

# Creating New Horizons:

Sharing the experience  
of **The Cedar Foundation**  
in the Closure of the Institution  
for Children and Youth with  
Disabilities in Gorna Koznitsa

By

**Lindsay Saltsgiver**  
**Margarita Parmakova**  
**Irina Papancheva**

and

**The Cedar Foundation team**



June 2012

# Acknowledgments

We would like to express our most sincere gratitude to all of the people who have put their faith in The Cedar Foundation and supported our efforts to make significant change in Bulgarian social practices. We would not have been able to achieve anything without their generous contributions of expertise, time, volunteer labour and funding.

We are grateful for the loyalty and tenacity of our former and current Members of the Cedar Foundation Board: Bianca Summerfield, Francis Ma, Hugh Fraser, Liane Macdonald, Michele Fedor, Penny O'Sullivan, Roy Campbell, Sally O'Brien, and Gencho Boyukliev, who have been steadfast believers in our cause, through thick and through thin.

The Cedar Foundation volunteers and advisors have played an indispensable role in shaping us as we grow through the years. For this and for their guidance, patience, enthusiasm and energy, we are forever grateful.

We would like to thank the Kyustendil and Bobov dol Municipalities for the indispensable partnerships which we have all nurtured, and for their faithful cooperation on this and many other projects. We thank also the Ministry of Labour and Social Policy, the Agency for Social Assistance, and the State Agency for Child Protection for their on-going collaboration and knowledge in the field of Bulgarian social policy.

To the former team of ARK (Absolute Return for Kids) Bulgaria, we want to say thank you for openly sharing your experiences and practices with us as we dove into unfamiliar waters and took on the challenge of closing down the Home in Gorna Koznitsa. Your perspective and feedback was absolutely invaluable, every step of the way.

We give thanks to all who agreed to give interviews and to share their views, opinions and experiences for this publication and the accompanying film.

Finally, many thanks also to all of our beloved former and current staff members in Sofia and Kazanlak, and to our tireless staff in Kyustendil – all of whom helped turn our struggles into successes, and who continue to contribute to our mission every day as they work directly with the children and young adults whom we serve.

This document was made possible by the joint efforts of The Cedar Foundation and the National Network for Children (NNC) and all of its members, working together in productive partnership to create better lives for Bulgarian children, and to change deinstitutionalisation policy on the local and national level in Bulgaria.

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# Why is this book needed and who is it for?

This publication is made available during a crucial period in Central and Eastern European social policy reform. In Bulgaria specifically, a mass deinstitutionalisation movement, managed by the government in close cooperation with local authorities and with the financial support of the European Commission, is at last gaining momentum. In February 2010, Bulgarian government authorities announced that a total of 137 institutions will be closed over a period of 15 years, beginning with orphanages for children with disabilities through the first project framework, “A childhood for all”.

These administrative and policy reforms, marked by national strategies, action plans and monitoring reports, are certainly a step in the right direction for the institutionalised children of Bulgaria. However, most participants are still left guessing as to *how* to put deinstitutionalisation into practice. Yet to be addressed are the challenges and problems stakeholders face as they undertake the practical aspects of closing an institution or establishing new community-based services.

Thus the purpose of this manual is to help clarify deinstitutionalisation in practice, by:

- Presenting the different stages of moving from institutional to community living through case study, and
- Outlining the challenges and problems this reform presents, which should be acknowledged and addressed by decision-makers, policy-makers and non-governmental organizations (NGOs) together.

This document presents a detailed record of the experience of The Cedar Foundation, which stands behind the successful closure of the Home for children with intellectual disabilities in Gorna Koznitsa, and currently manages six Small group homes (SGHs) in Kyustendil housing 24 of the residents from the institution. We aim to describe The Cedar Foundation’s practices – with their successes and their flaws – as well as the challenges we faced and the lessons we learned throughout this journey.

This manual is meant for municipalities, state authorities and NGOs which are or will become closely involved in the deinstitutionalisation process in Bulgaria. It does not presume to provide a one-size-fits-all solution; rather it is intended to provide readers with insight into some of the facets of the reform which – at this early stage – can help improve the chances for success in future efforts.

Finally, this manual is intended to become one of the many “best practice” tools which can be utilized to achieve the ultimate goal of the deinstitutionalisation reform in Bulgaria – full social inclusion and a better quality of life for current and future users of community-based services.

# Abstract

The countries of Central and Eastern Europe are entering a new era of reform in services provided to their many children and young adults who have been abandoned into state care. As part of this reform, deinstitutionalisation – the process of closing down institutions and creating community-based residential alternatives – is at last being emphasised as a means of rectifying the rights violations so long suffered by these vulnerable groups. Deinstitutionalisation is however a long, complex process and it is important for stakeholders to explore, share and discuss best practices in the field, in order to draw from the experiences of others.

This book, intended for practitioners, government authorities, non-governmental organisations (NGOs) and other concerned parties, shares the experiences of The Cedar Foundation and local collaborators in the deinstitutionalisation of children and young adults with intellectual disabilities from the institution in Gorna Koznitsa, Bulgaria. It focuses on the creation of high-quality, community-based Small Group Homes (SGHs) as a viable alternative to the institutional model, when foster or family placement is either not appropriate or available. The events which occurred are described in detail, openly revealing both the successes and the ‘lessons learned’ of the Foundation’s project.

In each chapter or “phase”, readers are presented with the actions of The Cedar Foundation and other stakeholders, the challenges faced in implementing the project, and interviews, quotes and anecdotes from a wide range of stakeholders in the project. Every section of this book culminates in a “Looking Back, Lessons Learnt” list of recommendations for current and future participants in the process of deinstitutionalisation in Central and Eastern Europe.

*The introduction* describes the **background of deinstitutionalisation** in Bulgaria, and how deinstitutionalisation has become a keystone for reform in social service policy for children and other vulnerable groups. The evolution of Bulgaria’s **National Deinstitutionalisation Strategy**, including the “Childhood for all” program, is explained and the policies’ accompanying frameworks and place within the European context are summarised. It explores the **definition and various aspects of deinstitutionalisation**, and how Bulgarian policy-makers define the principles of and approaches to deinstitutionalisation practice in Bulgaria. It outlines the **proven damages** inflicted by institutional living on children and adults and explains why deinstitutionalisation and providing children with a family-type environment is more cost-effective to the community as a whole. The introduction ends with an explanation of how readers can most effectively utilise this book.

*Chapter (Phase) One, “Analysing the Situation and Identifying the Key Stakeholders”* describes briefly the **history of the Institution** for Children with Intellectual Disability in Gorna Koznitsa, Bulgaria, as well as the factors which led The Cedar Foundation to commit to closing the institution. It discusses the importance of conducting a **situation analysis** before embarking on deinstitutionalising a Home, and outlines the **primary roles and responsibilities** which each key player in the Gorna Koznitsa closure project assumed in the joint effort to change the lives of the Home’s 58 residents.

*Chapter (Phase) Two, “Planning”*, underlines the importance of **planning all stages** of institutional closure well in advance. Crucial decisions such as the **location, terrain and architectural style** for new SGH services are explored, in the context of the Gorna Koznitsa project. It explains why the **new service framework** – the type of service, number of service users, and building setup – is one of the most influential factors in determining the outcomes of deinstitutionalisation. It discusses the preliminary work which needs to be conducted in the community before any closure project starts, from **analysing community services** to **developing productive partnerships** with the appropriate community stakeholders.

*Chapter (Phase) Three, “Preparing for Change”*, stresses that **the best interest of the child/client should be the primary guiding factor** in all preparatory phases for closure of any institution. It explores the **details of construction, furnishing and equipment** in the arranging of new services which reflect a family-type environment which can more effectively meet the needs of children and young adults with intellectual disability. The majority of this chapter is dedicated to what steps The Cedar Foundation took to **prepare those whose lives would most be affected by deinstitutionalisation**: the community, the caregiving staff, and the clients themselves.

*Chapter (Phase) Four, "Moving and Adaptation",* describes the **logistics** of how the children and young adults from Gorna Koznitsa were relocated to their new residences, and touches on the other **administrative tasks** surrounding the final closure of the Home. More importantly, methods for effectively **relieving transition anxiety** are thoroughly discussed: The Cedar Foundation describes its experiences in helping the community, the staff and the children/clients adjust to such significant change, with the least possible trauma. **Results** from the first rounds of clients' development assessment are shared.

*Chapter (Phase) Five, "The new service: A Case Study of Cedar's SGH 'Siyanie'",* suggests that **practitioner organisations** (most often NGOs) are most effective at managing SGH services. The chapter offers a comprehensive view of the **structure, programmes, and philosophies** of the SGH services managed by The Cedar Foundation in Kyustendil, Bulgaria, and how these programs have affected **client development** in the longer term.

