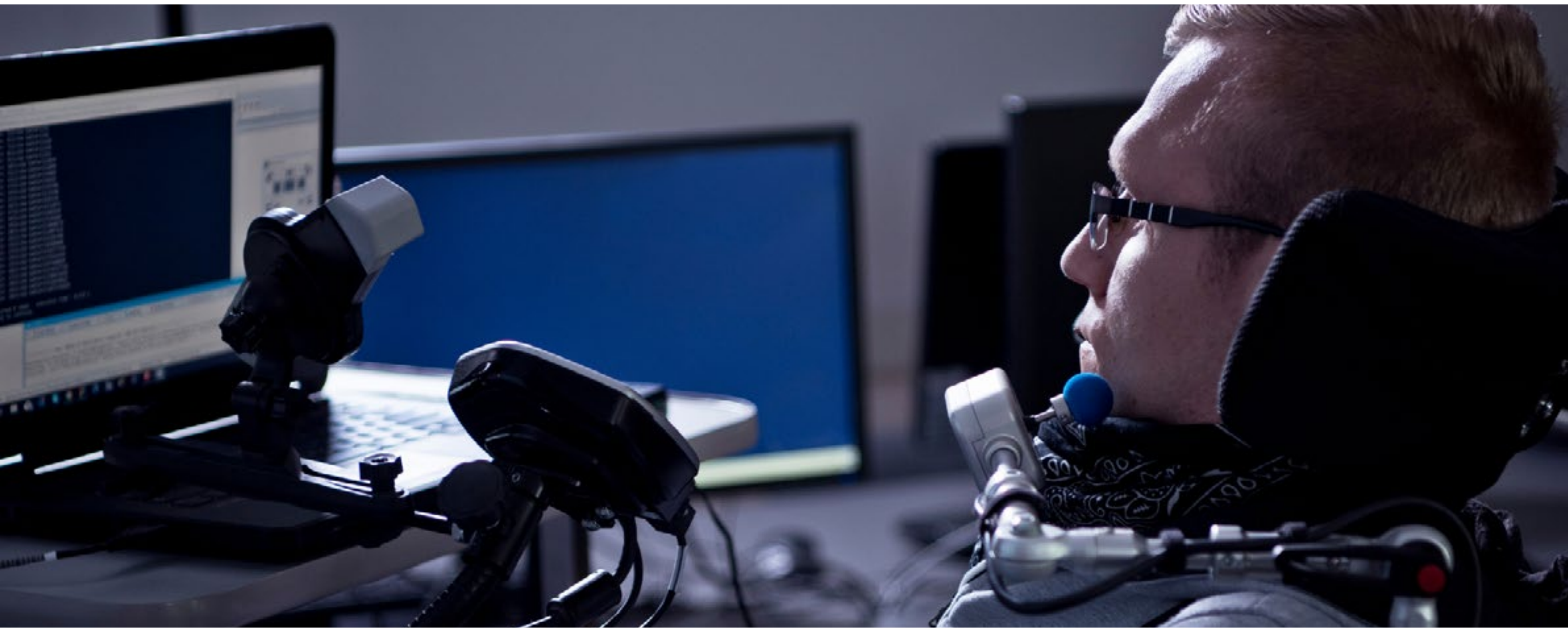
1. Gather relevant quantitative and qualitative data and information on the process from five examples in five countries (document research/analysis/expert interviews/persons concerned interviews).
2. Evaluate the effectiveness, efficiency, relevance, coherence and added value of the process of deinstitutionalisation. The extent to which it has translated into concrete practice; and, the extent to which it has informed and reinforced in the view of different kind of stakeholder. This are for example:

The barriers and the levers that promoted the change.

- ★ The community support models for individuals who were 'moved out''.
- ★ The funding required before, during and after the deinstitutionalisation process ended.
- ★ Changes in the support model for individuals who were relocated, with
- ★ information on staff/ratio, support available and their human rights (as set out in Article of the 19 UN CRPD).
- ★ Attention will be paid to the ways information, assistive and mainstream technology products and services were used to support inclusive living.

In cases, where this was possible, we represent the views of people with disability by gathering testimonies from residents who moved from institutions to community-based support.

The overall and main purpose of this study is to provide EASPD an evidence-based report on the evaluation of five successful transition processes from institutions to independent living within examples of successful deinstitutionalisation cases, including the learning's and the summaries of the implementation.



For this study it was essential finding five most popular examples of deinstitutionalisation across Europe and at this stage we can point out, that they are all different. So the aim of this research was not to clarify one gold standard. Rather it was a challenge to find various good practices across Europe that show a wider range of possible processes within services. For this, we completed a document research to record the special views. On this basis we identified five examples and five institutions across Europe and selected most popular interviewees. These were people intimately involved in the deinstitutionalisation process and could give us the most relevant information. We followed a theoretical sample methodological approach (Glaser and Strauss, 1967)[5]. The report delivers data on how the deinstitutionalisation process was conducted in different settings including persons with high support needs/multiple disabilities and/or psychosocial disabilities and how the persons who are relocated now living in community-based care settings receiving adequate support and with freedom to take choices over their lives. For a clear definition on institutional settings and community-based living and to have a structure for identifying and analysing practice, we refer to the Common European Guidelines on the Transition from Institutional to Community-based Care of the European Expert Group on transition from institutional to community-based living.

The study focuses on persons with high support needs/ multiple disabilities and/or psychosocial disabilities, and includes concrete examples of technologies, mainstream ICT (information and communication technology), specialised assistive technologies (AT) and commercial services and products contribute to support inclusive living within the framework of the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child. In some cases from previous decades e.g. Trieste, Italy or Lennox Castle, Scotland technology played a less pronounced role. Today, technology's potential to improve lives of persons with disabilities receives more public attention.

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[5] Glaser, B.G., Strauss, A.L., 1967. The discovery of grounded theory: strategies for qualitative research, Observations. Aldine, New York, NY.

3. Scope

The scope of the project was clearly identified by EASPD in the call, the key factors being:

- Five case studies from with the European region
- To include examples and information about support to people with 'high/multiple disabilities and/or psychosocial disabilities' (all ages)
- Changes in funding
- Changes in support planning and staffing
- To include examples and information about the use of assistive technology in the deinstitutionalisation process.

Our approach to the project is further discussed within the Method section. This process should start with getting clarity about key terms ensuring that we were consistent ourselves and in our investigations in work across Europe.

Key definitions:

People with high support needs/multiple disabilities:

People who require a high number of support hours, with specialist support such as expert input/supervision, or and assistive or medical technologies. We recognise that the experience of being institutionalised may have detrimental effects and create support needs.

Person centred technology (PCT) / Assistive technology:

Persons with disabilities can benefit from using a wide range of technologies. These include both simple aids and the latest information and communication devices. Specialist and mainstream technologies that can be used to enhance people's independence and safety, making them less dependent on carers. Based on a user centred approach, people with disabilities should benefit from new technological developments that empower them.

4. Methodology

By examining five cases of European countries, our research aimed at answering three questions:

- What is the aim of transition from institutions to community-based support models?
- What happened in specific cases of this transition process?
- How effective specific tool and strategies can be for closing institutions and implementing community-based support for persons with disabilities?
- What kind of role IT, AT and commercial product and services play?

Our methodology aimed at recognising the multiple processes involved in the transition from institutions to community-based support. These processes involve different populations, children and adults, people with different physical, sensory and intellectual disabilities and mental health problems. In addition, in many cases, the institutionalisation process itself contributes to further disabilities and dependencies in individuals. The transition towards community-based support, on the other hand, takes place in different economic, administrative and social contexts with different national, cultural, legal and institutional histories and resources.

To account for these diverse elements and processes, we defined two main areas: the transition process of closing institutions and moving people out, and the design and implementation of new community-based services.

When examining the transition process, we looked at:

Leadership

Who initiated and led the deinstitutionalisation process? What role did persons with disabilities and their families play in the planning and execution of the transition process?

Agencies

What stakeholders were engaged in the process and how? How did the deinstitutionalisation process and the new service model build on existing systems of health and social care services?

Institutional culture

When and how aspects of deinstitutionalisation process (e.g. housing, staff training, dignity, co-production) were discussed? And the operation, procedures and wider process: How and what agencies managed the transition process, how and what were resources provided?

Looking at the new community-based support model we identified eight elements: housing, finance (including financial plans and budgeting) workforce development (including transition, recruitment and training) community support care planning, co-production and persons with disabilities' and their families' involvement in decision making, community inclusion and participation, assistive and person centred technology provision in new services, finally safety and safeguarding.

When conducting research, a secondary analysis was conducted on research and policies relating to the transition to community-based support models. Based on this, we identified a number of candidate countries where successful deinstitutionalisation projects were reported to have taken place in the past. We made contacts with relevant stakeholders to verify these reports and decided to exclude four countries while identifying Ireland, Italy, Moldova, Scotland and Sweden as suitable case studies. Besides our actual case studies, additional cases were explored across Europe, contacts were made with Czechia, Croatia, Hungary, Spain, Romania, Slovenia and Slovakia. In each of the countries listed, it was unclear whether 'complete closure' had been achieved. In one or more cases, a large number of people had been supported to move out but there were still numbers being accommodated in the institution or there was not community-based support in place. While we aimed at including cases from various geographic locations, this was not possible within the constraints of this project. Data was collected by documentary analysis of policies and other relevant materials and by semi-structured interviews. Interviewees included service users, experts, activists, decision-makers and managers and where possible persons with disabilities who moved out.

Participants were recruited by identifying an initial pool of interviewees either based on official role or personal connection following the methodology of the Grounded Theory (Glaser and Strauss 1967). After conducting the first round of interviews, we asked our participants to recommend other relevant interviewees. Altogether, 17 interviews were conducted in English, these were recorded, transcribed and analysed. Because of the COVID-19 pandemic, interviews were conducted online, on Zoom. Beyond general principles of ethics, we considered issues of consent and conducting research with vulnerable people.

We produced a research Information Sheet and a Consent Form, participation was based on informed consent.

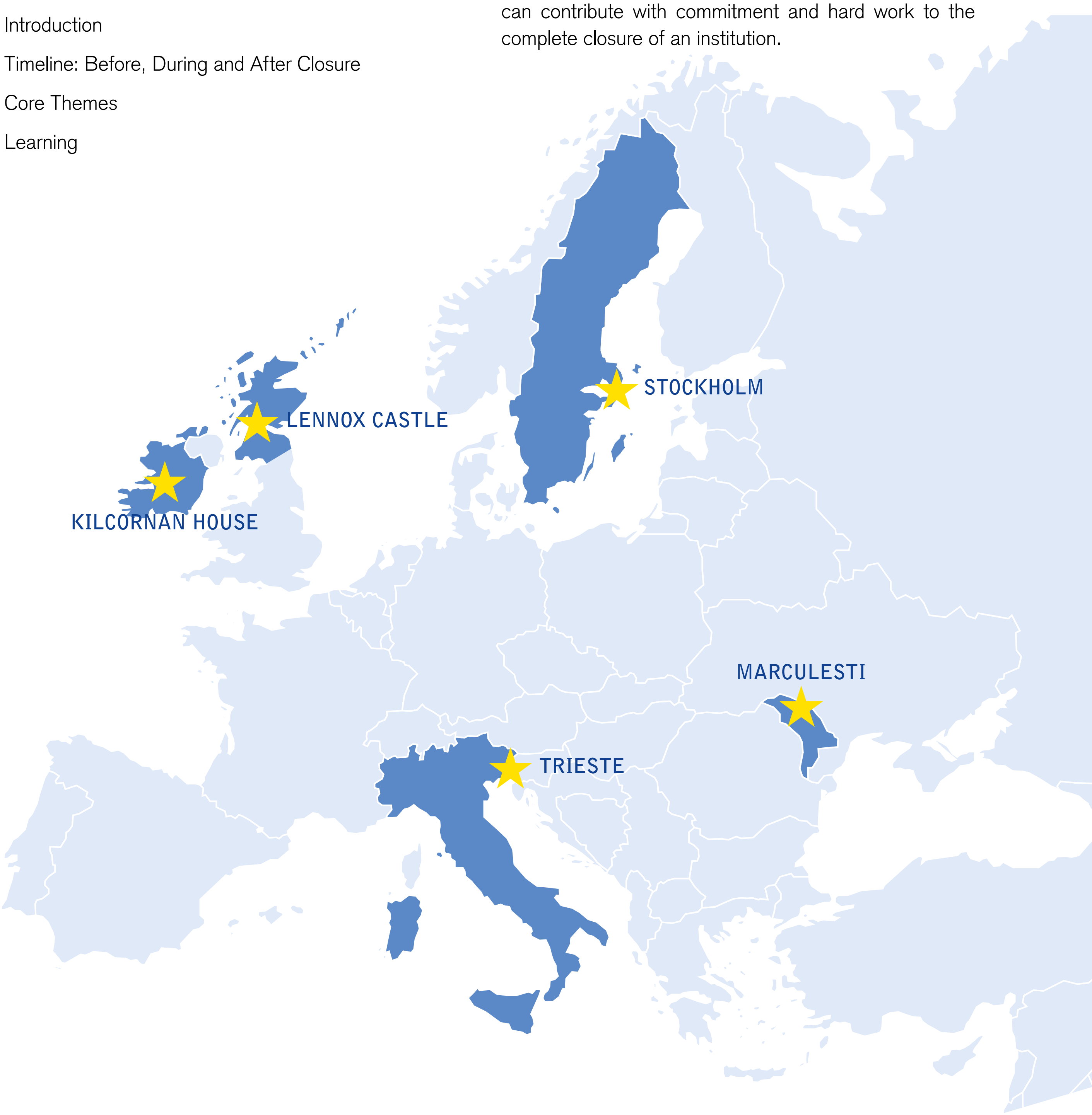
5. Case Studies

From the radicals setting out to close the institution in Trieste led by Franco Basaglia to the detailed and strategic approach in Moldova, these five case studies cover fifty years of work, each taking forward a better informed programme of work leading to complete closure.

Each case study is presented in the following structure:

- ★ Introduction
- ★ Timeline: Before, During and After Closure
- ★ Core Themes
- ★ Learning

It is important to note that whilst some closure programmes were fairly swift; in Moldova the institution was closed within four years, in others it was a longer, more drawn-out process. In the final section we draw out the learning from these case studies and following the timeline to explain three sets of activities (Foundation/Preparation, Implementation/Action and Legacy/Learning) that can contribute with commitment and hard work to the complete closure of an institution.



5.1 Trieste, Italy

The closure of a psychiatric clinic for people with mental health problems

MENTAL HEALTH DEPARTMENT (MHD), TRIESTE - ITALY

Introduction

The Trieste experience (Mezzina, 2014, 2020, Ridente and Mezzina, 2016)[6] is an internationally known example of the complete closure of a psychiatric clinic (1980). The local mental health department (MHD) now includes 24-hour mental health centres (CMHC) with a few beds each and only one 6-bed unit in the general hospital for a city of 240,000, a large number of social cooperatives and many innovative recreational and social inclusion programmes. The MHD in Trieste, accredited as a collaboration centre of the World Health Organisation (WHO), is considered a sustainable model for the proven effectiveness of service development in Europe and worldwide. The Trieste experience is characterised by a comprehensive definition of rehabilitation as a process of re-institution and (re) construction of full rights (political, civil, social) and citizenship for people with mental illness, as well as the material enforcement of these rights. Work taken forward in Trieste took diverse forms, all with a focus of achieving:

- legal recognition of civil and social rights and the material means to exercise them through diversified strategies;
- acquisition of resources (houses, jobs, goods, services, relationships), mainly from non-profit institutions through deinstitutionalisation and conversion;
- improving access to resources, primarily by developing the skills of key users and family members. This in turn requires training (life and professional skills, education), information (psycho-pedagogical, social awareness and information about rights and resources - when, how and where), as well as the creation of social support networks that enable the provision of resources through comprehensive non-profit services that are diametrically opposed to mental health institutions.