*Chapter (Phase) Six, "Moving to the next level",* focuses on ensuring lasting quality in an SGH service. Measures **for ensuring quality of care and genuine social inclusion** are discussed both in the European context and within the framework of the services managed by The Cedar Foundation. It details the **internal and external programmes** created and/or utilised by The Foundation, which make opportunities in education, employment, recreation, and specialised community services available to its clients. **Case studies** are included, in order to examine some of the most challenging moments which The Cedar Foundation has faced in its efforts to include the clients in community living.

*Chapter (Phase) Seven, "Sustainability and Additional Services",* states that residential services for all groups ultimately should be recognised as **a concern of the community** as a whole, and highlights the Foundation's vision for Kyustendil, Bulgaria in becoming a leader in quality social service for people with disabilities. Issues which affect the **sustainability** of an SGH service such as service effectiveness, financial security and support of volunteers and other community members is highlighted. It suggests the importance of developing a wide **array of community services** to meet the varied needs of people with disability in any community, to ensure that all children and young people are provided with equal opportunity and a higher quality of life in Bulgaria.

# Introduction

## A public outcry and the beginning of change

With the approval of the Child protection act in 2000, the Government of Bulgaria made a formal policy commitment to deinstitutionalise thousands of children housed in state-run institutions. Progress was later made in terms of developing a legal framework which supported deinstitutionalisation. However, until the approval of the national strategy “Vision for deinstitutionalisation of the children in Republic of Bulgaria” in February 2010, there was no (evident) political will to close institutions; as a result of this the reform has often been piecemeal and ad hoc. The concepts of “reforming” and “restructuring” institutions in many cases led to structural improvements in buildings rather than real changes in the lives of children.

In September 2007 the BBC film, “Bulgaria’s Abandoned Children,” aired in the UK and put Bulgarian social institutions in the international spotlight. The film uncovered the harsh realities facing children with intellectual and physical disabilities in the decrepit residential home St. Petka, in the village of Mogilino. The film invoked an international public outcry, forcing politicians and the general Bulgarian public to acknowledge the horrific conditions in its state institutions. It also served to fuel the movement of NGOs, Bulgarian and otherwise, which were mobilising to effect change in the sphere of human rights and deinstitutionalisation in Bulgaria. In March 2008 the film was screened at the European Parliament. In 2009 the EU Commissioner for Employment, Social Affairs and Equal Opportunities Vladimir Spidla set up the Ad Hoc Expert Group on the Transition from Institutionalised to Community-based Care, which brought together European umbrella organizations representing the rights of children, families, elderly and disabled people. A sub-group on Bulgaria was established.

This resulted in the uniting of forces between the European Commission DG Regional Policy and DG Employment. The Action Plan “Investing in improving the life of children living in institutions in Bulgaria” was created, and the decision was made to invest some 20 million euro from the Operational Programme for Regional Development 2007-2013 in alternative services for children institutionalised due to poverty, disability or lack of appropriate services. Later it was decided that funding for the process would also be provided by the Operational Programme “Development of Human Resources” and the Programme for Development of Rural Areas. A group of stakeholders gathered in Bansko, Bulgaria in September 2009 for a seminar called “Leaving No Child Behind,” at which the different aspects of the deinstitutionalisation process were discussed and the newly formed Bulgarian inter-ministerial working group was introduced. This event marked the official beginning of the deinstitutionalisation reform. Finally, the National Strategy “Vision for Deinstitutionalisation of Children in the Republic of Bulgaria” was created in 2010 (herein referred to as the “National Strategy”). The Action Plan guiding the National Strategy was later developed, and the first Monitoring report was published in 2010-2011.

## “Childhood for all”

The first initiative of the Operation “Leaving No Child Behind” was inaugurated during 2010, under the name “A childhood for all.” The aim of this program is to “change the philosophy of care for children with disabilities, as the most vulnerable group among the institutionalised children, putting the accent on institutionalisation risk prevention, support to families and ensuring a family or close-to-the-family environment for every child from a residential institution for children with disabilities”<sup>1</sup>.

The project is expected to conclude in 2014 and includes two components: 1. Planning measures for deinstitutionalisation and 2. Providing community-based social services. Its framework guides the transfer of children and young adults from the Homes for children with intellectual disabilities and Homes for medical-social care for children.

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<sup>1</sup> Challenging Behaviour: Analysis and intervention in people with learning disabilities, Eric Emerson, Cambridge University Press, 1995

The British-based Lumos Foundation, together with the State Agency for Child Protection, conducted joint studies from October 2010 through the beginning of 2012, assessing children with disabilities in the Homes for children with intellectual disability and the Homes for medical-social care for children under 3, and their families. These assessments provide a snapshot of up-to-date information in order to facilitate the planning process for the closure to be implemented in “A Childhood for all.”

A total of 1797 children and youth with disabilities over the age of 3, living in 55 institutions (23 homes for children with intellectual disabilities, 1 home for children with physical disabilities and 31 homes for medico-social care)<sup>2</sup> are expected to be deinstitutionalised. The project budget is estimated at 4 960 400,17 BGN<sup>3</sup> (2 543 794,90 EUR).

## European and international context

The deinstitutionalisation reform in Bulgaria exists within a wider European and international policy and legislative context, and is linked to a number of policy instruments which address the rights of children and adults with disabilities. These documents include:

- The UN Convention on the Rights of the Child,
- The UN Convention on the Rights of Persons with Disabilities (UNCPRD),
- The UN Guidelines for the Alternative Care of Children,
- The Charter of Fundamental Rights of the European Union,
- The Europe 2020 Strategy,
- The European Disability Strategy 2010 – 2020, and
- The Council of Europe Disability Action Plan 2006 – 2015.

These are the key legislative, policy and strategic documents which set the scene for change, establish the institutional setting to be a violation of fundamental human rights, and call for integrated living in the community.

A more detailed description of these documents is included in Appendix 1.

## The institution and its impact

The institution, as a concept, has many different dimensions. The institution not only is a building, usually a large one, where many people live together. It is a model, functioning under strict rules and a common agenda for all residents. It is a way of seeing, valuing the group or service as a whole, as opposed to the individual with his/her individual needs. It becomes a mind-set for those who have been institutionalised for a long time. It is a psychological condition. It is a framework, both visible and invisible.

Research has shown that institutional care has the following negative consequences on a child's development:

- significant delays in physical and motor development;
- considerable delays in sexual development and the onset of puberty;
- higher incidences of psychological and psychiatric disorders and stereotypical behaviours such as body-rocking and self-aggression;
- inability to form attachments: lack of attachment plays a key role in poor emotional development, behaviour, cognitive development, social competence and mental health;
- delayed social development;
- lower rates of IQ;
- lower measures of height and weight.

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<sup>2</sup> Action Plan to the National Strategy “Vision for Deinstitutionalisation of the Children in the Republic of Bulgaria”, Monitoring Report, 2010 – 2011

<sup>3</sup> Action Plan to the National Strategy “Vision for deinstitutionalisation of the children in the Republic of Bulgaria”, Monitoring Report, 2010 – 2011

Institutional care also has a negative impact on adults with intellectual disabilities, resulting in:

- exclusion from society;
- lack of personal life;
- lack of employment opportunities;
- lack of income;
- isolation.

Practice shows that, though it is a slow and gradual process, improvement is possible for children and adults who are taken out of institutional care and given the opportunity to experience life in a family and community setting. International research demonstrates that children taken out of institutional care have<sup>4</sup>

- significant recovery in physical growth;
- a reduction in psychological disorders;
- improvement in IQ.

Clearly, the older the person is, the slower the process of recovery from institutionalisation will be, and in some cases a *full* recovery may not be possible. That is why it is essential that children are taken out of institutions at the youngest age possible, that there is early prevention in place so that they never become institutionalised and – furthermore – that children are never placed into the institutional setting in the first place.

## What does deinstitutionalisation mean?

The definition, presented in the National Strategy “Vision for deinstitutionalisation of children in the Republic of Bulgaria,” reads as follows:

**Deinstitutionalisation is a process of replacement of institutional childcare with community-based family or close-to-family-environment care, which is not limited only to taking children out of institutions.**

ARK Bulgaria defines deinstitutionalisation as “being about transforming the system of and approach to the provision of care. It does, by definition, mean “deinstitutionalising” individual children. But it is not enough to change the lives of a small number of children if the system itself is left intact”<sup>5</sup>

The Cedar Foundation underlines another important aspect of deinstitutionalisation:

“Taking the person out of the institution is easy. The real challenge is taking the institution out of the person”  
Lindsay Saltsgiver, Operations Manager, The Cedar Foundation

Deinstitutionalisation is a complex process. It is about closing the old institutional settings and creating community-based alternatives. But it is also about working with families and with the whole community, and attempting to change the mentality of all, including the formerly-institutionalised.

## A multi-level process

The deinstitutionalisation process is carried out on many levels, including:

- Working with **families** in order to prevent children from being abandoned, or to support children’s reintegration;
- Training **professionals** to support the process;
- Ensuring **foster care** opportunities, and training and support for those interested in providing it;
- Working with the respective institutions and professionals toward the creation of programmes for social **support** and protection of the biological and extended family;

<sup>4</sup> Action Plan to the National Strategy “Vision for deinstitutionalisation of the children in the Republic of Bulgaria”, Monitoring Report, 2010 – 2011

<sup>5</sup> Transforming children’s lives, De-institutionalisation in Stara Zagora, Bulgaria, ARK Bulgaria, 2009

- Establishing **alternative** services and forms of care to create opportunities for taking children out of institutions or preventing their placement;
- Encouraging the development and careful monitoring of **adoption** practices;
- Involving **civil society** in the whole process of institution closure and service provision;
- Putting **children and families** at the centre of all work with children;
- Raising **awareness** among the general public (especially clearly articulating the meaning, purpose and public benefits of deinstitutionalisation);
- Encouraging **dialogue and cooperation** among all stakeholders;
- Modifying **legislation and policy-making** to serve the needs of the children and to support service providers with the goal of providing the best services possible.

## Main principles

The National Strategy has identified the following main principles for the deinstitutionalisation process regarding children:

- **Actions favouring the best interest of the child** – According to the UN Convention on the Rights of the Child, this is the leading principle which dictates that the interests of the child must be put above the interest of all others, including parents, potential adopters, foster parents or institutional staff.
- **The family is the best environment for child development** – All professionals working in the area of deinstitutionalisation must have an equal understanding of the negative impact of institutional care on children and about the importance of the child being raised in a healthy family environment.
- **The social inclusion of children is of primary importance** – This should be achieved by providing opportunities for all children to participate in all aspects of community life, including attendance at local kindergartens and schools and the use of local healthcare, transport and other public services.

We would add the following principles regarding deinstitutionalisation of both children and adults:

- **Users' involvement** – Children and adults must be allowed to participate in all decisions which concern them, to the greatest extent possible.
- **Person-centred approach** – All activities should be undertaken in support of the individuality and the specific needs and desires of the children and adults who are involved.
- **Social inclusion of adults** – In all aspects of life, adults should be given the opportunity to be included.

## How to approach deinstitutionalisation?

The following outlines the approaches listed in the National Strategy. These points are again focused on children, but most of them can also be applied to young adults and adults. By exploring the Cedar Foundation experience, it will become clear to what extent these are implemented in practice.

- There must be a needs assessment for every child, which must include an evaluation of family capacity and the possibility of the child being raised in his biological family.
- Not a single child should be taken out of the institution without an action or care plan developed in cooperation with the child and his current and future caretakers, or with his biological family, whenever possible.
- Maintaining positive contact and emotional connection between the biological family and the child, whenever possible, must be a main element of the provision of permanent care to every child, regardless of the possibility for future reintegration.
- A placement in a family or close-to-family environment must be provided for all children leaving institutions eligible for closure – no child shall be left behind.
- Institutions are not to be closed by moving children from one institution to another.
- Priority must be placed on placements in family environment – in searching for services alternative to institutional residence, primary efforts shall be targeted at reintegration of the child into his biological family when appropriate and does not threaten the child's well-being. When this is not possible, another permanent solution is explored in the best interest of the child, during which placement in a family of relatives is a primary option and after that – in adoptive or foster families.

- Children should be placed in residential services housing only a small number of children, when placement in a family is not possible. The search for family type care does not stop with the placement of a child into residential services.
- Looking for a permanent solution for the child is a key part from the action plan, in order to minimize the child's relocation from one form of care to another.
- Children must be included to the greatest extent possible in the process of choosing the form of care which shall be provided.
- Brothers and sisters must be located and raised together except where this is not appropriate or possible.
- After taking children out of institutions, capacity must be decreased until the final closure.
- Priority should be given to the closure of institutions for children with disabilities, in parallel with homes for medical and social care for children 0-3 years, because the housing of children in such institutions and at such an early age is the most devastating to their development.
- Active involvement of the institutional staff in the process of deinstitutionalisation, development and implementation of programs for training, re-qualification and redirection of the staff towards alternative social services in order to use the existing capacity and human resources.

We would add the following two approaches:

- Development of new integrated services (based on needs assessment) for support of biological families in order to ensure sustainability of reintegration as well as prevention (gatekeeping)
- Reinvestment of the funds, saved by the decreased capacities of institutions, into the new services.
- Institutional buildings should not be used again for a residential type of care for children after the children have been taken out and the institutions have been closed.

## Is it cost effective?

Deinstitutionalisation is not only about human rights, values and actions which need to be taken. It has also a financial dimension, involving considerable costs for the transition from institutional to community-based care and support. Significant investment will be required for:

- making assessments of institutional residents and individual plans for their transition;
- the recruitment and training of staff for the new services;
- re-training of social service, health and education professionals;
- information campaigns for preparing the community;
- campaigns for the recruitment and training of foster parents;
- offering *quality* residential services;
- the establishment of additional support services where needed.

In the beginning of the process, the old institutional setting and the new services might operate in parallel, in order to ensure the smooth transition of the residents. This will add to the financial cost. In the short run, deinstitutionalisation and new services are more expensive than the current status quo. However in the long run things look much different. ARK Bulgaria lists a few reasons which show that "it makes sound economic sense to support deinstitutionalisation"<sup>6</sup>:

- direct support to families is more cost-effective, as well as having measurably better outcomes for children;
- there are potentially very high economic costs related to the negative impact which institutional care has upon children and young adults given the significantly higher rates of unemployment, homelessness and criminality amongst institutional care leavers;
- care leavers are more likely themselves to become young parents and many are likely to struggle with raising their children, who may well then enter the institutional care system perpetuating the costly cycle of economic and social disadvantage;
- institutions represent a very inefficient use of resources given the considerable infrastructure which needs to be maintained.

<sup>6</sup> Transforming children's lives, De-institutionalisation in Stara Zagora, Bulgaria, ARK Bulgaria, 2009

## How to use this book



The complexity of deinstitutionalisation could hardly be grasped in a “seven steps to...”, “ten methods of...” or “know-how techniques” manual. Therefore, this document does not have the ambition to serve as an instruction book for deinstitutionalisation of Bulgaria. It does not assume that the model of the Gorna Koznitsa closure is the only viable model, nor does it imply that the practices of the Cedar Foundation were perfectly orchestrated.

This is an attempt at an honest reflection on what occurred from the year 2007 through the present day. This is a case study, demonstrating the practical experience of The Cedar Foundation in closing an institution, creating community-based family-type services and striving to provide a better quality of life for 24 children and young adults with disabilities. It will not protect the reader from encountering the same challenges Cedar faced, the difficulties overcome, the successes or the failures. It will reveal the strengths it has identified in the reform movement...as well as the weaknesses.

Three features, at the very least, distinguish the Cedar Foundation experience in Bulgaria:

- Gorna Koznitsa was the first completely closed institution for children with intellectual disabilities following the closure of the Mogilino home in April 2010;
- The process of closing Gorna Koznitsa started long before the “Childhood for all” project aimed to close all institutions for children with disabilities, and was completed independently of its framework and funding;
- The Cedar Foundation has the distinction of being staffed, directed and supported by people from all over the world, who bring with them unique experiences and a very international view on life, social justice and the social sector. More importantly, however, all Cedar employees live and work in Bulgaria, raising families, using public services, sharing in the joys and hardships of Bulgarian life. The Cedar Foundation is a Bulgarian organization.

In addition to the Cedar perspective, this document communicates the perspectives of its local partners and supporters in the process – the Kyustendil Municipality, representatives of the educational system, and local employers.

This document contains seven chapters, with nine Appendices. Each chapter is a chronicle, written in the present tense to allow the reader to make the journey alongside The Cedar Foundation. Interspersed throughout the text are interviews, case studies, and quotes illustrating the realities which the Foundation faced as it met new challenges. At the end of each section are included recommendations, based on the experiences the Foundation, intended to help others who have begun or will begin a similar endeavour.

The reader may draw on the information contained in this book in whatever manner he deems most useful. Some will pick and choose the sections which are most useful to their present circumstances; others will read it cover-to-cover in order to get a comprehensive picture of the experience of closing an institution and establishing quality social services. In all cases, the National Network for Children and The Cedar Foundation hope that by sharing this experience they will enlighten readers and make the deinstitutionalisation process just a little bit easier for others.

# Phase One:

## Analysing the Situation and Identifying the Key Stakeholders

Every good plan begins with a thorough assessment of the situation, which should include a good look at the history and characteristics of the institution. In this chapter we set the stage for the closure of the institution. We provide a background of the Institution for children with intellectual disabilities and describe the major problems in the Home, which ultimately lead to its closure. We explain how The Cedar Foundation got involved in the project and what attempts had been made to push for the closure of the Home before the Foundation began its work. We describe the main players in the project, their roles and responsibilities as they developed throughout the whole closure process, and we make recommendations as to how to effectively analyse the situation and move forward with deinstitutionalisation plans.