To achieve these goals, it was important to empower primary consumers, support family members, retrain and reorient professionals, provide health education, and create a cultural change in attitudes, especially among those directly involved in the delivery of services. All of these measures must minimize the constraints and social barriers that promote disability and stigma, and seek to end marginalising practices (such as long-term institutionalisation in forensic hospitals). A good reintegration programme for people with intellectual

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[6] Mezzina R. (2014): Community Health Care in Trieste and Beyond. An „open- door-no restraint“ Systemof care for recovery and citizenship. The journal of nervous and mental disease, volume 202. Number 6. 3.

Mezzina R.: (2020): Basaglia after Basaglia: Recovery, human rights, and Trieste today. Oxford university press. May 2020.

Ridente P. and Mezzina R. (2016): From Residential Facilities to Supported Housing. The Personal Health Budget Model as a Form of Coproduction. International Journal of Mental Health. 45-1. 59-70.

disabilities therefore requires skilled support not only to regain lost skills, but more importantly to provide places and situations where these skills can be used, i.e. opportunities in the home, work and social relationships.

Transition

When we view people receiving psychiatric care as passive rather than active and autonomous subjects who think, choose, and are responsible for themselves, we are undermining the effectiveness of the intervention. As Amartya Sen[7] argued, any qualification as disabled, poor, or sick - and the expected drawbacks or feelings of being labelled as such - supports the negative effect "on self-esteem and the way others see you" and neutralizes the benefits that an intervention could lead to. The skills approach emphasizes the importance of developing functions as the main instrument for accessing available social opportunities and resources: "What can a person do?".

Timeline

The work to close the institution began 1971 and ended as a programme in 1980 when the hospital was declared closed. However, a number of ex-inmates (around 300, ¼ of the former hospital capacity) stayed as "guests" in ex-wards, which were converted into group houses on the hospital premises. They gradually moved to the city (the last group of 19 people moved in 2016).

Before closure

Summary: Foundation / Preparation

- ★ Ideological push led by a team of people in Trieste resulting in national legislation to close institutions in 1978 (Law 180).
- ★ Work to close Trieste started in 1971 with the appointment of a new Director Franco Basaglia. A working group was established comprised of hospital team plus others from the community and activists who wanted to close the institution.
- ★ Financial support was received/ applied for from Trieste provincial authority and the hospitals funding.

Detail: Location, socio-economic cultural, political environment, numbers, decision about closure of the institution

This was a provincial psychiatric clinic, "Andrea di Sergio Galatti". It was built in 1906 and administered by the Amministrazione Provinciale in the city of Trieste. It was in a park on a hill not far from the city centre. It comprised about 30 buildings.

In Italy there was a strong "anti-institutional" movement in Gorizia (in the same region) in 1961, led by Franco Basaglia and his collaborators. In the following decade, 1971, he was appointed in Trieste. In the 1970s, around 20 Italian psychiatric hospitals were in a process of change, and Trieste, Perugia and Arezzo achieved complete closure. It paved the way for "Law 180" of May 13, 1978, which stated that all psychiatric hospitals in Italy must be overcome and severely restricted the use of coercion. The decision to close the hospital was made by the director along with the other HR managers during the departure.

During closure

Summary: Implementation / Action

- ★ Involvement of local community, activists and social co-operatives from an early stage;
- ★ all physical restraint were outlawed and mixed wards were established;
- ★ Five regional teams were set up to work within an area of the city to work within;
- ★ Hospital patients supported to get out and about with funding provided by Trieste provincial authority (promoting visibility of people with disabilities);
- ★ Events and gatherings were held within the hospital open to the community, a bar was set up in the hospital;
- ★ First hospital ward closed and opened as a community space for arts / meetings gatherings;
- ★ United Workers Co-operative and other similar co-operatives established giving patients work across the city, promoting social inclusion and contribution;
- ★ Workforce moved from institution to small group homes and support services in the community;
- ★ The local political mandate (F. Basaglia was appointed director by the President of the Province of Trieste, the local administration that ran the psychiatric clinic)

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[7] Sen, A., 2001. Development as Freedom, 2nd edition. ed. OUP Oxford, Oxford; New York.

and the recruitment of new staff (about 1/5 were new young doctors and nurses) promoted the initiative and the process. The new director, with the support of a collective group of staff, began planning the process of opening doors, humanising and personalising care, restoring rights, freedom, etc.

Detail: Responsibility for the decision to move out, process, assessment, staff, support

People were discharged, some to their families, or they were sent to small group houses outside the hospital or inside the hospital (reuse of empty wards). In May 1975, the first community mental health centre was established. It was supposed to support comprehensive clinical and social care, as well as social inclusion in neighbourhoods, and a second in June of the same year. In 5 years there were seven 24-hour CMHCs covering seven river basins. It was the first cooperative that did real work, to provide real work with real pay. This was established in 1972, then other 4 followed in a few years. The staff has been completely re-orientated to new functions, re-located to CMHCs and group homes, gradually leaving the hospital with their users. The wards were cleared and some were reused for life at home. The entire facility was in a precarious state until the 1990s when the administrations (local health authority, province, university) agreed to begin a remediation for full reuse.

After closure

Summary: Legacy / Learning

As a first closure the work in Trieste has continued with developments in support, community inclusion and the use of personalised funding meant that this case study is not simply an explanation of a time-limited closure but of an ongoing programme of learning development and action.

- ★ In 1971 the cost of the hospital services amounted to the value of approximately 55 million euros, in 2010 the total cost of the new community-based services was amounted to approximately 18 million euros.
- ★ 1,182 hospital beds became 140 beds distributed across the whole Trieste community.
- ★ Trieste identified as WHO Collaboration Centre; viewed as a model of practice to be shared globally. Wider change across Italy does not replicate the learning or success of the Trieste approach.
- ★ 4 new 24-hour Community Mental health services established, with accommodation services (max 8 beds) established; able to provide ongoing day-to-day support or if needed acute crisis support.
- ★ Longer term rehabilitation services including accommodation (total across city of 55 beds).
- ★ Network of social co-operatives providing support, access to employment, housing support and programmes focused on social inclusion were established.
- ★ Number of compulsory health treatments is 8 in 10,000, the lowest by some margin across Italy.
- ★ Developments in support continue - Individual Budgets and personal Plans were introduced in 2005 and Personal Health Budgets for Housing.

Detail: What happened to the to institutions, support for individuals, political changes

The city of Trieste (240,000 inhabitants) has not had a psychiatric clinic for over 30 years. The asylum has been replaced by 40 different structures with different roles and tasks, for example home care for patients. The results show that the new psychiatric support methods have also reduced spending in this sector. The strengths of the department are the 4 psychiatric centres in 4 parts of the city with 8 beds each, which are in operation around the clock. The psychiatric centres offer health and social care, psychosocial rehabilitation and, if necessary, treatment in acute cases. For those in need of longer-term help, sheltered housing has been created for small groups of people, providing a friendly and non-medical environment. The habilitation and accommodation service coordinates the activities for apartments (with 55 beds), habilitation, rehabilitation and social integration with workshops and projects across the city. Finally, employment opportunities have made it possible to ensure effective integration into society. The service coordinates 15 affiliated social cooperatives, which have been able to integrate around 375 people in the last 15 years through work grants. The psychiatric diagnosis and treatment service with 6 beds takes care of psychiatric emergencies, filters cases and directs patients to the local services. The number of compulsory health treatments is the lowest in Italy, averaging 8 per 100,000 inhabitants over the last 10 years. No citizen of Trieste is interned in the forensic hospital.

From the first group homes onwards, with the support of the mental health department, users received their rented apartment, either individually or in small groups, from the municipal housing department. For the past 15 years (as of 2005) personal health budgets have taken into account the needs of daily living through social cooperative support companies.

Economic subsidies, then disability pensions, were made available to users by the MH service. Many of them were offered to work in the social cooperatives or on the open labour market, always with the support of the service.

The CMHC was initially used for support and basic relationships, then support groups, social therapy clubs, micro-areas and associations developed programmes of social inclusion and rehabilitation.

Law 180/1978, as already briefly described, was drafted by Mr Basaglia and others after this successful experience. No additional funds were used at all. There was a full conversion of the expenses, but in 2018 it was calculated that the amount spent on MH services (the MH department budget) in Trieste was no more than 37% of the cost of the psychiatric clinic.

Core Themes

Housing

In community psychiatry, housing is the key to autonomy and the recovery process for people with mental health problems. The lack of a place or the inability to live in one place exacerbates any form of difficulty and exclusion and can lead to problems if they are obliged to coexist in undesirable or harmful ways, e.g. in group homes or hostels or prevent the person from experiencing further emancipation. People who have access to housing are mainly those with the lowest bargaining power, at higher risk for stigma and social disability, who are disabled in the exercise of basic civil rights, sometimes due to difficult family situations, severe social isolation and poverty, self-care skills. It is precisely this group of people who are most at risk of offering depersonalising management methods and ending up in institutionalised environments. From the second half of the 1990s, the number of beds in residential facilities in Italy has steadily increased. After the reform and the successful closure of all psychiatric hospitals in about two decades, a broad and quite controversial type of home care became common and there is still no clear definition from the general design approach to the housing method as a tool of social inclusion. There is often a lack of transparency about the criteria for allocating often massive resources to housing solutions - this is often the main item of MHD expenditure - not to mention the lack of adequate qualification of care and assessment of intervention outcomes. In this context, it is important to distinguish between home care and housing problems for people with severe mental illness and social exclusion who are sometimes left without a home. Another and clearer aspect concerns residential facilities that mainly focus on care. In most cases, residential interiors are a mix of all of these and primarily find a solution to the problem of "placing it" rather than the needs, pace and priorities of users. It is important to distinguish between the following points:

- ★ A residential therapeutic and rehabilitative community in which the working method is clearly focused and temporality is important;
- ★ The need for housing for people with severe mental illness with adequate support. These two goals are not easy to reconcile and can lead to different types of housing solutions and very different modes of operation of such facilities, although they are usually referred to as a unified concept in the literature.

There is a gap between the optimistic expectation that the home care experience should only be a temporary part of the overall care programme and the realisation that it is often not.

In the mental health system, home care should be one of the tools that foster and support the deinstitutionalisation process as it promotes the transition to assisted living with broader rights for people and restores empowerment tools and skills to enable social space through continuous use component to create inclusion process. Conversely, when home care loses its "outward" drive and focuses on increasing users' bargaining power, it blocks the process and ultimately freezes users in their eternal guest roles so that they never become "hosts" and people can provide life solutions that hardly correspond to their real housing rights.

> **R.:** *"It was a local action and not really planned. It was important to find good solutions. It has to be arranged group homes (10 people) in the city for the people who want go out of institution. The solutions were tailor-made under the construction of simple resources. There was further developed a group home for 3-4 people supported by the mentally centres. Providing support for those people living in the community and create new housing formats from ideas comming out of the community. Offering a life in the city, go to shops, restaurants, social rehabilitation a.s.o. With the personal budget Persons with disabilities get service in their own homes or get into new group homes. From time to time much more small group homes exists. The process was 'learning by doing' to find innovative housing."*

Finance

From 2005 the MHD of Trieste introduced a tool called "Budget di Salute / Progetto Personalizzato" (Health Budget / Personalised Plan), which made it possible to allocate resources, originally intended for home care, to the individual and to develop customised plans based on personal needs and aimed at differentiated living solutions. We can quote a British definition: A personal budget is an allocation of welfare or NHS (National Health Service) resources, or an integrated allocation of both, which is controlled by one person and can be used to achieve identified goals. PBs (personal budgets) and PHBs (personal health budgets) give individuals and their caregivers a greater say in how their health and social care needs are met. They do this by transferring control of public resources to individuals rather than having the state commission services on their behalf. Co-production means providing public services in an equal and reciprocal relationship between professionals, people who use services, their families and their neighbours. When activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change. It means recognizing people as assets, promoting, giving and receiving reciprocity (trust between people and mutual respect) and building social networks, as people's physical and mental well-being depends on lasting relationships.

In Italy the first health budget programmes related to the deinstitutionalisation of mental health care began as early as the 1990s and are now being implemented in several regions and areas. These are tools for policy reform in relation to housing and support for adults with disabilities, child housing services, support for families in community participation and employment as "long-term services and support" in the community. The personal health budget includes all economic, professional and human resources necessary to initiate a process that aims to return a person to an acceptable level of social functioning through an individual rehabilitation process. The individual, his family and the community all participate. It is a breakthrough funding method within the public-private mix, created by the complex welfare crisis and the integration of social and health services, that focuses on the economic resources of the individual.

Similar approaches to the use of personalised funding were developed in the late 1980's in the USA aimed at supporting deinstitutionalisation, and in Canada as a model for providing services. Direct payments for personal support services have been the focus of independent living for disabled adults, and programmes such as Money Follows the Person and mental health counselling / psychiatrists are other examples. In the UK the first experiments with individualised funding were in Scotland supporting the closure of Lennox Castle (see case Study), and a national pilot started in 2004. Australia followed with what has become their National Disability Insurance Scheme (NDIS).

Workforce

The reduction of residential interventions and the simultaneous increase in measures to support the most sustainable independent living and approaches with variable intensity (highly customised interventions in terms of support and time, on the selected need and with an increasingly frequent direct allocation of the household to the user) confirm the validity of the individual health budget tool for reallocating resources from high to medium and low intensity care solutions. This resulted in greater personal autonomy and personalisation of interventions in line with the whole-life approach. In addition, improved project personalisation and needs-based responses are elements that promote a general improvement in the quality of the intervention, especially if they enable the people directly involved to make their personal contribution and thus activate and promote their personal recovery process.

> ***R.:*** *"There was a reconversion about the institutions and the staff into the new situation e.g. nurses from hospitals worked in the new group homes. The training in the first case was humanisation, care giving role, training new skills. The new staff was not qualified but where trained in the mentally centres. The staff must have a university degree in social sciences and interest in human rights and interests."*

Community support / Care

> ***R.:*** *"New jobs in cleaning, cooking, catering, cafeteria and prepare services for the needs for persons with disabilities. Volunteer organisation exists preparing services and activities, social inclusion and participation."*

The use of the health budget method that has made significant changes is the way resources are used and the personalised approach to intervention within the MHD teams. It promoted transparency, clarity in spending decisions and a heightened awareness of the importance of the rational use of resources on the basis of an appropriate project turnover. Economic resources are invested less in facilities than in the processes underlying each project. A more dynamic system could dramatically reduce the time between a need being expressed and a response, even when multiple services were involved. By focusing on individual projects, the common practice of rewriting life stories with all actors was introduced, which increases the project customisation culture ("one person at a time") compared to predefined care packages based on cost-efficiency that are commonly used. The health budget tool allowed operations and resources to be tailored to individuals and their living contexts, despite the difficulties caused by the lack of protocols and common understanding between different organisations and services. This helped to achieve the necessary integration of several institutional actors, thus reducing the risk of delayed responses. Emphasis was placed again on integrated management of services, with the clear and open aim of combating the traditional dynamics of institutionalising services.