### 1. Reflecting on the past: The history of the Home in Gorna Koznitsa

The Home for children with intellectual disabilities in Gorna Koznitsa was founded in 1963. The institution first existed as a home for children aged 3 to 10 with intellectual disabilities and had a capacity of 70, until 2003 when the Home's profile changed. In April 2003 it became an institution for children from 10 to 18 years of age. By 2009 the number of children had decreased to 58, of whom 16 were children and 42 were young adults over the age of 18, who had by now come of age and never left the institution. The residents represented different ethnic origins, hailed from different regions of the country and were diagnosed with a variety of intellectual or multiple disabilities.

#### 1.1 Regional characteristics

The village of Gorna Koznitsa falls under the Bobov dol municipality and is situated between the towns of Kyustendil and Bobov dol. It covers an area of 25 square kilometres and has a population of 285 residents<sup>7</sup>.

The Bobov dol municipality is situated in Southwest Bulgaria, covering an area of 206 square kilometres, comprising 11% of the overall territory of the Kyustendil District. The municipality consists of 17 villages and one town – Bobov dol – with a total of 6767 citizens (according to data from 2008). Over 63% of the municipal population is concentrated in the town of Bobov dol. The local economy is closely tied to the mining of brown coal.<sup>8</sup>

The town of Kyustendil is a county capital in the Southwest region of Bulgaria. It, together with the other 71 villages and towns in the district, has a territory of 964 square kilometres. The municipal population is estimated to be at 74 000 persons.<sup>9</sup>

#### 1.2 Governance of the Home

The Home in Gorna Koznitsa at one time was under the financial and methodological jurisdiction of the Municipal service for social assistance (later renamed the Department for social assistance), a structure of the Agency for social assistance. This changed in January 2003, when all financial responsibility for its management was transferred to the Mayor of Bobov dol, whereas the methodological responsibility remained with the Agency. Despite such changes made in central governance, the consistent efforts of the institution management to improve the conditions in the Home did not lead to improved living conditions for its residents.

<sup>7</sup> Transforming children's lives, De-Institutionalisation in Stara Zagora, Bulgaria, ARK Bulgaria, 2009

<sup>8</sup> Bobov Dol Municipality, <http://bobovdol.eu/>

<sup>9</sup> Kyustendil Municipality, [http://kustendil.bg/index.php?option=com\\_content&task=view&id=15&Itemid=31](http://kustendil.bg/index.php?option=com_content&task=view&id=15&Itemid=31)

### 1.3 Problems in the Institution



As in many institutions, the following issues afflicted the Home in Gorna Koznitsa:

- **The facility was in poor repair.** The buildings were not constructed to serve the purpose for which they were being used. They were not big enough, lacked an adequate water and sewage system, were not wheelchair accessible, and after years of abuse and financial neglect the buildings were literally falling apart.
- **Individual needs were being neglected.** Due to the lack of qualified staff and the management structure of institutions, the minimum number of children grouped into one classroom was approximately 19. Often, up to 30 children and young adults were gathered into one classroom due to one or more staff members being on sick leave or vacation. It was painfully clear that one teacher, no matter how effective, simply cannot meet the individual needs of 30 children with intellectual disabilities.

*"In the evening time, when the institutional schedule dictated that all children and young adults should bathe before bedtime, three staff members – usually cleaning or medical staff, not qualified teaching staff – were responsible for bathing nearly 60 residents. As a result, complete chaos reigned every night, when ideally the residents would be engaged in calming activities to help them get to sleep. This was especially upsetting for the more sensitive residents and those with autistic disorders, and at times led to physical injury of residents. Another problem we identified was that none of the residents were ever taught how to bathe themselves. What struck us was that adult and child residents would be unclothed and bathed together, indiscriminate of their level of sexual maturity or vulnerability to sexual assault. Staff was quickly becoming frustrated with the situation and giving up on attempting to work responsibly."*

*Lindsay Saltgiver, Operations Manager, The Cedar Foundation*

- **The Home was isolated from necessary services and other communities.** The village of Gorna Koznitsa is located in a remote region. While the distance between the village and the nearby larger communities of Bobov dol and Kyustendil was not geographically great (20-30 km), lack of frequent public transport and condition of roads served to isolate the village. This led to:
  - Lack of appropriate support services, day care, rehabilitation services, educational opportunities, sport and leisure activities in which all residents have the right to participate. Thus existed a complete void of opportunity for socialization in a community context.
  - Isolation from appropriate specialist and medical care: While the Home in Gorna Koznitsa employed nursing staff, the multiple needs of the residents (especially psychiatric and psychological care) were not being met adequately. The trip to the larger communities for the care of one or several residents was often undertaken only in an emergency (emergency medical care of psychiatric care). Residents had not visited dentists in years.
  - Lower standards of qualification of care workers in Home: The physical location of the Home and long commute, which often included hours of waiting for public buses, discouraged potential qualified staff from applying for employment in the Home. While many of the staff members were dedicated and had the minimum required education, general public opinion stated that employment in the Home in Gorna Koznitsa was most undesirable. Potentially good candidates had no incentive to apply.



- Transportation problems: Roads were not cleaned effectively in the winter and the Home was often cut off entirely, with no way for staff or food deliveries to travel to/from the institution.
- Lack of community ownership over the problem: Due to the geographic isolation of the Home, community members, including specialists working directly with the residents, developed a ‘hands-off’ mentality regarding their responsibility towards the residents in the Home. As the children grew up in the institution instead of in a family in the community, residents were seen as complete outsiders.
- **Children were housed with adults:** This caused the obvious problems of safety and security, especially for the younger and more vulnerable residents. But it also served to create a strictly defined hierarchical structure within the Home, based on a system of bullying among the residents.
- **The management structure was inefficient and ineffective.**

*“For example, the job description for hygienists included, obviously, maintaining general hygiene of service users and facilities. But not only did this prevent all staff from believing that service users could be taught to maintain their own hygiene, but despite their frequent contact with the residents, it was not considered a primary duty of cleaning staff to interact with the residents, neither in their best interest, nor to work on the residents’ development. This used up precious staff quota on persons not directly held responsible for the well-being or development of residents. We often heard from cleaning staff that it was not their duty to interact with the residents, merely to keep them and the facilities clean.”*

*Lindsay Saltsgiver*

A total of 45 persons worked in the Home, though residents were directly cared for by only 71% of those staff members. The remaining 29% handled only administrative tasks.<sup>10</sup>

- **Financing was inflexible and inadequate:** There was a unified state standard upon which the budget and the number of staff members were dictated. The annual budget was 372 000 BGN (190 769 EUR) of which 190 000 BGN (51%) (97 436 EUR) went to salaries, and some 90 000 BGN (24%) (46 154 EUR) to heating. The rest was not enough to cover adequate support for the residents, staff insurance, or building maintenance.

*“Hiring additional staff members, or allocating money for education, supervision and introduction of good practices was absolutely unthinkable.”*

*Margarita Parmakova, former Director of the Gorna Koznitsa Home and current Manager of the small group home “Siyanie”*

- **The outdated legal system perpetuated inflexibility:** Legislation (combined with financial structures) made no allowances for changes in the staff-to-client ratio or flexibility within strictly defined staff responsibilities or areas of activity, which diminished any opportunity for team work or creative responses to problems which arose.

## 1.4 The First winds of change

The first attempts at initiating radical change in the Home were made during 1999 and 2000, when the Home Director Margarita Parmakova lobbied to have the institution moved into a building in the town of Kyustendil. The attempt failed (despite the fact that the building in question is still not in use today). Margarita attributed this to municipal leaders’ lack of acknowledgment of the problems of institutionalisation and their failure to accept these problems as their own.

After modified regulations governing social services for children entered into force in 2003, the first inspection of the Home, conducted by the State Agency for Child Protection, took place in 2004. The inspection focused on the compliance with the minimum requirements outlined in the Regulations. Two more inspections were conducted during 2005 and 2006 but the first official proposal for closure of the institution was made by an Interdepartmental Commission, headed by Tsveta Antonova, Unit Director for Standards and Analysis at the State Agency for Child Protection, in 2006. The proposal called for closing the institution and merging it into another existing institution in the “Hisarlaka” region of Kyustendil.

<sup>10</sup> For a detailed comparison of the institutional and Small group home staffing models, see Chapter 5, Section 3.1 “Staffing (Human Resources), and Appendix 5.

Several trainings, organized by the State Agency for Child Protection, followed in 2007 in an attempt to prepare institution leaders to reform and restructure specialized institutions for child care. At this time the first official plan for closing the Home for children with intellectual disabilities in Gorna Koznitsa was discussed. The plan was prepared by the Director of the institution, the Department of Child Protection and the Department for Social Assistance Bobov dol.