Inclusion / Participation

> ***R.:*** *"Convention for equal rights not to discriminate a person because of his or her diagnosis. They implement this idea in Trieste in the group homes. Persons with disabilities are not patients anymore, they are peoples of the society. Social rehabilitation model was implemented to change the view of the society and the people dealing with persons with disabilities in the community. People get a special training for this. They bring the stakeholders from the society together to develop the new situation. They install a participative commission and discuss the points with the clients and the stakeholders. Persons with disabilities ask for more jobs in the community. They did a lot of discussion with clients and people with disabilities and their families to find good solutions, for example, develop the theatre, city infrastructure and they do an anti-stigma campaign. They were closed to the community to make a good inclusion in society. Convince the community was a very important step as a kind of intervention, the neighbourhood was a good group."*

Assistive technology

Assistive technology did not play a big role in the case of Trieste because at this time ((170-80) less technical solutions existed. Today they give people with disabilities a wider range of support, e.g. connecting with other people via computer or handy or getting quick support in urgent cases (home safety).

Safety / Safeguarding

Since the start of the pilot, the number and type of community organisations (NGOs) involved in joint management of health budgets with MHD in Trieste has increased significantly. A change in the working style of the third sector partners is reflected in the relatively flexible approach to interventions chosen as a result of the increasing personalisation of projects. Another important result that was observed was closer collaboration and synergy between different agencies in the third sector, stimulated by the simultaneous involvement of several partners on the same project. Finally, the oversight and evaluation groups, which include MHD operators and partners involved in different projects, are definitely promoting the development of a more common design and co-management culture and language. In particular, personal health budgets have proven to be a practicable instrument to re-qualify and dynamically shape the social and health expenditure mode in the new welfare community. The shared decision-making process, which brings together two types of expertise, has contributed to the shift from a “gift model” to a “citizenship model’’ (Duffy, 2006)[8] with the individual at the centre of the service system.

Learning

As part of the general shift towards more independent and autonomous housing solutions for people with severe mental illness and complex problems, the introduction of the individual health budget method has accelerated the whole process. It was an opportunity for people with mental disorders to be more directly involved in defining the projects in which they were personally involved and in the activities of the services. With respect to MHD services, the health budget model introduced a number of significant changes in the way resources are used and the nature of care within teams that have learned to plan and develop customised solutions while they are doing take responsibility for the management of the associated resources and their conversion. As part of this participatory codesign process, partnerships have been developed that offer a new type of relationship with non-profit organisations. Today it seems to be crucial that non-profit services organise their actions to promote, evaluate and actively support the ability to empower users, their families and NGOs as expressions of social participation of local communities and to find common answers to different needs - to a real co-production. The model under the Trieste case has shown remarkable advantages in terms of management efficiency, practical effectiveness and ultimately cost efficiency. The philosophy behind the health budget model is based on the awareness that external resistance to the exercise of learning, educational, socialisation, employment and housing rights are the elements that ultimately turn a vulnerable or “at risk” person into a “case”. The health budget model paves the way for a form of flexible implementation that is not influenced by the characteristics of what is available but is based on the real needs and “civil rights” of the individual and is a lifelong approach. This tool enabled the MHD in Trieste to improve their care programmes, which through personalised integrated social and health interventions were able to achieve appropriate therapeutic and rehabilitative responses in the community and really improve the quality of life of the people who otherwise would have been intended for institutional solutions of containment and restraint.

- ★ Individual health budget
- ★ Tailormade solutions, that focus on real needs of people with disabilities and their familes
- ★ Participatory codesign process, partnerships that offer a new type of relationship with
- ★ non-profit organisations
- ★ Learning, educational, socialisation, employment and housing rights are the elements that ultimately turn a vulnerable or “at risk” person into a “case”.

> **R.:** *“Rather reacting to changes. Not to have a plan, being flexible. Look at the individual person and their needs and not at his/her disability. Concentrate on the social side of the person. Include persons with disabilities and their families in the process because they are the driver of change. Being very sensitive to the persons with disabilities.“*

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[8] Duffy, S., 2006. Keys to Citizenship: A Guide to Getting Good Support for People with Learning Disabilities. The Centre for Welfare Reform, Birkenhead.

5.2 Stockholm, Sweden

Introduction

The Kingdom of Sweden is a nation of more than 10 million people who live on a 450,295 km^2 landmass in Northern Europe. The GDP is 52,500 USD per capita, and the Human Development Index is 0.945, which makes it second in the world only preceded by Norway, Ireland, Switzerland, Hong-Kong, Iceland and Germany. While in the 1960s around 14,000 people with intellectual disabilities were institutionalised, as the result of the milestone *Act concerning Support and Service for Persons with Certain Functional Impairments* or LSS legislation (1993)[9], today no persons with disabilities live in institutions in Sweden.

Timeline

Before closure

Summary: Foundation / Preparation

- ★ The process of deinstitutionalisation was informed by the Nordic social model and the normalisation principle. The former is a set of social and economic institutions such as comprehensive welfare state services, strong unions and collective bargaining.
- ★ While the Nordic model shapes society as a whole, the normalisation principle focuses on persons with disabilities and originates in vocational rehabilitation. Nirje summarises the normalisation principle as the idea that everyday lives of persons with disabilities should be 'as close as possible to the norms and patterns of the mainstream of society' (1969)[10]. General services should be able to provide services for persons with disabilities. This led to a general programme of transforming mainstream services to include a wider set of people, thus reducing the need for specialised systems for persons with disabilities.
- ★ Deinstitutionalisation was part of, and conditional on, a much wider discussion of better, community-based living arrangements for persons with disabilities. As Ericsson notes 'The question of which services would replace the institution was critical, closure being possible only if there were adequate alternative services for the persons to move to' (2002)[11].
- ★ Grunewald (2001)[12] also notes that deinstitutionalisation in Sweden was underpinned by demographic change: with the eradication of poverty, the total number or children born with disabilities, or acquired disabilities decreased. Within this population, the children with more extensive disabilities also decreased. At the same time, more children with disabilities survived and the number of adults with disabilities living in society increased. Parallel to this change, support for persons with disabilities shifted from institutions to community-based services and waiting lists and admissions for institutional places were first reduced and then eradicated.

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[9] Kingdom of Sweden., 1993. Act concerning Support and Service for Persons with Certain Functional Impairments. passed on 27 May 1993.

[10] Nirje, B. (1969). The Normalization principle and its human management implications. In Kugel, R.B., Wolfensberger, W., 1969. Changing Patterns in Residential Services for the Mentally Retarded. President's Committee on Mental Retardation.

[11] Ericsson, K., 2002. From Institutional Life to Community Participation: Ideas and Realities Concerning Support to Persons With Intellectual Disability. Uppsala Universitet, Uppsala, Sweden.

[12] Grunewald, K., 2001. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. in Läkartidningen nr. 44.

Detail: Location, socio-economic cultural, political environment, numbers, decision about closure of the institution

Historically, the Swedish care system segregated persons with disabilities, who received support and care in a parallel network of often underfunded institutions. Parents of a child with disability did not receive any support other than an institutional place, and clinicians often encouraged families to ‘forget about’ their child, move on and have another, healthy baby. There has been a significant stigma linked to having a disabled child. This started changing in 1956 when the Association of Parents for Children with developmental Disabilities (Föräldraförbundet för utvecklingsstörda barn) was formed[13].

Institutional change started in 1955 when the Care Act was enacted. It identified county councils as responsible for the education and care for people with learning and developmental disabilities in large scale institutions. As the Normalisation principle became more influential, the Care Act was revised, attention shifted from securing places to what institutions should do, and community-based alternatives were defined as favourable to institutions. The 1967 Disabled Care Act recognised the desirability of moving people from institutions to mainstream society, and institutions were transferred from central to regional (county) governments’ remit. Parents of children with disabilities were now offered support to raise their children at home, and in 1968, day services for adults were formed.

In the Carlslund residential home, closure was prepared through a planning project conducted by management, families of residents and labour unions representing staff and was led by three politicians. A working group was appointed to conduct analyses necessary for closure such as administrative and financial issues, labour issues that arose as a consequence of closure. Needs and alternative services were assessed and planned, and staff’s willingness to more to new settings was also surveyed (Ericsson, 2002)[14].

During Closure

Summary: Implementation / Action

- ★ Since community-based support was seen as favourable to institutions, Sweden started building the former before the 1980’s (Grunewald, 2001)[15]. Until the 1980’s, two parallel system existed. The focus was not only on the closure of institutions but also on integrating persons with disabilities into Swedish society as equal citizens.
- ★ Persons with disabilities’ and relatives’ organisations, which demanded full participation in society, played a crucial role in this process.
- ★ The closure of children’s homes met with no resistance from parents because they could see and immediate improvement in their loved one’s lives.
- ★ In the case of relatives of adults, 50 to 80% resisted or at least questioned institution closure. They cited concerns about possible exposure to risks. These attitudes might have been also informed by the stigma linked to disability in Swedish society.
- ★ Yet, local municipalities were slow in implementing changes; ultimately, the central government had to provide community-based support so institutions could be closed.
- ★ A cost equalisation system was enacted between municipalities and the Swedish Social Insurance Agency.
- ★ Community-based flexible housing solutions proved to be more suitable and economically preferable for supporting people with more extensive needs.

Detail: Responsibility for the decision to move out, process, assessment, staff, support

In the Stockholm City region people with disabilities lived in a number of institutions usually located in the outskirts of the city, surrounded by big parks so that, in effect, residents were cut off from the outside world. The largest of these were Carlslund with 500 residents, Akersbergahemmet with 180 residents and Bjornkulla with 350 people who had especially extensive needs.

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[13] https://www.bolagsfakta.se/8180004643-FORALDRAFORENINGEN_FOR_UTVECKLINGSSTORDA_BARN. Accessed 21 December 2020.

[14] Ericsson, K., 2002. From Institutional Life to Community Participation: Ideas and Realities Concerning Support to Persons with Intellectual Disability. Uppsala Universitet, Uppsala, Sweden.

[15] Grunewald, K., 2001. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. in Läkartidningen nr. 44.

In the late 1970's, in Carlslund a plan of closure was formulated and accepted in 1981, and systematic work went into establishing new community-based services. As Ericsson notes 'Conditions were therefore created for the persons to leave the residential home' (2002). In 1988, the last resident moved out of Carlslund. At the same time, progress was not always as fast; for example, in Bjornkulla resistance to closure was especially strong, staff protests took place, and the last resident only moved out in 2000.

The move of people with disabilities into community-based services started as early as the mid-1950s. Plans were drawn up to move everyone to community-based support. Yet, in the next decades, thousands of people remained living in healthcare institutions. The process was escalated by government reports, conducted by Karl Grunewald in the 1980s on living conditions of persons with disabilities, which shocked the Swedish public. Under a new revision of the Care Act in 1985, new admissions to institutions were banned. County councils and private owners of institutions were required to draw up a plan for closure, but no deadline was specified. Subsequently, *some* persons with disabilities were gradually moved to community-based support arrangements. There were no waiting lists for admissions for institutions, yet there remained regional disparities in the number of people moved to the community. The running of institutions was transferred from county governments to municipalities, who became responsible to close them. This also meant that disability services became part of mainstream social provision, persons with disabilities received these as citizens and not as patients. Also, in 1985, new standards were introduced for the building of community-based services. Accessing government loans to build these became conditional on each resident having their own, minimum of 40 m^2 flat. This represented a change, since before residents would have only their own bedroom, or smaller flat, and more than 6, typically 12, residents were housed together (typically 12).

Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)

In 1993, the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)[16] replaced the Law on the Disabled Care Act[17]. The LSS Act is an entitlement law that regulates the rights for people on the autistic spectrum, people with intellectual and developmental disability, adults with acquired brain injuries and people with physical or psychological disabilities that prevent them from fulfilling everyday activities and necessitates extensive support. LSS stipulates ten types of support: advice and other personal support, personal assistance, companion service, support by a contact person, relief service, short-term stays away from home, short-term care for children, supported living in family homes or housing with special services for children and young people, housing with special services for adults, support with daily activities. Besides the LSS, these are governed by a framework of legislation such as the Social Services Act (SoL), the Health and Medical Services Act (HSL) and the Education Act (SkolL).

The LSS also completed the deinstitutionalisation process: parallel to the new legislation the Swedish government accepted the closure of all institutions by the year 2000.

In the 1990's the rate of institution decommissioning slowed down. Sweden took an economic downturn. Municipalities lagged behind in drawing up assessments and action plans or openly resisted accepting new residents. Staff raised concerns about employment conditions and resettlement as the result of deinstitutionalisation, while family members highlighted risk and safety issues and discrimination. They felt that community-based support might not be adequate for their loved one and, in many cases, they received support from the media. The 1997 Settlement Act ruled that by the end of 1999 all institutions had to be closed. In effect, this was forcing councils and institutions to allocate individuals so that institutions can close; it was necessary insofar as many actors wanted to keep institutions open. While some welcomed the government's deinstitutionalisation policy, others, especially some among staff in institutions, family members and persons with disabilities' organisations expressed concerns and resistance. The central government requested institutions and local municipalities to draw up personalised plans moving to community-based services for every individual.

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16 Kingdom of Sweden., 1993. Act concerning Support and Service for Persons with Certain Functional Impairments. SFS 1993:387

17 Kingdom of Sweden., 1955. Lag om undervisning och vård av psykiskt Efterblivna. (Law on education and care of the mentally ill backward). SFS 1954:483.

Decommissioning institutions involved allocating residents to specific municipalities. This process considered their place of birth, their choice and available places. As a result, some municipalities received more residents, and a cost-equalisation system was worked out between local governments and the Swedish Social Insurance Agency.

At the beginning of this process there were no protocols for communicating the purpose and process of deinstitutionalisation for family members and neighbours, and there were no standards for the availability of day services. These concerns were later allayed by general and targeted information campaigns that dealt with the issues raised by staff family members and prospective neighbours. In Stockholm, neighbours of newly opening group homes were invited for a coffee and cake that gave them the chance to meet service users, and to understand their needs and the type of support they will receive (interview R.K.).

After Closure:

Summary: Legacy / Learning

- ★ In the new community-based support services people with disabilities received more person-centred support, felt safer and more in control, could build more contacts with other members of society. The need for medication and hospital admissions decreased.
- ★ Service users' behavioural issues overall improved. But this improvement was more pronounced in group homes in smaller towns as opposed to cities. This might be because of the availability of trained and expert staff.
- ★ Staff felt that they had more overall control and freedom to use their own initiative in community-based services. At the same time, they reported that they received less training and supervision compared to their previous jobs in large institutions.
- ★ While before deinstitutionalisation about 50 to 80% of relatives questioned this process, following closure about 80% reported improved satisfaction. They listed better living conditions, privacy, proximity to their loved ones as advantages[18].

Detail: What happened to the institutions, support for individuals, political changes

Bjornkulla was redeveloped into a block of flats, while Carlslund now houses refugees. Old buildings housing the institutions were used differently also depending on their value and historical status. People previously living in institutions could move to either group homes, or a small minority to independent living arrangements. Moving people to community-based support services soon produced positive outcomes, people presented less challenging behaviour and staff numbers could be reduced. As service users' quality of life improved, the provision of support itself became of a more predictable and enjoyable form of work for staff (interview R.K.). Living in the community and close to their family members, also allows a form of scrutiny and control that prevents abuse and ensures a better standard of support. Interaction with persons with disabilities, on the other hand, led to more knowledge and reduced prejudices within the general population.

Institutions were replaced by two forms of the community-based support model: about 28,000 people live in supported living in group homes and 16,000 people use personal assistance and live independently. While the former group consists predominantly of people with learning difficulties, the latter is people with physical disabilities, with the exception of some 800 people with intellectual disabilities who live independently. Most people moving from institutions moved into groups homes.

When first provided, group home support was organised by municipalities and even today many of the group homes are owned and run by local councils. In the last few decades, however, there was increasing political pressure to open up disability services for private enterprises. In the last ten years, as more companies entered the sector, disability support started to resemble more a competitive market. The following section details supported living in group homes, followed by a brief discussion on independent living.

Core themes

Housing

The building of groups homes started before the decommissioning of institutions before the 1980's, but the homes at the time had only private rooms and housed more than 5, in some cases 12 residents. In 1985, Swedish law set important accessibility and quality standards for housing, it prescribed that group home residents should have their own flat of minimum 40m^2 comprised of a private bedroom, living room, bathroom

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[18] Grunewald, K., 2001. Avvecklingen av anstaltsvården för utvecklingsstörda nu fullbordad. in Läkartidningen nr. 44.

and kitchen. Groups homes should have no more than 6 residents, and while they would have communal living room and kitchen, it would be up to residents whether they want to socialise or and have meals with others and spend time in their own flats.

Group homes should be located in residential areas also to prevent the creation of new 'mini-institutions. The LSS explicitly prescribed that group homes must not be connected to a hospital, elderly care facilities; and they must not be grouped together, sharing the same building or gate.

Many of the group homes were newly built by local municipalities or purchased from private landlords. Homes built before 1993, had to converted to comply with LSS standards. In Stockholm, city owned housing association houses were allocated to be group homes.

Finance

Institutional histories led to some disparities in the geographical distribution of group homes: when institutions were closed, many ex-residents expressed that they would like to continue living in the same city or area. As a result, some municipalities ended up with a disproportionate number of group homes. These received additional funding from the central government through the cost-equalisation system.

Within group-homes, service users are required to pay rent and for food, but the on-site support from staff is free of charge. Initially, the LSS did not specify personalised budgets, funding was allocated for services, i.e., group homes. This, however, meant that people with more extensive needs were seen as less desirable as service users insofar as they presented a larger demand on resources. This changed when individualised funding was introduced, and this meant that rather than people were matched to available support, the latter was adjusted according to each individual's need. Support plans are now assessed for each individual by a social worker and reviewed annually. If someone's support needs change for a period longer than 3 months, for example because of chronic illness, the individual's support plan will be also reassessed.

Workforce

When Carlslund, Bjornkulla and Akersbergahemmet were decommissioned, some staff decided to retire or change their career and simultaneously new staff was recruited. Integrating staff form institutions like Carlslund, Akersbergahemmet and Bjornkulla involved the creation of smaller, new group home-based teams both from staff already employed in institutions and newly recruited members. This also meant nominating new team leaders. Staff received a multiple day induction and training on the LSS, but there remained resistance. The role of team leaders was crucial in enacting the new type of institutional culture in line with the LSS.

Deinstitutionalisation marked a shift in the recruitment of support workers. In institutions, training focused on nursing and healthcare-oriented skills were valued. As people moved to the community, support staff in community-based services were expected to take on a much more educational-developmental role, and background in this field is considered an advantage when recruiting personnel. Some staff who worked in institutions often expressed scepticism and resistance to deinstitutionalisation, but these concerns were tackled with targeted information campaigns, educational and leadership practices.

Support work is considered low status, low paid work often done by immigrant workers. There is no educational threshold to enter the field, there is no training curriculum standard set by the government. More recently, some municipalities come together and started commissioning training together for their support workers.

Community support / Care

Service users in group homes can decide whether they want to move into a flat or not, and this might be especially significant in terms of matching people with similar age groups. The flats in group homes are unfurnished, so individuals are given total choice in what furniture they want to buy and how they want to shape their environment.

In the case of people who have no mental capacity to make decisions about their finances, a “good man” or trustee can be nominated. The trustee can be a family member or another person who is knowledgeable about the legal framework. The “good man” system ensures protection for the resident if he or she cannot make decisions themselves. It also ensures that support staff never make financial decisions for service users, thus avoiding conflict of interest. The trustee is entitled to a reasonable fee and this is paid either by the service user or the municipality depending on the income.

Inclusion / Participation

Community integration is partly achieved by locating group homes in residential areas, where service users can build new relations with neighbours. In some cases, this to the place of organised events and ‘open houses’, but at the beginning of the process there was no procedure to engage neighbours. On the other hand, community integration happens through NGO’s and other organisations. In some cases, e.g., in Stockholm, group homes held open days where they invited their neighbours for a coffee and cake, which gave a chance to meet the people moving in and understand their needs and living arrangements.

Assistive Technology

Technologies, relevant for persons with disabilities, fulfil different functions and were provided by different agencies in the Swedish system. The three main groups are assistive technologies that enable the user to be more independent, adjustments of the home environment and support and care-related technologies used primarily by support staff. Adaptations to one’s home, for example handle-bars or stepping out of the bathtub or accessibility or technologies like hoists, which relate to support and care delivery, are paid by the municipality. Assistive technologies represent a different group. These are used by the residents themselves and enable them to act more independently. Assistive technology provision is organised as part of the healthcare system and delivered on regional level. Usually, each county has an assistive technology centre that provides specialised technologies for all groups of persons with disabilities. Assistive Technology centres are comparable to large warehouses, stocking wheelchairs, communication devices, white canes, and other technical tools for people belonging to a variety of user groups. This is also a site where assistive technologies can be accessed and trialled by the user to find out whether they are usable and useful for a particular person.

Access to these technologies is conditional on assessments by healthcare professionals, e.g. occupational or speech and language therapists who can establish user’s need and whether they can potentially benefit from using technology. If one’s need or potential benefit from use is established, technologies can be accessed free or tied to a nominal annual fee. Assistive technology centres also offer a wide range of support services (e.g., training the user, personalising and maintaining technology).

Technologies provided by these centres are limited to specialised assistive technologies. If the user needs a technology that is commercially available, he or she has to buy it using their own budget. For example, someone using a specialised Augmentative and Alternative Communication (AAC) device could get it using state provision, but when using an iPad for assisted communication or a scooter for mobility, the user has to buy it themselves. When this is the case, there are some grants offered by NGOs, but their scope is very limited.

Depending on the size and diversity of the user population and related to this, the development of the service, there are significant regional differences in what technologies are available where. For example, an Assistive Technology (AT) centre in the capital city Stockholm with a large and diverse population, will have experience in providing a much wider variety of technologies than a scarcely populated remote region. While AT centres have a standard, established set of technologies that they offer, in this quickly moving field new devices and applications appear every day. If users need technologies outside the already offered set of devices and can make the case and demonstrate that they could benefit from using new technology and the AT service might be able to provide this for them.

Safety / Safeguarding

The Health and Social Care Inspectorate (IVO) is the responsible watchdog overseeing disability support services, focusing on the participation and right to self-determination of persons with disabilities. Service providers have a duty of reporting and justifying to the IVO changes in their service delivery and possible shortcomings and accidents. The IVO also conduct spot checks. Parents or concerned parties can also contact the watchdog directly if there is a suspicion of abuse. Recent high-profile scandals of abuse of persons with disabilities in the media created additional scrutiny of motivation for disability services, which might serve as additional motivation to comply with standards.

Independent living / Personal assistance

While most people who left institutions live in group homes, some people, and those with physical disabilities live independently and use a special government grant to hire personal assistants, who are paid both by the central government and municipalities. These people rent privately and are in charge of all aspects of their lives. They have complete control over their finances. Personal assistants are hired by the disabled persons themselves, who do not have to take recommendations from health or social care agencies in this process. Many persons with disabilities prefer to train their own support, so they learn their specific needs. There are a number of organisations, companies and cooperatives that provide background services for persons with disabilities who employ personal assistants e.g., in HR, invoicing, such as tax administration or processing payments. Many clients chose to use cooperatives that are self-governed by persons with disabilities themselves.

In recent years, there has been increasing political pressure to limit the number of people using personal assistance. The assessment process receives much more scrutiny and needs have to be regularly reassessed. In many cases, when the applications of persons with disabilities were rejected by local municipalities, this led to litigation in court.

Learning

Sweden's community-based support system is linked to the robust universal social services of the Nordic model and the Scandinavian principle of normalisation. Rather than focusing on closing institutions, it is centred around the inclusion of persons with disabilities as fully-fledged citizens. The two main models of these are independent living largely pursued by people with physical disabilities and people with intellectual disabilities living in group homes. Changes to and debates about the Nordic social model also affected community-based support.

- ★ It highlights the significance of the overall economic model.
- ★ Focus on the inclusion of people with disabilities in society through a community-based support system rather than the closure of institutions.
- ★ The plurality of supported and independent living models. This also raises questions about suitability to individual needs.
- ★ The institution of trustees which enabled the separation of support work and financial decision making.
- ★ Well-developed Assistive technology provision system.

5.3 Lennox Castle, Scotland

The closure of a hospital for people with intellectual disability

Introduction

In the 1980s, the UK encouraged the trend of people with disabilities leaving institutions and leading independent lives (Dalrymple, 1999)[19]. That trend was much slower in Scotland. In the 1980s, plans were made to remove adults with learning disabilities from all hospital care in England and Wales. At the same time, new hospitals for the learning disabled were opening in Scotland and the rate of withdrawal in existing Scottish hospitals was much slower. First an average of ten years later, in the early 1990s, things began to change. There were two main reasons for this. The first was pressure from the Scottish Office; they threatened those health authorities who were unwilling to develop concrete plans to significantly reduce their number of long-term beds. The second was the implementation of the NHS and the Community Care Act. These laws have a dual focus on developing community-based social and health services to enable people to lead independent lives and make a successful transfer from long-term hospital to living in a community care setting.

The conception and strategies for a new style of learning disability services take place in several parts of Scotland, such as:

★ Royal Scottish National Hospital, Larbert (in the Forth Valley Health Board area)

★ Gogarburn Hospital, Edinburgh (Lothian Health Board area)

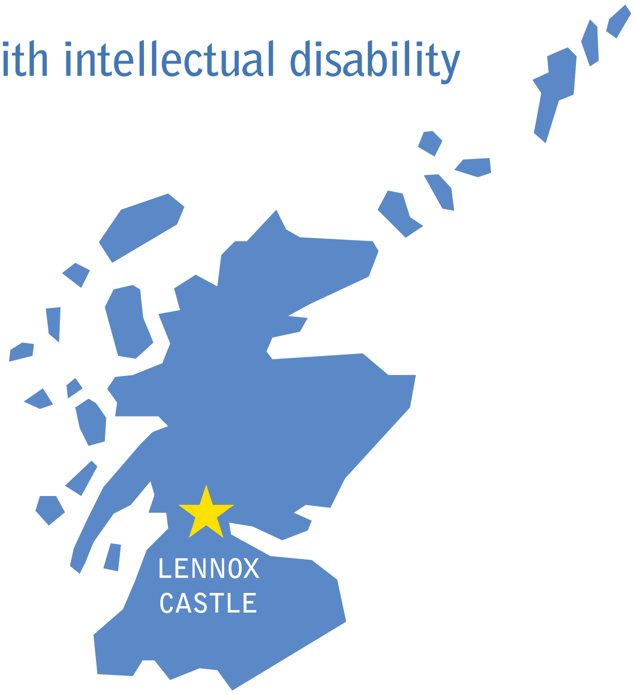
★ Lynbank Hospital, Dunfermline (Fife Health Board area)

★ Merchiston Hospital, Renfrewshire (Argyll & Clyde Health Board area)

★ Birkwood Hospital, Lesmahagaow (Lanarkshire Health Board area)

★ Arrol Park and Strathlea Hospitals (Ayrshire and Arran Health Board area)

★ Crighton Hospital, Dumfries (Dumfries and Galloway Health Board area).



In particular, the plans developed in the Greater Glasgow area (affecting Lennox Castle Hospital) formed a larger national picture. A very important thing that made the process successful was the Scottish Bureau's encouragement of health authorities to submit bridge funding requests to aid in their implementation. For example, the Lothian Health Board had managed to secure bridge funding and the Secretary of State's permission to close the Gogarburn Hospital. The Fife Health Board had made similar progress on the Lynbank Hospital. Yet only the Greater Glasgow Plan received this type of funding from the Scottish Office. This created considerable uncertainty about the future of services in other areas whose requests were actually denied.

Timeline

Lennox Castle opened in 1936 and closed in 2001. The decision to reduce the size of the facility was made in the 1992-95 period. Permission to close the facility was requested and obtained in 1998, and during that year the closure of half of the site was completed.

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[19] Dalrymple J., 1999. Deinstitutionalisation and Community Services in Greater Glasgow. Tizard Learning Disability Review. Vol. 4 Iss: 1 pp. 13 - 23.

Before Closure

Summary: Foundation / Preparation

- ★ Bridge funding was provided by the Secretary of State for Scotland via the health authority to take forward the Greater Glasgow closure programme (Lennox castle).
- ★ The creation of the 'HomeLink' team to identify and provide housing for people moving out of the institution. The emphasis being on the use of existing housing stock and not building new smaller institutions or congregated communities.
- ★ Greater Glasgow Health Board, Strathclyde Social Work department and Greater Glasgow Community and Mental Health Board set out a joint 'learning disability' strategy with the funding provided by the Secretary of State.
- ★ Infrastructure established - assessment and commissioning team based at Lennox castle, a project working group including representatives from housing and wider stakeholders, all answerable to the Joint Learning Disability Project Board.
- ★ Preparatory agreements were made between the Greater Glasgow Health Board (GGHB) and the Strathclyde Regional Council (SRC) between 1992-95. These focused on political agreements to significantly reduce the number of people with learning disabilities living in GGHB-funded facilities (Lennox Castle was the largest of these, but the number of GGHB-funded people also lived in facilities across Scotland and also in England). It was an unlimited transfer of a certain level of funding per person, which was issued by the GGHB to the SRC.

Detail: Location, socio-economic cultural, political environment, numbers, decision about closure of the institution

Lennox Castle is 12 miles north of Glasgow, Scotland, in the small village of Lennoxtown. For health purposes it was in the area of the Greater Glasgow Health Board. For social work / community maintenance purposes, it was located in the area of the Strathclyde Regional Council (until 1995) and then in the area of the East Dunbartonshire Council. For people with learning difficulties living in Scotland, national policy was the responsibility of the UK government until 1999 and has been the responsibility of the decentralised Scottish government since then.