In mid-2007 the Regional team to the Regional department for social assistance, including representatives of the municipalities, the child protection departments and directors of residential institutions in the region, was created. The team, supported by experts from the State Agency for Child Protection and consultants from UNICEF, was charged with implementing the municipal strategy for child protection and the institutional restructuring projects at the regional level.

Still, all the while, Gorna Koznitsa continued to operate.

## ***Interview with the Home Director Margarita Parmakova***

### ***How did you come up with the idea that the institution must be closed, being its Director?***

*In the years when I was a Director there I had the chance to see other services, in England. In January 1997 I visited such a service in the field of social care near London and what I saw made a great impression on me – the buildings, the way the overall work was organized, the relationships with the users – and I decided that this is the direction we should take. But this was a long time ago, when no one was talking about deinstitutionalisation in Bulgaria. At the time the general opinion was that the existing institutions are good enough, well-structured and functional. And my ideas didn't take off. No matter how much I tried to change the structure of the Home in Koznitsa and the way of providing care to the users, nothing was happening. And when the first inspections by the State Agency for Child Protection started in 2004, I took the opportunity to tell them that the institution could not continue to exist under this form and I was putting myself out there to insist on making a proposal for its closure. And this happened. The first plan which we made to the best of my knowledge was the first plan for closure of a home for children and young adults with intellectual disabilities in Bulgaria. Even then I was not yet aware that this plan and my ideas could be really implemented. But later when I met Mark, and with the support I received from the Foundation, I saw that they could be realized.*

### ***Didn't you have fears that with the closure of the institution you might not find your place in the new structures?***

*At that moment I was not thinking about this. The way in which the institution existed and what was happening in it couldn't continue because this was a cruel fight for physical survival. Not to talk about the quality of care. My fight was related to ensuring warmth, food and clothes for the children and the young adults. These are basic needs which I was obliged to ensure were met. I didn't think whether there will be a place for me in the future services or not, and I didn't aim at proving myself. My main aim was something to be created in which the residents of the institution felt equal to all other people. My fears were about whether or not I would manage to convince all the rest – the staff, the other institutions, the municipal management – that this is the way forward. And there was a lot of resistance in all of them.*

### ***So you faced mostly resistance from the staff?***

*Definitely. Even now former colleagues tell me when I meet them: 'Where did these crazy ideas to close the Home come from? This shouldn't have happened. What was wrong there – quiet, calm, no one bothered the children...' Some of them still cannot see that the closure was necessary.*

### ***How did you try to convince them?***

*We had many conversations – at the general staff assemblies we included items about discussing the necessity of closure. They themselves accepted the residents in the Home as their children, they were attached to them, and we implored them to understand that these children need a change. And that this situation in which we were artificially keeping them, could not continue forever. I tried to explain that there were also other opportunities for their professional realization such as foster care, and that they themselves can apply to be foster parents, that there were many alternatives for them...but only very few of them took an advantage of these alternatives.*

### ***When Mark O’Sullivan visited, were you suspicious of his motives or commitment?***

*Our attempts for closure dated back earlier but overall the support of the people around me was not very strong. We had many visits before Mark of representatives of foundations and NGOs and at first I thought his was one of the usual visits where people come, express interest, curiosity, discontent and desire to help but in the next moment they leave and that’s it. But the meetings with Mark and the conversations about what could be done continued for several months and I understood that the intentions of the Foundation were indeed more serious and deeper than superficial interest. And they backed me up and supported me. I could call Mark at any moment and ask him for support. And I always received it.*

### ***When did you start believing that they will succeed?***

*There was this situation when we tried for the first time to introduce foreign experience to Gorna Koznitsa – a team from England came to lead the first training for the staff. This however was not possible without receiving the approval of the mayor, of the Agency for Social Assistance and the whole chain of institutions. The English team, Mark and I went to Bobov dol and were waiting for permission from the mayor for them to enter the Home. We were sitting in the garden in front of the municipality and we were waiting for the communication between the mayor and the Agency for Social Assistance to happen for hours. There were phone calls and emails the whole time and the final approval was not coming. And then I realized how deep Mark’s conviction was that things must change. He said he wouldn’t leave until we got the permission and that is what happened at the end. The Agency realized that they had to let the team in.*

## **2. Cedar gets involved**

During late 2007 Mark O’Sullivan, Executive Director of The Cedar Foundation, visits the institution for the first time. He plans to propose to support them with a repair of the heating system by changing the cauldron. Costs for heating in the winter are high and there is an urgent need for repair of the heating system. However after an analysis and assessment of the situation the Foundation decides to target the funds to different areas in the Home, which would have a more significant effect on the development of the children and young adults, such as improving the living conditions, improving staff to client ratio, improving quality of care and introducing foreign good practices.

Increasingly Mark and the Cedar Foundation Board of Directors become interested in the Foundation getting involved in coordinating the closure of the Home. As quickly as they had entered the lives of the children and young adults in Gorna Koznitsa, they were taking steps to make permanent positive change. The Foundation’s headquarters move to Sofia, and the first Sofia staff members are hired to begin the process of helping Bulgarian authorities close the home properly.

## ***Interview with Mark O’Sullivan, Founder and Executive Director of The Cedar Foundation***

### ***How did you first learn about Gorna Koznitsa?***

*I was speaking to a couple who had been involved in bringing aid to different orphanages around Bulgaria and they spoke to me about some of the things they witnessed in Gorna Koznitsa. They said that basically as far as they are concerned it was one of the worst homes in Bulgaria for the living conditions that were there. So this sparked my interest. That’s why I went there – just to check it out. I never went there with the intention of closing it down. But I was completely flabbergasted that the place existed. I had already moved to Bulgaria and I thought: If I have to be living in this country I need to do something about this place. I never blamed the staff down there. I always had a sense of that this is everybody’s responsibility. Everybody who lives in Bulgaria – the government, the public – they all have responsibility to actually make sure that something like this doesn’t happen.*

### ***What struck you so much there?***

*The screaming. The half-naked kids. Boys dressed in girls’ clothes, wrong fitting clothes, somebody with one shoe on and barefoot, the complete chaos in the place, the feeling of fear, you could almost touch it. It was so tangible. It wasn’t*

the sort of place you can sit and be relaxed. It was as stressful as Wall Street – I imagine something like that, the thick tension. And as well the depravity of the kids – they were like animals. There were all sorts of abuses there and the smell was unbelievable, both out and inside. When you were inside you could hardly breathe, the smell was so bad. There was sewage everywhere – it was just a nasty, nasty place.

### **Did it immediately occur to you that you want to close it?**

Immediately. That this place has to close down. Right away we decided (it was me and our Board Director Liane): “We’re going to close this place down.” We just thought: “This is absolutely insane”. Sometimes it helps for somebody completely unrelated to come in and to view and experience something. Once you begin to be part of a system you become more and more desensitized, you begin to actually lose the shock that you would have with certain things that are going on and unfortunately the staff in Gorna Koznitsa had been there for so long that they couldn’t see it. I didn’t know how to close a home. I didn’t know how to set up new services. I just knew very clearly that you cannot have a place like this.

### **What was the first thing you did to turn the idea into a plan?**

To be totally honest I don’t remember the exact order but we went to the government, to the relevant institutions, just asking for meetings and said: “Do you know what is going on in this place?” At the same time contacting people in the UK and bringing myself up to speed, to help me gain an understanding of the field as quickly as possible. I had some understanding since I have made part of my degree in informal education; this involves looking at how people develop in the community and how to educate people, particularly from marginalized backgrounds, if they don’t fit into normal institutions like schools. So I had some experience and exposure to social work, I wasn’t alienated to it. But literally it was very simplistic approach as this: “Do you know that this is happening? It’s got to stop.” It was quite funny since people were saying: “Oh yes, we have a monitoring body. The place is up for closure.” But it turned out it had been up for closure and had been monitored several years previously but if we hadn’t given such a strong signal, probably in six years’ time it would have still been “up for closure”.