The main environmental factor driving the decision to close stems from the socio-political imperative that facilities like Lennox Castle are inappropriate human habitats. However, the closure process has been opposed by the vast majority of those employed in the institution, their unions and their local political representatives due to its economic impact on the East Dunbartonshire area. The people who lived at Lennox Castle at the beginning of the process represented a cross section of people with learning disabilities with a very wide range of support needs. However, the population was weighted for those who were older, had physical disabilities, or displayed challenging behaviour.

During Closure

Summary: Implementation / Action

- ★ Work led by Joint Learning Disability Project Team - including community-based support providers.
- ★ Individual person-centred support plans developed for each individual.
- ★ For people with higher/more complicated support needs the planning process was led by an appointed community-based support provider - Inclusion Glasgow.
- ★ For this group of people, a new methodology of funding was trialled, individual budgets were put in place. An individual budget was a combination of health and social care funding. It was allocated individually, and the intention was that this funded all the support for the person. The individual budget was managed by the community-based support provider.
- ★ Housing for individuals was identified by 'Home Link' from the local authority housing list.
- ★ A small number of 'small group homes' were also part of the transition process from the institution to community living.
- ★ The implementation phase started in 1995 and coincided with a restructuring of the local government. The SRK was dissolved and replaced by localised units of local government. These are responsible for social work / welfare, which required further negotiations between the GGHB and local government agencies. By 1998 the "upper" part of the Lennox Castle site was closed. Also, in 1998, the Scottish Secretary of State approved the closure of Lennox Castle, not just its downsizing. In 2000, the newly decentralised Scottish Parliament approved a policy document ("The Same as You?"). This called for all institutions such as Lennox Castle to be closed by 2005. Lennox Castle was closed in 2001.

Detail: Responsibility for the decision to move out, process, assessment, staff, support

The underlying assumption was that everyone would move out, an assumption that was further confirmed once permission to close the hospital was given. An assessment ("Essential Lifestyle Plan") was carried out for each person by the "Assessment Team" and each ELP was translated into a "Care Plan" by the assignment team. Both social and health needs were met within the facility. Unfortunately, the housing needs were not taken into account. The care plans developed addressed all three areas and described how they would be treated in the community. Lennox Castle employees were offered support and an opportunity to leave GGHB's jobs and take up employment with one of the organisations that provide services to individuals in new community environments.

After Closure

Summary: Legacy / Learning

- ★ Two hundred and fifty people living in Lennox Castle were supported to move out between 1995 and 2003;
- ★ Lennox Castle work contributed to the development of the Scottish national Learning Disability Policy 'Same as You?';
- ★ The personalised support model developed by Inclusion Glasgow using individualised funding contributed to the long-term transformation of social care across the UK (Putting People First, 2007, [20]);
- ★ The main legacy effect was to demonstrate the improvement in the quality of life for people with learning disabilities who do not have to live in institutions. Notwithstanding this finding, a small number of people with learning disabilities have continued to be placed in institutional settings, especially those who display "challenging behaviour".

Detail: What happened to the buildings, support for individuals, political changes

The buildings etc. of Lennox Castle were demolished after the closure and the land it stood on was privately sold to developers and the Celtic Football Club. It was a step-by-step closure programme in which individual "wards" of the "hospital" - possibly with up to 20 people each - were closed one after the other. Major policy changes took place during the closure programme, such as the restructuring of local government in Scotland (1995); the election of a Labour government in Britain after eighteen years of Conservative government (1997); the creation of the decentralised Scottish Parliament (1999).

Core Themes

Housing

By definition, almost everyone who left the hospital under the resettlement programme has faced the problem of long-term homelessness. However, initially there was no mechanism to ensure that this situation was addressed as a priority. This was, in part, the result of changing assumptions about the extent to which community care placement and support should be the responsibility of individual parts of the system, and the balance of reliance on dedicated housing with special needs versus more general housing. But it was also the result of the lack of an agreed commissioning authority for housing construction that corresponds to the existing one for social and health care. The creation of the Home Link team fixed many of these issues, and its success has been significant. It must be noted, however, that the activities of this home team have been limited, at least formally, to the homelessness of people leaving the hospital (and the needs of people leaving the psychiatric hospital). The housing needs of adults with learning disabilities who live at home or in inappropriate dormitories have remained outside their scope.

> ***J.:*** *"The biggest complications are the bureaucratic and administrative restrictions. It was a very complex process and define the responsibilities per stakeholder."*
>
> ***Testimony (H. went out of Lennox Castle)***
>
> ***H.:"*** *'I've lived here for 25 years….I was scared to move out, because I didn't think I'd get out….I didn't know how people would treat me coz I'm from the hospital'.*
>
> *Feeling very happy with my life now….have friends, a sister and support that works.*
>
> *I don't what I have right now ever. I was glad to get out of there, just glad to have my own place. I've done good...Inclusion Glasgow helped because they*

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[20] Great Britain, Department of Health. 2007 Putting people first: a shared vision and commitment to the transformation of adult social care.

> *understood what was happening at the hospital, scared to go back after meeting with them, felt like my life was over that I wouldn't last long if I stayed there, tried so many times to kill myself because I thought I wouldn't get out of there...Inclusion Glasgow helped me make the move, make the transition...They came to the hospital and listened to me."*

Finance

Most of the discussions within the partnership have been about money. There were very real reasons for this, based on the financial difficulties faced by the Ministry of Health and local authorities, when the central government further curtailed public spending on so-called "priority services". It is worrying, however, that concerns about financial problems should dominate the deliberations of leaders and practitioners to the exclusion of almost everyone else. Also, of concern is that it should become the focus of much cross-agency conflict and mistrust. The extent to which discussions about money are the main dynamic in the bureaucratic partnership has a dramatic negative impact on persistent concerns about quality outcomes for people with disabilities. Rather than being a means, albeit an essential one, of achieving important results with and on behalf of people with disabilities, money management is an overarching priority with concern for quality sometimes in a relatively unimportant place. In this environment, for example, it becomes quite possible for some to argue the legitimacy of the widespread use of nursing homes and nursing homes for many people leaving the hospital. It depends also on the fact, that these are the services that many people in other countries primarily use and will be available. These services are offered to Community Care customer groups, mainly because the unit cost savings for such internships are so significant. In these arguments, what is known about the quality of such services is largely ignored, viewed as irrelevant or, at best, secondary.

> ***J. + J.M.:*** *"Resource transfer was the most important fact. The resource funding mechanism for the hospitals where very difficult and was conflicting. The financial budget was enough to make a good transfer. The project manager had to make it quickly and cheaply and the pressure from different kind of stakeholder (economic, policy, time) was exhausting for them. In the future, it would be good create a clearer project management tool."*

Workforce

Hospital workers were generally concerned about the impact of the strategy on their future employment, implying a significant shift in policy from hospital services to non-profit services and a significant geographic shift from Lennoxtown to various communities in the Greater Glasgow area. The Bridging Funding Award identified funds to assist employees in transitioning from their current healthcare employment to social employment. The realignment needed to support this transition was significant, encompassing human resource issues related to professional development, future business conditions and commuting, and aspects of professional training related to skills, attitudes and language. However, very limited progress has been made to help hospital staff make the necessary switch. Some have argued locally that Scotland has benefited from its more cautious approach and has managed to avoid what is viewed as the worst excesses of an overly hasty approach to dismantling hospital systems elsewhere. While there is some truth in this argument, it cannot be said that it was the result of a deliberate political framework. A national political vacuum has been observed in the Scottish context for many years, which has encouraged Scottish health authorities and Scottish local authorities to maintain the status quo. While certain aspects of the UK Community Care Policy support changes that should lead to better quality services for the learning disability (at least in terms of the type and location of housing), Scotland did not have a national policy framework. This would help get better results for people. This creates a sense of extreme relativism in discussions taking place at the national level in Scotland. Without a national strategy to guide local planning and without a clear statement of what quality services might look like, any learning disability strategy that is deeply anchored in every general community care plan is as good and valid as the next, regardless of the degree of variation. Besides a national political vacuum, there was also no strategic initiative from the Scottish Office. This is a major factor due to the strong interdependence of the various plans in different parts of the country due to historical cross-border traffic.

While most of Lennox Castle Hospital's services were purchased by the Greater Glasgow Health Board for people in Greater Glasgow, most of the other Scottish health authorities also purchased services there, some in significant numbers. While the Greater Glasgow Health Board bought most of its learning-disability services in hospitals from Lennox Castle, it bought around 25% of its total hospital services from hospitals and trusts outside its area. With such a tangled historical and institutional web, it is simply not possible to make a coherent shift to localised care services in the style and quality dictated by law and professional practice without a more consistent quality of strategic support than ever before in the Scottish Office.

> ***J.:*** *"Lennox Castle had its own job market and many people had to take other jobs in other villages or towns. Some staff development problems were present. For the younger folks, there was a lot of support for the move. But there was a lot of discussion. New employees received local advertising and were trained for the new job, e.g. a new way of thinking in dealing with people with disabilities. The project manager brought the current and new staff together. It was a balance between present and new people. This is a major political issue to study the employment opportunities of current and new staff. It is important to facilitate the transition from institution to deinstitutionalisation. In particular, to reflect their way of thinking despite human rights and the positive aspects of these people (persons with disabilities)."*

Community support / Care

Essentially, two broad resources need to be managed to create new non-profit services for people who are either leaving the hospital or already living in community facilities: those associated with the provision of social and health services and those associated with the provision of housing related. The resettlement programme made it possible to discard some of the more bureaucratic approaches to these tasks and introduce highly individualised, person-centred future planning (Essential Lifestyle Planning (ELP)). In most cases these have translated into the commissioning of new services, for example Inclusion Glasgow, which are usually genuinely domestic and where the provision of care and support was separated from the provision of housing. Funding transferred from the health service to local authorities was made available to develop services in this way, supplemented by additional local funding.

> ***J.:*** *"There was a commission team to create new support for an individual or for a group. You have to know about the real needs of the individual person. ELP: Essential Lifestyle Plan, you need to have a commission team and a service team to make a specification. It is a complicated process and need to build public relation to find new service providers."*

Inclusion / Participation

For people who don't leave the hospital but may need to leave the family home or return home from an inpatient childcare internship, or simply want to reconfigure their existing community care service, the outlook was much more limited. Mainly because no parallel sources of funding were available. The approach to evaluating and appointing such individuals was much more like rationing scarce resources than a real attempt to capitalize on the needs, hopes, and desires of individual men and women and their families. This would allocate "spots" or "vacancies" (if available) in existing residential buildings of various types and configurations - both locally and in many locations outside the area. (Paradoxically, it was evident that significant financial resources could often be hastily secured for internships outside the area when funding for those who did not leave the hospital was generally severely limited.)

The implementation of the hospital relocation programme has certainly resulted in a much broader base of social service providers providing services in the greater Glasgow area. While new agencies in the area were mainly hired to provide services to people leaving the hospital, over time they received a small number of referrals from staff working with people who were out of the hospital and were in some cases will be able to develop services for such people. This pattern of new services, mainly provided to people leaving the hospital through an increasing number of independent social security agencies, developed in a context where there has been little commitment to the notion of active care management for adults with learning disabilities. For people leaving the hospital, the historical assumption for many years has been that hospital-based social workers would remain in charge of care management indefinitely. Adults with learning disabilities who already live in a community rarely deserve the assignment of caregivers in a broader social work service dominated by the priorities of children and the elderly. In some areas it was even assumed that the task of care management could appropriately be left to social institutions. The sheer dynamics of the relief programme in its later stages began to change in this situation as more community-based community resources were released.

However, the entire service system continued to suffer from a general infrastructure that was either dominated by other priorities that were seen as more pressing (social work care teams) or poorly informed about the needs of people with learning disabilities (general practitioners and related health care workers). The specialised infrastructure, on the other hand, either remained of an extremely institutional nature (day-to-day services of local authorities) or was overly dominated by health care doctors (community learning disability teams). This latter circumstance led the health system to provide the most professional and dedicated foundation of the social care system for these men and women.

> ***J.:*** *"It was a top down process involving those people and their families. The friends of Lennox Castle were very sceptical. 95% of the families of people with disabilities don't want the transition. So what we learned from this is, that people are very against this process before it hasn't been fulfilled and became into reality. They assumed that the life is safe and they have invested in the hospital as a right place to live. The people with disabilities liked the transfer because they want to life an independent life. So, for the sceptical people they arranged visits in accommodations to show them a positive side. It is very important to bring the new life model into practice and make it visible. This is a very good tool to invest into the trust of those people. It has to be demonstrated. "Make it concrete, make it visible, bring it into reality so that they see, that it is an improvement of life". They need every - day - support service provider. The service has to be much more detailed and specified."*

Assistive Technology

Assistive technology didn't play a big role in the case of Lennox Castle as few technical opportunities existed at this time. There was one example getting quick support in urgent cases (home safety for the night by having sensors at home). Today they give people with disabilities a wider range of support. For example, connecting with other people via computer or handy/mobile phone. Deliver support for people with intellectual disabilities, dementia or learning disabilities (J. + J.M. 2020).

Safety / Safeguarding

Therefore, it has been found that some quality elements in the actual delivery of services to people leaving the hospital are intact. The convergence of innovative evaluation, commissioning and housing practice led some very persons with disabilities to switch to services that were characterised by a high degree of individualisation, personal responsibility and security. The people themselves and many of their relatives, who were initially sceptical, were very satisfied with these services. It was also possible to develop some new, non-institutional, daytime services for many of those who leave the hospital. As the number of agencies that took action as a result of the programme increased, a much wider range of community-based options had become available. On the other hand, commissioners and service providers have not devoted enough time and attention to the task of working together to ensure that agencies old and new can develop their capabilities in the face of rapid growth and many new challenges. In general, most of the positive results were limited to those who leave the hospital. Additionally, there was little evidence that the basic fault lines in the infrastructure for non-profits were permanently fixed. In this case, many factors seem to speak against the durability of quality in service development:

- Lack of national policy
- The ambivalent, disinterested attitude of the central government towards the development and implementation of local strategies
- An ever-changing and unhelpful complex set of administrative arrangements by local and health authorities within which the local strategy is struggling to survive and be coherent
- Relying on a shaky series of partnerships between large public bureaucracies ruled by separate and often conflicting interest groups
- Dealing professionally with time and money issues at the expense of detailed best practice
- Overemphasis on hospital resettlement due to neglect of general service development.

In the book Lennox Castle, written to mark the establishment of the facility in 1936, the medical superintendent wrote: “The vagaries of the defective are numerous and often militate against his progress. Patience and perseverance are the virtues required at any time and any season of the year for those supervising the mentally handicapped, and it cannot be imagined that any other area of medicine or nursing is as badly needed as the non-profit quality. Alternative analysis suggests that, at times, it is the many vagaries of public administration and professional practice that more effectively hinder the progression of people with learning disabilities into lives of greater purpose and fulfilment, and it is these men and women who do theirs. Patience and benevolent impulses are constantly required. The story continues, of course. On November 30, 1998, the Scottish Foreign Secretary approved the Greater Glasgow Health Board’s renewed application for permission to close Lennox Castle Hospital. The following day, at a one-day conference, the Scottish Office launched a national review of services for the learning disabled, the task of which was to provide ministers with a strategic framework for developing social and health services for adults and children. In addition, final agreement appears to have been reached on the allocation of bridging funds to the large numbers of people from across Scotland who live at the Royal Scottish National Hospital near Falkirk. The way in which these separate, albeit related, processes are implemented and completed has had and will have a significant impact on the life prospects of present and future generations of Scottish men, women and children with learning disabilities. It is only to be hoped that this opportunity will always be understood and used with imagination and enthusiasm to take steps that will help people with learning disabilities to take their rightful place as equal citizens in mainstream Scottish life.

> **J.:** *“The most relevant stakeholders were the professional level of the communities from an international perspective. There was a transformation in the community thinking about “make life for people with disabilities better”. From the professionals, good practice, academic side and the political side. The persons with disabilities had less pressure make the change. There families don’t want a change. The process wasn’t linear. The process was a roller-coaster. The key thing make it happen was working in a core team in the hospital working day by day together on this project, solving problems, real and clear focus and with a clear commitment.*
>
> *You need to have clarification why do you do it, simplify the process, take away the pressure from the stakeholder, attitude the mind-set, keep it simple as possible. Know a lot about people with disabilities. The people went into houses with 3-6 people. Person-centred approach was very important to have an individual specification. We tailored the support for the people they need. Often they where over-supported, they don’t want to live with the people in the small group homes. You have to have a good assessment process, learning step by step. Some people want go back to institution because of less trust in the new situation. The process is very dynamic because this are people.“*

Learning

★ Pressure from the governance is very helpful: National policy framework.

★ Take the social care service model (J.M. 2020).

★ Use the participation approach to talk to Persons with disabilities and their families, ELP: Essential Lifestyle Plan (J.+J.M. 2020).

★ Bring independent life models into real life, make it visible.

★ Create specialised infrastructure and community learning disability teams.

★ Use a structured project management tool with a good assessment process.

★ It is a circulated process, learning by doing in the individual situation and context.

★ Take away the pressure from any stakeholders.

★ Change the mind-set in as much as possible peoples' head. But first in the heads of professionals.

★ Coaching and support for new service providers, for example, with trainings.

5.4 Kilcornan House, Ireland

Introduction

The Republic of Ireland is nation of almost 5 million people who live on a 70,273 km^2 and occupy 26 of the 32 counties of the island of Ireland[21]. Historically, the Republic of Ireland has been part of the United Kingdom and won its independence in 1922. The GDP is 87,000 USD per capita, and the Human Development Index is 0.955, which makes it second in the world only preceded by Norway. Institutions for persons with disabilities in the Republic of Ireland are called *congregated settings* and deinstitutionalisation is referred to as *decongregation*.

A special characteristic of Ireland's health and social care system is that most congregated settings were managed primarily by voluntary agencies, charitable bodies often with religious affiliation. 78% of the population identify as Catholic in the Republic of Ireland, and the church's influence is difficult to understate, but since the 1980's this is shifting due to several of changes in society.

The move towards community-based services reaches back to previous decades, the first Report of Mental Handicap was prepared in 1965. Yet, deinstitutionalisation became official policy only in 2011, when the *Time to Move on from Congregated Settings – A strategy for community inclusion* (HSE, 2011, 2012)[22] was published. This was set by the Health Service Executive *(HSE)*, Ireland's public healthcare provider. The strategy defined congregated settings as living arrangements where ten or more people share a single living unit; and set a seven-year target to close these. At the time of the publication of TTMO, over 4000 people lived in congregated settings, 93% of them had intellectual disabilities and 73% of them had lived there for 15 years or more (Grene et al., 2018)[23].

The TTMO concluded that community-based support services could be delivered within the budget for institutional disability services, new housing, transitioning and 'bridge funding' would be required. Following the publication of the Time to Move On strategy available funding was limited because of austerity policies. This changed in 2016 when the incoming government committed to provide €100 million investment into disability services in a multi-annual programme. Progress has been slow, in 2017, still, 2,370 people lived in congregated settings. This delay is partly attributed to the lack of strong rights-based framework: While Ireland signed the UN CRPD in 2007, it was only ratified in 2018 because additional legislation had to be ratified that would underpin decongregation policies REF. Some argues that decongregation policies were slowed down by the effects of the austerity policies following 2008 North-Atlantic financial crisis.

Nationally, the implementation of decongregation policy was championed by the Health Service Executive and the Health Information and Quality Authority (HIQA). The latter agency that acts as the inspector of disability services. Although the HIQA does not have regulatory powers, its reports on large institutions often led to improvements and the closure or congregated settings. The Republic of Ireland is divided into nine Community

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[21] This section draws on the unpublished report 'The Transformation of Kilcornan Services' by Ms Mary Hazlett.

[22] Health Service Executive. 2011. Time to Move on from Congregated Settings: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings. Dublin: Health Service Executive.

Health Service Executive 2012. New Directions: Review of HSE Day Services and Implementation Plan 2012-2016. Dublin: Health Service Executive.

[23] Grene, H., O'Hare, S., Flynn, E., 2018, From institutions to community living: drivers and barriers of deinstitutionalisation Case study report: Ireland 2018. European Agency of Fundamental Rights.

Health Organisations (CHOs), which are tasked to lead and monitor the deinstitutionalisation process. Within this system, *voluntary* agencies have Service Level Agreements with the Government to provide local public services. While voluntary agencies might operate in different CHOs, they have their own ethos and service standards; hence, they approached the decongregation process differently. While some were more successful in moving people to community-based support, others proved slower and even admitted new residents into congregated settings. This led to significant regional disparities in deinstitutionalisation results and arrangements. Historically, voluntary agencies receive funding annually based on the number of services they operate and not on the basis of supported individuals. In 2011 the HSE found that, on average, each individual is allocated €106,000, and 83% of this cover staff-related costs[24].

Timeline

Before Closure

Summary: Foundation / Preparation

Decongregation as an objective was first announced in 1993, but it took a long series of negotiations and work to ensure the conditions for every service user to move out. It would be a mistake to see deinstitutionalisation as a linear progression, it was rather a gradual process that allowed experimentation and working out the best arrangements tailored to the needs of each service user and staff member.

★ To start this project, a series of meetings took place with service users' families and staff.

★ In 2004, a management and union partnership committee were formed with an independent chair.

★ Training was provided for the partnership members, and visits took place both within Ireland and to Scotland to learn from other cases of deinstitutionalisation.

★ Ms Mary Hazlett was appointed as project coordinator to support the deinstitutionalisation process.

★ A number of fora were established to negotiate between staff, labour unions and management, and the latter and the HSE.

★ In 2005 a series of assessments took place using the Support Intensity Scale and 'Individual Needs Assessments' took place. A report on the needed additional capital and revenue costs was submitted to the HSE. The Kilcornan Partnership Committee was restructured into the Kilcornan Transformation Committee as the main forum to discuss industrial and service-related issues. A staff survey was conducted to explore perceived issues.

Detail: Location, socio-economic cultural, political environment, numbers, decision about closure of the institution

The Brothers of Charity (BoC) are a Catholic religious institute founded in 1807 in Belgium. Today, BoC operates education and health care services in 30 countries. In Ireland, BoC has been operating schools and congregated services for persons with disabilities since the turn of the 19th century. The McCoy report documents that historically abuse have taken place in BoC services[25]. Kilcornan House is located in County Galway, Western Ireland. In 1952, it was initially set up as an all-male institution staffed by brothers. It is located near the village of Clarenbridge, and surrounded by forests. At the time of its funding, over 100 residents were housed in a central building, with a poor staff to service user ratio and overcrowding. This changed in the 1970s when the leadership of BoC started considering more community-like models. In 1975, following a Dutch example, a 'village' of 13 purpose-built bungalows were opened, housing 120 people. In 1982, the number of service users in Kilcornan house reached its peak, accommodating 135 residents and also providing day services for 20 people.

Moving people to community-based support started in the 1980 with the establishment of community homes in county Galway and Roscommon. in the coming decade, 109 people were transitioned to live outside congregated settings. At this time, the Service was renamed Kilcornan

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[24] Grene, H., O'Hare, S., Flynn, E., 2018, From institutions to community living: drivers and barriers of deinstitutionalisation Case study report: Ireland 2018. European Agency of Fundamental Rights

[25] McCoy K., 2007. Western Health Board Inquiry into Brothers of Charity Services in Galway. Accessed 16 June 2018.

Training Centre, reflecting the focus on developing skills and preparing residents for community living. Still at this time, new admissions were made and the places of people moving out were taken by new service users, who usually had more extensive support needs. Some of these newly admitted people were previously misdiagnosed and placed to psychiatric hospitals. Many of the newly transferred people presented behaviours characteristic to individuals who lived extensively in in institutional settings. This new wave of residents caused also an overcrowding, where as many as ten service users lived in a bungalow with 5 bedrooms, often three people sharing one bedroom. Still, at the time, this was seen as a preferable alternative to large dormitories. While in the 1980's the process of moving people into the community continued, vacancies were simultaneously filled in with new service users. Concerns about the quality of care related to ageing population, more extensive support needs, and behavioural issues led BoC to announce first in 1993 that they intend to close Kilcornan House and move all service users into community-based settings. By this time, problems started to present with the once modern bungalows. As a result of assaults on staff by some residents, staff and management became more aware of safety issues relating to challenging behaviour. In 2001 BoC formulated a new ethos in 'Going Forward Together', and in 2003 a Service evaluation was conducted; these both pointed to discontinuing support in congregated settings.

During Closure

Summary: Implementation / Action

- ★ In 2005, two individuals with complex challenging behaviour were moved to two adjacent apartments in the community, and four service users moved to a house in a nearby village.
- ★ In 2006, an independent consultant company was commissioned to carry out further assessments for all service users, recommend community-based service models and assess costs. A pilot project was set up with HSE funding. This pilot project was instrumental in demonstrating what community-based support might look like, while also fostered discussions and dispelled fears among families and staff who would have resisted deinstitutionalisation.
- ★ In 2005 a series of assessments took place using the Support Intensity Scale and Individual Needs Assessments were took place. A report on the additional capital and revenue costs was submitted to the HSE. The Kilcornan Partnership committee was restructured into the Kilcornan Transformation Committee.
- ★ In 2007 the HSE commissioned an independent psychologist to review the needs of each individual living in Kilcornan and their support needs plans, and a Joint Project Team was established between BoC

and the HSE. Based on individual assessments, BoC submitted a detailed transformation plan that included costing to HSE. Two other groups of service users moved out to a community-based house.

- In 2008 the HSE and BoC agreed a proposal outlining a redevelopment plan for Kilcornan Services. This was reviewed on an individual basis. Another group of service users moved to community-based support.
- In 2009 additional revenue funding was agreed between BoC and the HSE that enabled three other groups of service users to move out. A new service model was agreed between management and the unions that set the framework for future moves.
- In 2010 a final agreement was reached between BoC and the unions. Another group of residents moved to community-based support.
- In 2011 another group and three individual service users moved to community-based support.
- In 2012 another group of people moved to community-based support.

Detail: Responsibility for the decision to move out, process, assessment, staff, support

During the process of closure, service users were gradually moved to new homes in small groups. This process was carefully negotiated and involved individual decisions. In each case, a number of assessments took place first by staff, later by in-house departments, independent consultants and HSE commissioned psychologists. These assessments informed the planning of community-based support arrangements and costings. The BoC built a strategic partnership with the HSE, and gradually involved them into the assessment of individual service users need. At the same time, funding was secured for small groups of people, this required smaller annual commitment from the HSE and meant that they could better plan and control these processes both their own budget and managing risks.

Parallel to this, staff participated in discussing the support models and thus their own work arrangements. Ultimately, by 2009 a template was agreed that specified the practicalities of moving to new support arrangements. Families were involved throughout the process and encouraged to visit new community-based locations. Service users and staff moving to new locations provided an opportunity for learning for those still living and working in Kilcornan House and their family members, to understand what community-based support could entail.

After Closure

- Today Kilcornan House is owned by the BoC and operates as a day centre.
- Moving people into community-based support services took place seeking consensus between families, management and staff.
- Service users were moved together with other people, both service users and staff, with whom they developed positive relationships.
- Residents in new community-based services became active in their new communities.

Detail: Happening to institutions, support for individuals, political changes

Today the historic building of Kilcornan house serves as a day-centre, offering activities for people with disabilities. In the new community-based services, residents live in modern spacious houses, which they share with a maximum of 5 other people and have their own bedroom which offers much more privacy. Residents have the opportunity to shape their own environment by decorating their rooms or the garden. They can also participate in daily activities such as shopping, going to the hairdresser, cinema or cafes. Some chose to visit day-centres and engage in activities like swimming or crafts. In their homes, residents can host friends and family, and have celebrations e.g. birthdays together. Staff found that working in community-based services in smaller teams enabled them to take on much more responsibility and work through positive engagement with service users, focusing on the needs of development of each individual in person-centred ways.

Core themes

Housing

When establishing new community-based houses, some of the new services could buy properties while others arranged rented accommodation with an average number of five individuals. In the new houses adjustments and adaptations were carried out and fire alarm systems were installed.

When commissioning these buildings, it was crucial that residents can enjoy sufficient space. Every service user has their own bedroom, houses with a kitchen or living area, and a suitable garden were selected.

Individuals who present challenging behaviour were provided additional space, as part of managing and reducing incidents. This led to a significant reduction of challenging behaviour-related incidents and assaults on other service users or staff members. In some cases, houses were adopted for individuals who preferred to have their own separate living space.

Finance

During the process of de-congregation, a number of detailed assessments took place. These not only examined the support needs on an individual basis but also gave an indication of the additional resources needed. BoC first commissioned the 1066 Healthcare consultancy to assess support needs. This was followed by other assessments jointly conducted with the HSE, after each new community-based service was established and a group of people moved out into the community.

In 2007, a detailed Service Plan and timescale for future developments and transformation was drawn up, this reassessed Kilcornan's financial position and provided a costing plan for future developments in both day and residential services on a phased basis. This included details about procuring properties and plans and for relocating service users and a projection of required staff supports and staff skill mix.

BoC's partnership with the HSE proved critical during the deinstitutionalisation process, as the HSE provided not only leadership in directing the project, but also contributed to the assessment of individual needs and funding required at crucial stages.

Workforce

Staff policies were based on three pillars during the deinstitutionalisation process: partnership, labour relations, and training. Initially, the decongregation process met with serious concerns, doubts and resistance among staff. Many staff members expressed doubt about whether community-based services can meet the needs of Kilcornan residents. Some staff expressed concerns about isolation when living and working in community-based support services.

But partnership and an ongoing conversation were established between management and staff based on the consensus about improving the quality of life for all residents.

An ongoing partnership between the Management Team and staff and the three labour unions, representing various factions of the staff, was an essential part of a successful deinstitutionalisation process. This was established at the very beginning, first in the form of Kilcornan Partnership Committee and later the Kilcornan Transformation Committee. These were led by independent chairpersons and facilitated robust debate about industrial relations related to change in service provision.