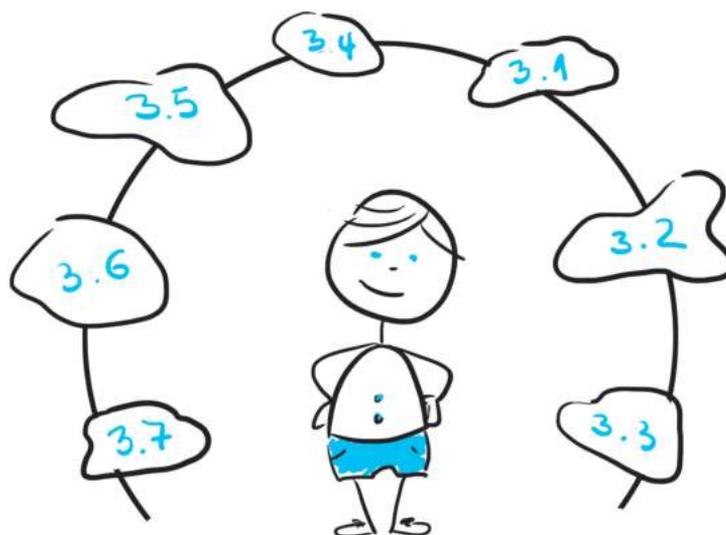
### **Were you convinced that you will succeed?**

I knew when we started seeing the municipalities and they agreed – Bobov dol wasn’t so enthusiastic but they agreed. In Kyustendil, the Mayor was on board. But the problem was that nobody really seemed to know what needed to be done. There seemed to be complete disconnection between the Home, the municipality of Bobov dol, the municipality of Kyustendil, between the government agencies. So then we began the process of just running between all these different stakeholders, trying to make them do their bit and to be totally honest it was a very weird feeling. I realised that a crucial part of our work is to support as much as we can the state and municipal people who are working in this field.

At that time there was no real belief that the homes will close down. The staff was convinced it wouldn’t. It was a very difficult job. I remember I kept telling people that we would resource what needed to be resourced since obviously they didn’t have the resources. But I believed that God would back me. I was talking to the Mayor of Kyustendil, saying: “We [the Foundation] will support you. We will finance it.” Talking to the central government saying: “We will support you. We will finance it” and then when actually we got everybody on board, it was 7 o’clock in the evening down in Gorna Koznitsa, everybody had agreed, it really hit me like “Oh, what have we done?” because we have convinced all the stakeholders that this really needs to happen, we don’t know what we are doing, all we know is that this needs to happen and they are now looking at us with the energy which we were trying to get at the first place but they are now saying: “Ok, we will do it.”

But I didn’t lose my determination to succeed in this, or the faith that it will happen. And about a week later there was a phone call and the person said: “The government has released 3 million to close the Home”. We just thought: “That’s absolutely amazing”. Of course then the struggles weren’t over. We had to stop them from closing it too quickly. Margarita started getting different visits from people who had never visited the place, who were supposed to have visited it, saying: “These people, we need to send them here, we will send five of them there, and we’ve got to build this house in Kyustendil to host 26 of them. We had to stop them and to say: “No, this has got to be done correctly”. And then we had to do the same meetings which we did previously, saying: “No, you won’t just shut the doors and kick everybody out”. This was a bigger project. The bigger problem would be if we started shipping them to different institutions around the country. And that was a huge battle. Because even to this date still the right services aren’t developed in Bulgaria to cope with people with severely challenging behaviour. So it became an impossible situation there with them saying: “What do you want us to do with these people? You cannot expect them to be living in the community”. Even though I couldn’t see any real solution I thought: “It’s not good enough to simply not have a solution. We have to find the way”.

### 3. Identifying the Key players



The Cedar Foundation is quickly learning that the closure of the institution in Gorna Koznitsa (and that of any other residential institution) will not be possible without the active participation of a number of key players. More importantly, each player should be working in coordinated sync with the others, clarifying what roles they will play, communicating often, problem-solving productively, and negotiating different elements of the project when the need arises.

Cedar Foundation identifies and describes here the most central players in the closure of the Home in Gorna Koznitsa, and the roles which they play in their coordinated efforts in the Gorna Koznitsa project:

#### 3.1 The Director of the institution

The director of the institution, Margarita Parmakova, will play a very central role. Margarita recognizes early on that the institutional model presents an insurmountable obstacle to the individual development of the residents housed in the Home. In 2007, in partnership with the Bobov dol Department for Social Assistance and the State Agency for Child Protection, she develops a project proposal asserting that the Home should be completely restructured, even before The Cedar Foundation or Bulgarian ministries come to the same conclusion. This fact encourages the Foundation that the project will be success, and foreshadows the indispensable partnership which the Foundation forms with such a progressive administrator.

##### Primary functions

The key functions of the Institution Director are as follows:

- With permission from the Municipality of Bobov dol, provides the Foundation with full access to the institution and its staff as appropriate, to assist in smooth coordination of closure and transition into new services.
- Acts as primary liaison between institution staff and parties responsible for coordinating closure:
  - eases fears of staff members regarding future of Home; voices these and other concerns with coordinating authorities;
  - assists the Foundation and/or future service providers with conducting assessments of staff in institution.
- Provides the setting and support for training of staff in the Home, as needed.
- As primary guardian of majority of institution's residents:
  - oversees the preparation of all necessary documentation within the Home for relocation of residents;
  - assists the Foundation and/or future service provider with conduction of skills and needs assessments of residents in institution;
  - is a key player in the multidisciplinary team tasked with choosing future placements for the Home's residents.

- As primary trustee of the institutional estate:
  - oversees the accounting and documentation for all institutional property for financial closure of the institution;
  - distributes all administrative documentation among the Municipality of Bobov dol and the National Archives.
- Advises the Foundation on the Bulgarian regulatory framework and assists in the development of policies and procedures for the new services (if appropriate).

## 3.2 Bobov dol Municipality

The Bobov dol municipality manages the Home in Gorna Koznitsa and therefore is the acting authority responsible for closure of the institution. The municipality also elects to open new services to house 20 adults from the Home, in the town of Bobov dol, and thus also becomes responsible for the construction and service provision for the new SGHs in the Bobov dol community.

### Primary functions

The Bobov dol municipality acts in its capacity:

- As closing authority of the Institution in GORNA KOZNITSA:
  - audits all accounting of institutional property;
  - liaises with State and district agencies and the Foundation to make key decisions regarding timing and process of closure;

Provides permissions and works in cooperation to allow access to institution of the Foundation and its trainers.

- As host community for new services:
  - manages architectural design, tender and construction for building and remodelling of new houses, including managing state financing;
  - provides municipal property for location of new services;
  - submits project proposal to the Bulgarian government for state funding for new service operation – funds
  - are managed by service provider via municipal accounts;
  - conducts processes for outsourcing of service management to NGO;
  - conducts financial audits on service provider and monitors outcomes measuring quality of service;
  - controls strategic planning to provide proper auxiliary services for residents of the new services.

## 3.3 Kyustendil District authority

The Kyustendil District authority plays an important part in the Home closure as well. Especially important is the Regional Directorate for Social Assistance, headed by Snejana Koznichka.

### Primary functions

The Directorate's role in the process is to:

- Monitor all processes involved in the closure;
- Act as liaison between the municipalities and state government;
- When necessary, work on the strategic level to ensure that all necessary services are available within the region of the residential services;
- Participate in multi-disciplinary meetings as necessary
- Represent the local coordinating council on Deinstitutionalisation for the District of Kyustendil.

## 3.4 Kyustendil Municipality

The creation of the new services is impossible without the active support and participation of the Kyustendil Municipality.

#### Primary functions

The Kyustendil Municipality as host community for new services carries out the following foremost activities:

- Manages architectural design, tender and construction for building and remodelling of new houses, including managing state financing;
- Provides municipal property for location of new services;
- Submits project proposal to the Bulgarian government for state funding for new service operation – funds are managed by service provider via municipal accounts;
- Conducts procedures for outsourcing of service management to NGO;
- Conducts financial audits on service provider and monitors outcomes measuring quality of service;
- Controls strategic planning to provide proper auxiliary services for residents of the new services.

### **3.5 Bulgarian Agency for Social Assistance and State Child Protection Agency**

Both agencies play a central role in the creation of the new services and putting them into operation.

#### Primary functions

The Agencies are especially valuable in:

- Providing guidance on regulatory frameworks for new services (the current methodology for SGHs, at the time, was still being written and no other methodological frameworks existed);
- Supporting the municipalities and district governments in understanding new roles as host communities for new services;
- Working with the Foundation for identification of appropriate services by providing advice and cooperation;
- Approving relocation applications for residents moving into new or existing services;
- Assisting in identifying appropriate existing services across Bulgaria, as necessary;
- Acting as liaison between municipal and district governments and the appropriate Ministries (Labour and Social Assistance, Finance, Regional Development).

### **3.6 Local Department of Child Protection and Department for Social Assistance**

#### Primary functions

As bodies working under the supervision of the national Agency for Social Assistance, these authorities are responsible for:

- Providing methodological guidance;
- Managing the documentation on individual residents;
- Acting as part of the multidisciplinary team to choose future placements for the residents of the Home.

### **3.7 The Cedar Foundation**

Cedar Foundation becomes an engine for the reform, acting at all levels and cooperating with all stakeholders.

#### Primary functions

The primary functions in the closure of the Home in Gorna Koznitsa are:

- Coordinating with authorities and planning all steps in the closure process and development of new services, as well as establishing the pace at which activities are undertaken;
- Ensuring that all residents leaving the Home are relocated into residential services appropriate for the client's wishes, abilities and needs;
- Lobbying government officials (local, district and national) to conduct activities for closure of the Home and opening of new services in a manner which protects the rights of the residents and follows best practices in the field as much as possible;

- Managing all pre-transition activities in the Home to allow for smoother transition – staff training, resident assessments, hiring of additional staff members to assist in the transition process, development of transition plans;
- Becoming outsourced service provider for services in Kyustendil: creates entire structure of new services and currently manages SGH services for 24 residents in the community;
- Acting as part of the multidisciplinary team to choose future placements for the residents of the Home;
- Assisting in the relocation of 10 residents into existing services in Bulgaria and providing induction training for the staff of those services;
- Developing and implementing new assessment tool for skills and needs of residents.



## LOOKING BACK, LESSONS LEARNT:

The lessons which we wish to share with you reflect the challenges which we at The Cedar Foundation faced during this tenuous time, especially as we strived to plan ahead the coordination of the whole closure process.

They are as follows:

- **Hold regular meetings to discuss progress.**

There was unfortunately many times a general lack of communication between interested parties – no structure existed at the time to ensure effective communication among stakeholders in the process. Round table meetings were very few and far between. This should be the function of the Regional Commissions for Deinstitutionalisation, together with any NGO involved in work in the respective Home and/or with experience in deinstitutionalisation. Regular bi-monthly meetings are at the very least necessary for regular monitoring of procedural progress and timely identification of risks.

- **Start with a SWOT analysis.**

We now know that at this early stage we should have analysed the situation more thoroughly by conducting a SWOT (Strengths, Weaknesses, Opportunities, Threats) analysis, *at the very beginning of the process*. With the participation of all stakeholders and coordinated by a Regional Commissions for Deinstitutionalisation, this tool would have been useful in getting stakeholders to come to a consensus on our ultimate goals, timeframes, and in identifying potential risks and pitfalls, *before* encountering them.

# Phase Two: Planning

Planning, and using a thoughtful approach in considering what lies ahead, is the most important starting point of every successful deinstitutionalisation story. From identifying and contacting the potential partners to carefully contemplating and clarifying every step in the process, the planning phase will structure and direct all actions towards achieving the ultimate goal.

The Cedar Foundation had a very short period of time to dedicate to planning and strived to make use of this time as efficiently as possible. In this section are chronicled the following events:

- How Cedar located communities willing to accept the new SGH services;
- How Cedar worked with those communities to identify suitable terrain;
- How the partners developed architectural plans for the new buildings;
- How stakeholders negotiated the details of the service framework (number of service users, types of services, how the services would fit into then-outdated regulatory framework);
- How Cedar analysed the existing supportive services in each community; and
- How official partnerships were formed during the planning phase.

The Foundation's project flowchart for the closure of the Home in Gorna Koznitsa is included in Appendix 2 of this publication for reference.

## 1. Setting the stage: Identifying communities, locating terrain and designing architecture

Vitally important to the deinstitutionalisation process is recognizing that the issue does not belong solely to the institution itself. It should be acknowledged as a concern of the municipality and its general public as well. It is also essential not only to define the key participants in this project, but to actively involve them in all preparatory processes.

In 2007-2008 very few municipalities had a clear vision or well-planned municipal strategy regarding the development of the social services in the territory. Without such strategy, authorities cannot clearly justify the development of residential and supportive social services, and there is a very real risk that deinstitutionalisation will be misunderstood by the authorities involved. Deinstitutionalisation should be an irreversible process which moves in a forward direction and does not accept compromises.

*"We still had to convince some people in civil service of the necessity of integration and inclusion of children and adults with disabilities after all the years of isolation and neglecting their rights. It was difficult to overcome the local attitude that people with disabilities cannot live in the town, that they are not able to socialize and integrate and that the town is not the most suitable place for them. Even more so when the municipality did not have a clear position on the matter."*

*Margarita Parmakova, Manager of Kyustendil SGH "Siyanie"*

### 1.1 Identifying the municipalities

The first stage in planning is to identify the municipalities where the new services will be created, and to reach an agreement with municipal leadership.

*"Together we were tasked with creating new services and providing opportunities for equal access to all existing services in the two municipal centres in the areas of health care, education, culture, sport and other social services."*

*Margarita Parmakova*

Cedar Foundation finds support from the Mayor of Kyustendil, Mr Peter Paunov, who demonstrates an understanding of the problem and openness to cooperation. Once having supported the idea of creating new SGHs in Kyustendil, he offers several plots of municipal land which could serve as the base of the new houses.

The situation is slightly different in Bobov dol. The town itself is dealing with several difficult problems, including a steady exodus of the population due to the closure of parts of the local mines. There is stubborn opposition between the political interests of the municipal management and the Municipal Council. It is difficult to convince the Municipal Council to approve the complete closure of an institution which had existed for almost 45 years and the transfer of part of the residents to the town.

Representatives of the Agency for Social Assistance support the Foundation in its efforts by participating in a number of meetings with the municipal management and by looking for a suitable piece of land for the construction of the new buildings.

## 1.2 The struggle for the “23”

Another major obstacle facing the Cedar Foundation is the lack of adequate alternatives for placement of an additional 23 young adults from the Home after its closure. At this time, a total of 58 residents – 15 children and 43 young adults – live in the institution. The funds from the Ministry of Labour and Social Policy to Kyustendil are *originally* allocated during 2008 as follows:

- Approximately 1 600 000 Bulgarian leva (BGN) (820 513 EUR) for the creation of two small group homes with a capacity of 14 children each in Kyustendil (total 28);
- Approximately 1 300 000 BGN (667 000 EUR) for the creation of two small group homes with a capacity of 10 young adults each in Bobov dol (total 20).

In the attempt to prevent the creation of another institution in Kyustendil (The Cedar Foundation emphasises that 14 children in one SGH constitutes an institution), this proposal is later changed and the capacity in Kyustendil is decreased to a total of 15 children from the Home and one child from another local institution. This leaves a total of 23 young adults in the Home for whom no alternative residential option was available.

In search of a solution to this problem Cedar turns to the Ministry of Labour and Social Affairs and the Directorate for Social Assistance Bobov dol. From this moment on the Foundation repeatedly attempts to draw the attention of the state, district and municipal authorities to the young adults who now have no alternative.

During the year 2008 Cedar Foundation meets with the Mayors and/or Deputy Mayors of the municipalities of Pernik, Radomir, Blagoevgrad, Dupnitsa, and Sapareva Bania, in the search for another municipality willing to welcome some of the 23 young adults left in the institution. All decline to participate in the project, due to lack of interest in the issue, conflicting strategic priorities, fears of financial insecurity, plans to establish services for children from their own institutions, and/or a supposed lack of human resources in the area.

UNICEF supports Cedar in its search of a host municipality and makes contact with existing services in other municipalities in the Razdol, Velingrad, Montana and Blagoevgrad districts. All of them decline to host the new services due to being at full capacity of their own group homes. What is particularly frustrating is the fact that, of the 58 residents in the Home in Gorna Koznitsa, only 7 were born in the Kyustendil or Bobov dol area. 13 were born in the Blagoevgrad District and 9 in the Pernik District. There is simply no incentive for a municipality to reach out to care for their own.

The Cedar Foundation hosts a round-table meeting with key stakeholders during July 2009 to address the problem and find solutions. Present are representatives from the Agency for Social Assistance, the State Agency for Child Protection, the Kyustendil Regional Directorate for Social Assistance, and two NGOs working in the field of deinstitutionalisation. Participants search for openings in appropriate services around the country.

As a result of this meeting two existing Protected Homes – in Marchevo (Blagoevgrad) and Ardino (Kurdjali) – are identified and approved by the Cedar Foundation, and agree to accept a total of ten residents from Gorna Koznitsa. Initially, staff from these homes is instructed by authorities to travel to Gorna Koznitsa to “pick out” their respective residents, pack them up and bring them home. Cedar interferes and, while it does not succeed in preventing the directors from choosing their residents, it does insist on the implementation of a transition period, which includes the following:

- two 'get-to-know-you' visits to the protected homes, accompanied by staff members from Gorna Koznitsa
- transition plans and risk assessments
- meetings between Gorna Koznitsa and protected homes staff to discuss individual plans and needs of residents
- 3-day 'handover', during which Gorna Koznitsa staff stays at the protected homes with the clients during the move.

*"We find this to be the very minimum of what should be mandatory for any transition, especially from an institution to a community-based service. Moving, in itself, is a difficult experience for anyone; 'being moved' with no regard to personal preferences, relationships developed with staff, or familiarity with the new environment is a trauma which can feel life-threatening to a person with intellectual difficulties, and should be banned as practice."*

*Lindsay Salts giver, Operations Manager, The Cedar Foundation*

Ten young adults are transitioned into their new Protected Homes in Marchevo and Ardino during October 2009. The Cedar Foundation, committed to the well-being of all residents in the Home in Gorna Koznitsa, continues to visit the protected homes in Marchevo and Ardino for a year after the clients relocate, and implements training programmes with the staff in each of these services.