Through the Transformation Group as a forum, unions and management was able to discuss issues about compensation for staff members, such as staff moving from Kilcornan in order to work in a new community-based service, seeking permanent contracts for staff employed on a temporary basis, and introducing a 37.5-hour working week for nurses. In addition, an annual leave proposal was discussed and accepted. This proposal suggested that involving staff teams in planning and structuring annual leave while ensuring equity in holiday provision. The Transformation Group was instrumental in discussing a template of moving residents to community-based services, through this forum unions were involved in the decision making that became the blueprint for future moves. It was established that the new services should have domestic staff support, so that trained staff can focus on supporting service users. Typically a 0.5 FTE domestic staff was allocated for every new house.

Training and staff support presented the third important element in this process. The roles and details of Team Leader, On-Call support and multidisciplinary staff support were outlined and training was provided on supporting Personal Outcomes, Individual Planning, low arousal approaches, manual handling, client protection, computer and word processing skills.

As staff started to work in community-based services, they started reporting back to their colleagues about the new roles and working conditions and this helped to allay concerns.

Community support / Care

Support planning was based on a number of assessments carried out both internally and externally by independent experts. Individual Plans drew both on the insight of individual staff members who developed relationships with service users and the expertise amassed by interdisciplinary teams.

These assessments looked at individual service users and details included personal data, and family contacts, support and health needs, risks and health and safety issues, communication and consent, individual taste and preferences, essential information for staff supporting the individual, skills, preferred activities, future plans and goals. Now, individual support plans and risk assessments are regularly reviewed and updated.

When moving individuals out of Kilcornan, one of BoC's principles was sustaining positive relationships the individual built with other residents and staff members. This affected discussions about forming groups, which people should move into the same house, and which staff member should support them. This was essential when making decisions about the practical solutions that required for each move. This included the composition of the group, staffing arrangements and skill levels, domestic support arrangements, reporting relationships, team leadership, protected time for the team leader, levels of staff, skill mix of staff, emergency plans, on-call support, support systems, maintenance support, night support, multidisciplinary support, day services and transport arrangements.

Co-production

The process of transitioning to community-based support was underpinned by a rights-based approach that sees everyone as a unique individual and equal citizen who has the same needs and aspirations like other people in that community, and they should be respected and supported in a person-centred way to achieve their goals. In In the case of residents who do not communicate verbally, consultation involved family members. In this sense user's involvement in decision-making remained indirect, and focus was placed on receiving and providing care according to each person's needs. In some cases, service users directly expressed a wish to move out to community-based houses, and this was accommodated. In other cases, meetings were set up with families to start a series of discussions about transitioning and a contact person. Usually a key or social worker was identified as a contact person for the family. Families' reaction to moving to community-based settings was initially mixed but ongoing dialogue and visits to already established services enabled could allay their concerns. Families quickly recognised that community-based services offer more space, better quality housing and more home-like environment for residents.

Inclusion / Participation

The deinstitutionalisation process received support from people from many walks of life including members of local communities who welcomed individuals into their village or town. Moving to the community often became a start for developing new friendships and participating in local events and venues including pubs, schools and community groups.

People with different needs and preferences found different ways to engage with their new freedom and place in the community. BoC adopted a person-centred approach, where some service users prefer to access local events, communities and Resource Centres directly. Others participate in more structured activities e.g. classes or workshops, while some, also depending on their age, might prefer to stay at home.

Assistive Technologies

Physical adaptations included access to the bathroom, hoists, emergency exits; alarm and contact systems were installed. People who use wheelchairs were moved to houses that were adopted accordingly. All houses were given two mobile phones for staff use. Where appropriate, staff also received technology training. All houses have their own vehicle. Some individuals made contributions themselves to purchasing suitable means of transport.

Safety / Safeguarding

During the deinstitutionalisation process, significant attention was paid to health and safety issues, challenging behaviour, how staff and residents should cope in an emergency or an adverse event occurring. Challenging behaviour was mitigated by providing additional space for individuals, and training for staff in low arousal approaches and client protection. Individual risk management plans and reporting procedures were developed and installed.

Learning

BoC's reports 925 incidents of challenging behaviour in the first half of 2004; 144 of these were classified as serious assaults on service users or on staff. In comparison, in the first half of 2011 only 229 reported incidents of challenging behaviour were reported and none of these was serious assaults. What is even more important, that to date families of service users living in community-based services all report that they are satisfied with their loved ones' living conditions.

While the deinstitutionalisation process focused primarily on individual support needs and consulting service users, who are nonverbal, through their families, this left less space for service users to be involved directly in shaping their own lives. This points to the challenge of involving non-verbal people in the deinstitutionalisation process.

- ★ Clear communication throughout the process.
- ★ Keeping residents central to the process.
- ★ Seeking win-win situations or at least compromises.
- ★ Working on a template while also accommodating residents' on a case- by-case basis.
- ★ Kilcornan House's success in creating community-based support services for its residents lie in a number of strategic partnerships and robust negotiations between management, staff and unions representing them, the HSE, and families.
- ★ The deinstitutionalisation process was facilitated by a Project Management Team and project co-ordinator who was appointed at the beginning of the transformation.
- ★ The individual was seen within a network of positive relationships that he or she built over time with other service users or staff. When moving to community-based services, the Project Management Team take into account these in making decisions about who should live together.
- ★ The process benefited from visits to other services.
- ★ Working through Incremental change within a larger plan of global transformation which suited the limited financial means. Gradual change, moving groups of people over a longer period of time enabled service users, staff and families to learn from other locations from the newly established services where residents already moved to the community.
- ★ While learning was important when transitioning service users and designing new services, the Project management team also recognised that each individual and group have their own needs and preferences and these have to be accommodated unique tailor-made solutions.

5.5 Marculesti, Moldova

Marculesti Residential Institution, Floresti region, Moldova

Introduction

A residential institution for one hundred and twenty one children and young people (2008) with 'mental disorders', run by the Ministry of Education. The institution is situated in the village of Marculesti, a rural part of Moldova some 10km from the nearest regional centre.

Timeline

Before Closure

Foundation / Preparation

The project to close the institution was a partnership between Lumos and the Moldavian government. This partnership was supported with legal arrangements setting out responsibilities, outcomes and an evaluation framework. The partnership agreement was signed in 2008. Work started in 2009 to set out a detailed plan of work to close the institution, initially the work was led by a Commission (The Commission for protecting the rights of children in difficulty) and then taken over in 2010 by a Ministerial Committee. The national government supported this with a number of orders and decrees, including:

- ★ A moratorium on new admissions to Marculesti Residential Institution (2010)
- ★ An Order transferring ownership of the residential institution to the local government in 2011
- ★ An order to transfer the funding for the residential institution to the local government in 2012
- ★ An 'Order of Closure of the Marculesti Residential Institution' issued in 2011 followed by order to liquidate the institution in 2012

The team leading the work was based with Lumos. The team included child psychologists, children's service experts and project managers. The team were able to draw on wider international experience of deinstitutionalisation through the Lumos network.

The team's role and tasks were agreed with the Commission and Ministerial Committee and they were accountable for delivering the plan. The financing of the work, and the changes in use of and responsibility for budgets was held by the national government prior to the Order in 2012 where responsibility for the budget and the actual budget were delegated to the local government.

The first step was sharing plans and information with all the stakeholders; the workforce, the children and young people, the families and the wider local services who would be starting to support them. This moved on to meetings with smaller groups / teams. Children and young people were met individually as part of the next step in preparation, 'evaluation'.

- ★ The individual evaluation of every child or young person at the residential institution. These evaluations were carried out in a child-centred way with games, fun activities and food. The evaluation was led by a child psychologist.
- ★ The evaluation of their families; capacity, parents, living situation and risk factors.
- ★ The evaluation of the workforce and design of a new workforce plan that identified new roles/jobs and skills gaps.
- ★ The evaluation of the spend; the budget for running the institution and the cost per child of continuing to accommodate them in the institution.

- The evaluation of the local services, communities and schools in each of the regions the children would be returning to live.

During Closure

Implementation / Action

This information provided a base upon which all the work could go forward. A placement, in most cases with birth family/extended family was identified for each of the children and young people. For 18 young people this meant 'graduating and moving on into 'adulthood' with appropriate support to access social security payments, seek work and finding a place to live. For some of this group a small group home was identified as a first step to independence.

For the ninety-four children living in the institution in 2010 when work began, the following future 'placements' were identified:

- 33 children – re-integration within birth family
- 4 children – re-integration within extended family
- 10 children – placement within family type substitutive services (foster care)
- 29 children – placement within small group homes (social services)
- 18 children – graduates of the residential institution (support and assistance for social inclusion)

For the group of 'graduates' planning activities included:

- Offering psychological, legal and professional orientation assistance;
- Assisting with developing life skills;
- Assisting graduates with their registration in vocational schools, colleges;
- Offering financial support to graduates to ensure their socio-professional integration.

For the group of children moving on to their birth families/ extended families or other support including foster care the planning activities included:

- Informing the child about the likely future
- Consulting child opinion about the transfer
- Psychological counselling, information
- Filling up the "Life story"
- Creating the profile for each child placed in a service;
- Discussing each case of transfer at the meeting of the 'Regional Commission for
- Protecting the Rights of Children in difficulty' and making a decision regarding the placement and implementation of each individual assistance plans.

A more child-centred example of how the children were involved would be that for those being placed in a foster care or family type small group home the child was invited to be involved in decorating their new room.

Evaluations were also undertaken of the 'destination' whether this be the birth family/extended family, foster care or there was a need for a small group home placement due to there being no family/foster care available to welcome the child.

- Financial responsibility and ownership of resources delegated to region
- Moratorium on new admissions
- Individual plans developed with each child/young person
- Recruitment of foster carers
- Small group homes established for 29 young people 'graduates' moving on into adulthood
- Safeguarding reviews carried out for each destination family / provision
- Assistance funding made available
- Specific advice and support offered to 'graduates' enabling them to move on to adult society

After Closure

Legacy / Learning

- 112 children and young people successfully supported to move on (2008-2012)
- A further six institutions for children and young people with disabilities including psycho-social support needs closed in Moldova using the same approach
- New 'Family Support' Services set up linked to regional social services
- Whole workforce supported to move on, retire and/or retrain for a new job in the new support offer
- 20% of those initially interested in being foster carers currently providing foster care to children and young people and the number of foster carers growing

Alongside acknowledging the need for greater investment in community inclusion the project team list a number of lessons they learnt:

- It is a far more complex process than it may seem and requires a team with a large diversity of skills from financial planning to child psychotherapy to community work and inclusive education, as well as skilled project management.
- The credibility that came with a national government initiative and from being led by Lumos made a substantial difference to the end result and was a key support throughout the project.
- The need to stop new admissions through an order / moratorium was very helpful.
- The longer-term work to put in place preventative support around the family and school is essential.

Core Themes

Housing

For the children and young people involved the focus was on reuniting them with their biological families, if this was not possible then the project incorporated the development of new fostering services. Fostering was not an option prior to this project in Moldova. Housing was not a project focus or a challenge for the project. For the group of young people who were moving on to adulthood and where it was not possible for them to move home small group homes were set up.

Finance

Institutional budget

Financial analyses were undertaken covering 2009 and 2010, the running costs of the institution were established and the cost to maintain an individual child in the residential institution was identified. These budgets set the amount that could be invested locally to build a new social service offer of family support and to enable children once educated in the institution education in local mainstream schools.

- 2009 – 41,000 lei per child, Total spend year 2009 (116 children) = 47,560 thousand leu (approx. 2.35 million Euro)
- 2010 – 42,040 lei per child, Total spend (94 Children) = 39,480 thousand leu (approx. 1.94 million Euros)

National and Local Government

In 2012 the national government passed a decree transferring ownership of the institution to the local government. In the same year the budget funding the institution was transferred to the local government. This placed responsibility for taking forward the institution closure (Order issued in 2011) lay with the local government.

Reinvestment Plan

With the local government taking on responsibility for all resources including the buildings and the budget the next step was to set out a reinvestment plan; a plan developing a new local social service offer of family support, new fostering services (including payment to foster carers), to ensure local medical and health services were inclusive and to develop skills and capacity in local schools.

Workforce

Evaluating staff currently working at the institution (total staff - 66 people (83 available job positions): administrative – 3, teaching / educational staff – 27, medical staff – 2, auxiliary staff – 34); evaluation data was also collected regarding education level and age (number retiring or retiring in the next four years).

A detailed plan for a new workforce was constructed; new social service family support services, support in school for inclusion of children, fostering services and new family type homes.

The whole staff group, teams and individuals were all consulted with; offers of retraining and new employment were made. There were opportunities to develop child therapy skills, be part of the new family support teams and to become a foster carer.

This approach meant that, with the government's 'order of closure' all the staff were able to understand that they had to move on from working at the institution. For 19 staff this meant retirement, for others it meant the opportunity to train for a new role / job. Those leading the project felt that this approach decreased the resistance to change and brought the workforce on to the same side as the project team. In some cases, this mean that it was possible to maintain long term worker-child relationships, particularly in developing fostering support. The leader of the project team describes as 'like stepping in to the darkness *together*', your eyes becoming accustomed to the new light and gradually seeing more clearly.

Alongside training and new roles study visits were arranged for the workers taking on new roles. They visited new services that had been set up elsewhere in the country following an institution closure, this helped through the sharing of the new work people had taken on and what it meant for children and young people.

The way that the institution's workforce were supported to step into new roles and/or different futures was a clear strength in this closure process and provides many lessons on how to 'walk together into the darkness of a new way of doing things'.

Community support / Care

Early evaluation of the seven regions that children would be returning to established that each has school, medical support, and some social services that would grow to include family support. The schools lacked skills and capacity to include a more diverse pupil groups so some investment was made into inclusive schooling. This included training and the provision of additional teaching support staff. It was necessary to ensure that each child had access to local health services as and when needed.

Alongside the new family support services was the development of foster care. As this new role provided an income to the 'foster parents / family' the team reached out to those in areas of low income. They put up posters and held events; at the events they explained the project, gave a strong message of helping our children, and explained the new role of 'foster carer'. Of the original group recruited 20% went forward to become state-funded foster carers supporting children who moved out of the institution and now others. There was a clear and strict approach to assessing, training and supporting the new foster care workforce, including pairing and ensuring children had the chance to talk about their prospective foster home before arrangements were finalised.

Co-production

Co-production for this project was all inclusive: local services, children, family members, the workforce, organisations and people from the local community.

There was an extensive communication and information sharing element to the project with a simple message 'our children need your help'. With a strategy backed up by clear government orders regarding closure there was no stepping back from closure and this meant that everyone was able to participate.

An example of how children were involved in meaningful ways was how those moving into foster care / small group homes were able to decorate their own rooms.

Inclusion / Participation

As explained above evaluation/assessment identified local services and training needs, especially around inclusive schooling. The process of school inclusion started with meetings with the school administration, arranging visits to classes, establishing 'home rooms', providing individual information and the drawing up of an 'Individual Education Plan' for each child.

In all cases work was centred on making local 'universal' services more inclusive, and only developing specialist / skilled support where absolutely necessary, for example in the new family support services.

The project team estimate that the new 'family social support assistant' will need to work alongside the child, their family/foster family and the local school for two tears after moving out of the institution for the situation to be stable enough to withdraw the direct family support.

Discussion during the interview identified the need for greater investment in community inclusion in the future, i.e. the wider 'preparedness' of the wider community, attitudes and support. This did not happen 'enough' due the high cost of such a wider programme.

Assistive Technology

The children were those defined as having psycho-social and intellectual disabilities. Assistive or person-centred technology did not feature as a component of the project or the support needed/offered to families.

Safety / Safeguarding

Each family was assessed for 'protective' and 'risk' factors, and plans were drawn up to build on strengths and address possible risks. Individual Placement Plans were written for each child and each child was allocated a family support social services assistant to support them.

Financial assistance was available to address increased costs of providing for the child and in tackling any issues around housing and accommodation for the child.

Where no family members were alive or able to welcome the child alternatives were sought in the form of foster care and if this was not possible then a small number of children were

supported to move into 'small group homes'.

Safeguarding featured in all training and was part of information sharing undertaken throughout the work of the project.

Learning:

Strength:

★ The core strength of this project was the assessment/ evaluation process. The methodical and detailed collection of information provided a strong base upon which to take forward the closure.

★ The upfront leadership from the government making the necessary legal changes including the move of ownership and finance on to the local government and the clear order of closure meant that there was no question of failure. This built a strong feeling of everyone working together.

★ The moratorium on new admissions

★ The attention paid to the workforce, the planning and offering of new employment undoubtedly made a difference and is a lesson to be applied in the future.

★ Successful development of a new foster care offer and workforce

Weakness:

★ As identified by the team in Moldova, earlier and greater investment in community inclusion: attitudes, hate crime, accessibility, children's rights and creating a more welcoming community for children and young people with disabilities

★ Insufficient foster care support so ongoing reliance on small group homes

6. Person centred / Assistive Technology

Persons with disabilities can benefit from using technologies both directly and indirectly. These technologies might include both digital information and communication technologies, and simple tools and adjustments. They can be specifically designed and provided for persons with disabilities but also commercially products specifically repurposed for the disabled user's needs. On the other hand, users also show a remarkable diversity. Two people with similar diagnoses might use completely different technologies, or use the same technology differently according to their needs, skills and preferences. Therefore, it is very important to consider each specific person as an individual and plan their technology use and support in a personalised way.

In the five deinstitutionalisation cases examined, we found that the most common technologies were simple tools and adaptations to one's home, for example handle-bars or stepping out of the bathtub or accessibility or care related technologies like hoists or alarm systems. These include both specifically designed devices and mainstream products like mobile phones that could be used by support staff to communicate and alert each other. There seems to be an assumption among managers and staff about what counts as technology, and more simple mundane tools are not considered as such in spite of their vital role. On the one hand, assistive technologies are often not known for the people who could use them, on the other, not every assistive technology is recognised as such. While wheelchairs, Braille print and similar low-tech tools have lost their novelty today, arguably, these relatively 'simple' technologies had the biggest impact on the lives of people with disabilities. Our hypothesis is that technology played a somewhat opaque role in the deinstitutionalisation process. Managers themselves did not always recognise the important technological work involved in moving people into community-based settings, mainly because these focused on single individuals.

When planning support, one has to keep in mind that different technologies serve different purposes and users, and one has to be very clear about who is benefitting from their use. Does it primarily serve the disabled person to enable independence, or staff or family members to deliver care and ensure safety and control, perhaps it has a more explicit medical function e.g. in the cases of ventilators? These functions and uses can be all legitimate as they benefit the user but one has to be clear about their intended purpose.

Technologies have to be always seen as part of people's wider support and care arrangements, first because they must be tailored to the individual user's needs to function. Second, because besides the end user they will be also maintained and operated by family members and support staff. While it is a common fantasy, it is very rarely the case that technology could replace human support. Not only because it offers a different type of service but because technology use remains dependent on a host of human co-users. For example, a communication technology, while it enables the user to 'speak' it also places specific demands on communication partners e.g. longer waiting times and paying attention to cues and turn-taking.

The commissioning, use and support of technologies can be planned on the level of the individual, user group or membership, and general accessibility. Nevertheless, these plans should be always aligned according to the individual's needs. Considering accessibility, it is good practice for example, to build houses with wheelchair users in mind, and take other accessibility features into account. On the level of groups, some features e.g. tactile signs for blind and partially sighted people can be implemented when developing a service `specifically for this group. Similarly, as the case of Kilcornan house shows, alarm systems can be implemented for safe service delivery. Finally, and most relevantly for assistive technologies that enable independence, these have to be planned with a specific individual in mind. Just as well as persons with disabilities vary according to their skills, needs and preferences, there is a vast variation in the technological products and the way they can be used. On the level of the individual, it is crucial to consider the one's preferences and, either by taking into account their views directly or by listening to family members and support staff who know them best. In sum, while technologies are generally relevant to organisations that support persons with disabilities, it is very rare that a single device or technology would become significant for *all* service users. Support has to be planned specifically on the individual's level should be an integral part of the individual support plans. In accordance with the participatory approach, is one of the core themes of the CRPD in understanding dealing with persons with disabilities.

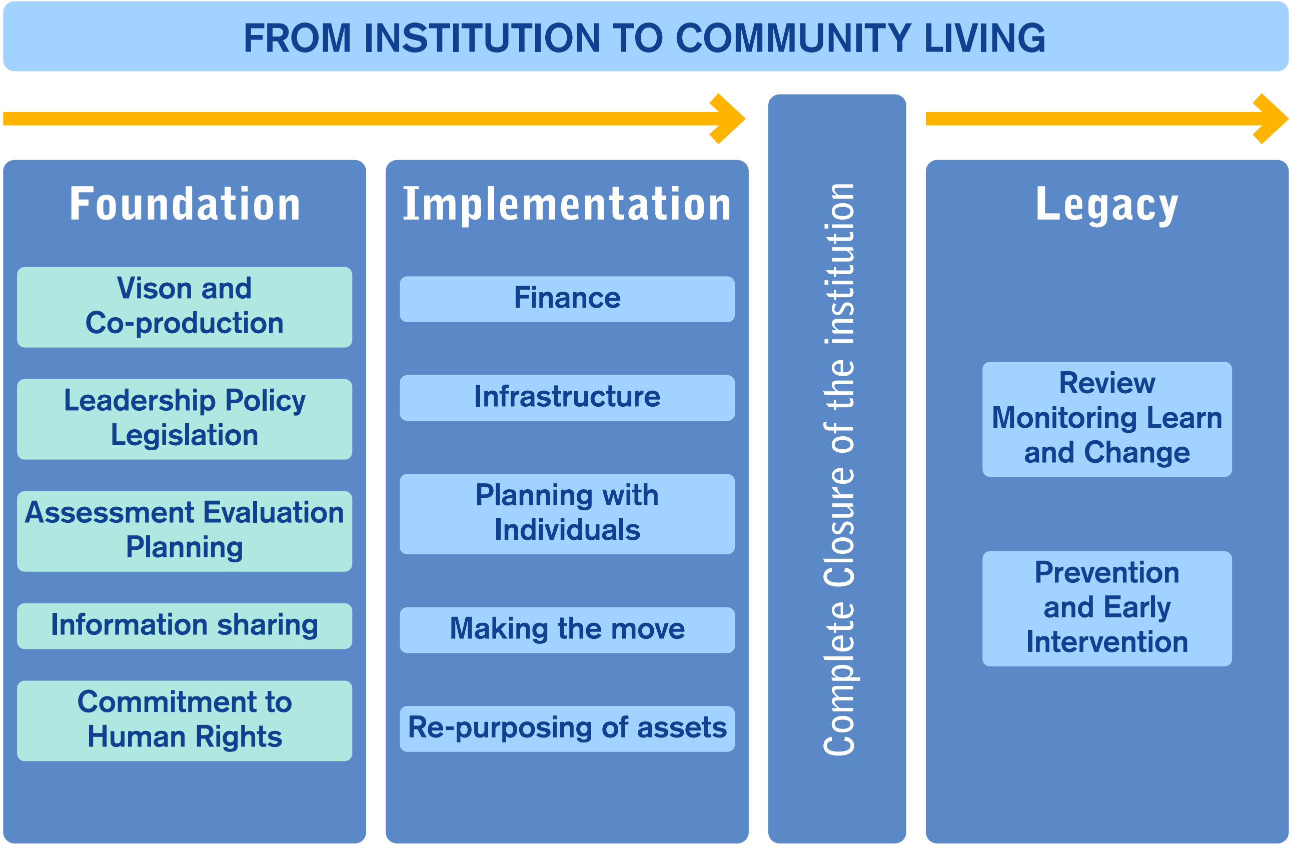
Technology for persons with disabilities is a fast-moving field, with continuous innovation and technological tools and products have a great potential for enhancing their users' lives. At the same time, when considering assistive technology use, one should pay attention to a number of questions:

- ★ Take a holistic approach to technology, including both high-tech products and simple tools and environmental adjustments.
- ★ Who is the user of technology, what is its purpose and how would persons with disabilities benefit from its use?
- ★ How are technologies form part of the wider care arrangement?
- ★ What is the role of support staff in technology use, and what are their training needs?
- ★ Differentiate between planning technology for individual users, the population of service users including potential users.
- ★ How do persons with disabilities and their families feel about this kind of support?
- ★ How do their family members feel with this kind of support and service? Do they feel safe?
- ★ Are persons with disabilities involved in service development from beginning to the end?

7. Framework of Recommended Action

A consistent set of themes are highlighted across the five case studies, along with innovations or approaches that clearly contributed to the successful closure of institutions and describe a timeline. The project team have gathered these together under each of the titles Foundation/ Preparation, Implementation/Action and Legacy/ Learning to illustrate what the five case studies tell us about the work and activity needed to successfully close an institution. The roots for each case study were very different as were the political and social environments in each country; the themes of action were common or were clearly highlighted as a core action within the closure process.

FIGURE 1 | From Institution to Community Living



Foundation

1. Vision and Co-production

a. Involvement of all stakeholders

b. Develop a shared vision

c. Use as foundation of the plan to close

2. Leadership, Policy and Legislation

a. National and local government involvement and necessary leadership

b. Commitment made public and clear message given

c. Commitment seen in policy review/change and new development of policy and legislation

d. Moratorium on new admissions

3. Assessment, Evaluation and Planning

a. Assessment of current policy and legislation (what works, what needs to change and what new legislation is needed)

b. Assessing the individual

c. Assessing the destinations (people, housing, provision of health care and other local services)

d. Assessing the support and local community resource (support provision, community inclusion/ attitude and knowledge of plans)

e. Assessing the finance current and planned (cost of institution, cost per individual, budget per individual to support the move, long term commitment to support funding)

4. Information Sharing – Workforce and local Communities

a. A clear message – there is ‘no turning back / there is no failure / this institution is going to close’

b. Clear information about future employment, offer of training and support to those retiring

c. Information to local communities about the support to be in place for people being supported to move out and encouragement to think about inclusion, what it means and how everyone has a part to play

5. Commitment to Human Rights

A strong, visible and proactive commitment to people’s human rights, their right to live independently, to be treated with respect and to be part of society as opposed to being segregated and excluded through their internment in institutions

Implementation

1. Finance – Changing Investment, Development Funding and Procurement / Commissioning of new Support and Service

a. Deliver the new financial investment plan

b. Commission / Procure new community-based support – facilitate the recruitment of support workers / newly moved institution staff enabling their involvement in ‘transition’ from institution to community

c. Commission / Procure new social care capacity including individual social care transition support

d. Ensure local health, work/education and leisure services are invested in facilitating participation and inclusion

e. Ensure services in place to support and enable the use of personalised funding including direct payments

2. Infrastructure – Housing, Social Care, Support Provision

a. Ensure that housing and accommodation is in place and secured before any individual is supported to start planning their move into the community

b. Ensure that each person being supported to move on will have access to a social worker / health worker

c. Ensure that each person being moved has an appropriate support package in place enabling them to start to live more independently

3. Planning with Individuals

a. A person-centred approach to building on assessment and planning a new life

b. Ensuring that support will match the person's strengths and aspirations for their new life

c. Focusing on inclusion in local life and support needed to maintain independence

d. Transition support – for many, especially those who have been institutionalised for a large part of their life there is a need to acknowledge that the move to a new home may be difficult and also that they may have experienced trauma during their stay at the institution. All plans should be aimed at reducing 'transition support over time'

4. Making the Move – Ongoing Transition Social Care / Health Support

a. Each Personalised Plan will include individual 'transition plans', these will set out how the individual can be supported to see this as positive and enable them to make the best start to their new life

b. For those with multiple and complex support needs this will include necessary 'introduction and blending of support' where existing support is gradually replaced by the new support from services in the local community they will be moving on to

c. Expectations for a simple and successful transition should be balanced with the knowledge that for some, especially those who have been

d. Institutionalised for much of their life and those with multiple and complex support needs this will be a major life changing event and that it won't always go to plan

5. Repurposing Resources and Realising Assets

a. The building and the associated assets will have financial value. Information about this and the responsibility for realising this value and the use of the income generated will have been agreed early in the project work. The final stage in the closure process will be the re-purposing / closure of the building and the reuse of assets and finance to support people in their new lives.

Legacy / Learning

1. Review, Monitor, Learn and Change

a. Ongoing support in the form of social worker assistance will be in place. Support arrangements should be reviewed and the expectation should be on improvement as the support services gets to know the individual better. The focus should always be on better outcomes for the person and how support needs to change to ensure that this remains the focus.

b. Information across the whole group should be collated and used to inform on-going work to drive forward 'independent living for all' as a governmental initiative.

2. Prevention and Early Intervention

a. Attention has to be turned to ensuring that those supported to move out are not replaced in this or other institutions by new admissions. Energy has to be directed at prevention, this is best done by adopting an 'early intervention' approach, where support is offered early in the person's life / when they first start experiencing difficulties. This support, usually a joint offer from social care and health with support from welfare funding should focus in maintaining life in the community.

8. Conclusion

Finding examples of ‘complete closure’ has been a major challenge to the project team. Despite extensive research and access to large networks of people involved in advocating for and leading the closure of institutions we have encountered many pieces of work that have stalled or changed due to a number of reasons not least of which is the dominant political landscape within those countries and the priority attached to the inclusion of people with disabilities. As explained in the framework (Figure 1) a foundation stone is a commitment to human rights, whether this stems from disclosure of systemic abuse, support for the United nations Rights of the Child or a wider societal awakening to the situation within institutions this commitment to the human rights of individual people is and will, the team feel, be a factor of success. Without this commitment the work becomes a process and an exercise in system change without the wider change to society and the promotion of inclusion. As described in the purpose of this report there is no gold standard. There are different trajectories for successfully closing institutions and including people with disabilities in wider society. As these case studies show, these trajectories are shaped by institutional legacies, cultural and historical context, responsible agencies and the involvement of persons with disabilities in the process.

How this large scale and frequently encountered risk can be mitigated is beyond the work of this project. Large organisational networks such as that hosted by EASPD have some part to play in this but in the end whether the European Commission and the pan European lobby can exact enough leverage to ensure that institutions are closed and people are able to move on to more ordinary lives in local communities is in reality down to the democratic process and the will of wider society.

We hope that this report, although small, contributes positively to work on the ground across Europe and moves us all closer to where all citizens have the support they need to live independently, contribute to their society and community and able to enjoy, like their peers an ordinary life, if needed with a good support and understanding of IT, AT and conventional product and services from different kinds of stakeholders.

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EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 17,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.

IMPROVING SERVICES
IMPROVING LIVES

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