At this point, the Foundation decides also to create separate small group homes for at least a portion of the young adults. The Municipality of Kyustendil provides two flats in different parts of the city for the settlement of 8 young people from the Home in Gorna Koznitsa.

### 1.3 Finding the appropriate terrain

The Cedar Foundation seeks appropriate terrain in the municipalities of Kyustendil and Bobov dol, according to the following criteria:

- The terrain should not be isolated or a long distance from the city centre.
- The plot should be located near or among other residential buildings, so as to be integrated into the environment.
- The different services – for children and for young adults – should be in different locations in the municipality.
- The area should have pleasant surroundings and be as accessible as possible, allowing persons with disabilities to be mobile out in the community.
- The homes should not be located in close proximity to each other or to other social services, where the result can resemble any kind of large institution, or give the impression of being closed off, isolated or remote.
- The terrain should be large enough to provide for bigger grassy areas and spaces for walking or recreation.

The idea is to create a social service which closely resembles a family home. The terrains selected are those which most fully meet the requirements of the Foundation.

*"Many of the meetings were disappointing as we didn't see sufficient will in the municipal authorities to change the system. But many of them couldn't understand the deinstitutionalization idea and that the new services shouldn't be small institutions but family houses. We were aiming to do the best for children and we didn't see understanding on behalf of some local authorities, even the central, that this is a good practice and that the new services should be built in this way."*

*Toni Stoykova, Marketing and Communications Coordinator, The Cedar Foundation*

The most appropriate plot of land in Bobov dol is large and located directly in the centre of town. It houses an old kindergarten, to be refurbished into a Centre for Rehabilitation and Integration (a support facility to serve both the incoming residents and people with disabilities from the general community). The Cedar Foundation recommends the second SGH to be located in a different area of the community. However, the municipality proceeds independently with developing the architectural plans for the builds, and Cedar is later shocked to learn that all 20 adult residents are to be housed on this one plot of land, along with the rehabilitation centre. This clearly characterizes the creation of one "small institution", right in the centre of the town of Bobov dol.

Together with the Bobov dol municipality and the Agency for Social Assistance, the Cedar Foundation searches for appropriate homes or empty plots of land for purchase in the area, placing advertisements in public places

all over the community and imploring the municipality to contribute a municipal apartment for the cause. No appropriate buildings or plots are, however, located – houses are not wheelchair-accessible, or are located on dangerous terrain, apartments are too small to house the appropriate number of residents, or plots are too close to the mines, or located in remote villages rather than the town. Thus the Foundation is forced to proceed with the municipality's original architectural plans, where all residents are to be located on one plot in the centre of town.

## 1.4 Architectural planning and Tender procedures

The Municipality of Bobov dol themselves commission the architectural plans for the building and remodelling for 20 adult residents in Bobov dol. In Kyustendil, a Sofia-based architectural firm, LP Consult, supporters of The Cedar Foundation, donates fully-completed architectural plans based on information gathered from the Municipality of Kyustendil and the general guidelines provided by the Cedar Foundation.

As with any construction project managed by a local municipality, pre-construction phases are heavily regulated by law. Architectural plans must be approved by the Municipal Technical Council and building contractors must bid in a public tender to win the rights to the project. These phases, and the processes involved, can take a considerable amount of time, and project planning should take into account the low feasibility of a quick turn-around of each phase.

In Bobov dol this process is expedited by the fact that municipal architects design the buildings. The tender procedures flow smoothly.

In Kyustendil the process proves to be a bit more difficult. After the architectural plans are completed, the Technical Council takes close to four months to approve the design due to several factors. The biggest roadblock is presented by confusion within the Technical Council regarding the type of building to be built and under what standards it should be assessed – by the standards set for a residential building, or according to those for an institutional building (see section 2.1 of this chapter, “Negotiations regarding type of building”). The Cedar Foundation, in the end, is required to provide the Council with written consent from the Agency for Social Assistance that the buildings should, indeed, be considered residential, in the spirit of creating a home-like environment for the residents as opposed to an institutional structure.

The floor plans for the new structures in Kyustendil can be found in Appendix 3.

For Cedar the key requirements for all buildings housing the residents from Gorna Koznitsa are:

- Maximum two residents should be placed in one bedroom.
- Size (square meters per person) and accessibility (full access to all points in all buildings) must meet the requirements set by other EU countries (Cedar uses the United Kingdom Department of the Environment, Transport and the Regions' 1999 Building Regulations for Access and Facilities for Disabled People).
- Each new building, while housing 8-10 people total, should be divided into two completely separate living quarters for up to five people, with separate entrances.
- Each household should resemble a normal household, and should avoid creating an institutional environment, to the greatest extent possible. All aspects of the home, including details such as location of the washing machine, size of storage space, and living/dining room layout should be modelled off of a *regular* household.
- Eating and cooking facilities, especially, should hold only a small number of clients (no more than five). This is especially important as children and adults with disabilities who have been institutionalised often experience a manifestation of their fears and anxieties most vividly during mealtime. Food stealing, violence, and chaos sometimes result when too many residents are grouped to eat together.

### Apartment remodelling

The municipality of Kyustendil commits to accepting 24 residents from the Home into the town of Kyustendil. However, once the architectural plans are complete and all parties are satisfied regarding numbers of residents and layouts of the buildings, only 16 residents can be housed on the municipal terrain originally set aside for the new services. At this point Cedar begins the process of identifying additional terrain for the remaining 8 residents (it is not yet decided who those residents would be). These additional 8 spaces will be for young adults, which presents the perfect opportunity for the Foundation to support them in apartments nestled within the community.

*“The municipality happily showed us the apartments which it had available. We agreed immediately to one apartment, in a block building, in a neighbourhood close to the new builds. This apartment was in dire need of remodelling but The Cedar Foundation committed its funds and human resources for the project, which took approximately three months. One apartment was located in the very centre of town, right off of the plaza, flanked by the wedding chapel and a newly-built residential and shopping centre. It was one of the few pieces of real estate which matched our criteria for where we could house four of the eight residents. However we were faced with quite a bit of resistance from some in the municipality, due to its very location – We heard, more than once, that ‘these people don’t belong in the centre of town’. We were grateful, however, that we were able to find progressive leaders to support us.”*

*Lindsay Saltsgiver*

The Cedar Foundation lobbies to procure this apartment, as it meets their criteria for living space. They plan to house the highest-functioning young adults in this apartment and work steadily with them on independent living skills, until they can support themselves in an observed, rather than 24-hour-care environment. The Mayor assents and grants this apartment after approval from the Municipal Council.

Cedar uses the following criteria to find apartments suitable for the target group:

- Living space should be spacious enough for four people to not feel crowded.
- There must be a fully-functional kitchen and full bath.
- The apartment should be on the first or second floor of the building; if on the second floor there should be a working elevator.
- There must be enough bedrooms to allow 2 residents per room.
- The building should be close to neighbourhood stores, cafes, and other common community areas.

Some of the biggest concerns during the remodelling of both apartments included:

- Making the apartment energy-efficient (insulation under flooring, using the least expensive clean form of heating in the apartment, installing new windows);
- Ensuring that any glass in the apartment – windows or doors – is made of safety glass or thick, unbreakable glass (even under normal circumstances);
- Ensuring that the electrical and fuse boxes are lockable; that all electrical sockets and switches are tightly screwed into the walls, if not level with the wall itself (to prevent residents from pulling them out)
- Installing laundry dryers – in the winter it is nearly impossible to keep such large amounts of clothing dry;
- Windows can be opened in several ways, either cracked open (opening at the top) or fully open (swinging to the side);
- Windows positioned low on the wall have a bar to prevent anyone from falling out
- Paint colours or wallpaper is chosen considering the favourite colours of service users, if possible; if not, should reflect the gender of the residents to live in given space.



## LOOKING BACK, LESSONS LEARNT:

Here we share the lessons we learned as we set the stage for the new services in Kyustendil and Bobov dol:

### Identifying appropriate municipalities and choosing terrain

- **Have a clear vision**

All parties, especially the municipality, should have a clear vision and thorough strategy, in which people with disabilities are given the place and the support that they deserve in the community.

- **Focus on the real needs of the users**

When faced with the challenge of creating completely new social services, it can be tempting for leaders to focus on financial issues and pressure to close the home as quickly or as cheaply as possible. However the real needs of the users should be the priority at all times, when solving problems or making decisions regarding their interests. Deinstitutionalisation is neither sustainable nor practical if the services will not meet the needs of its clients.

- **Consider larger communities and smaller village communities with good access to larger towns**

*“When we were searching for locations for the new services, we did everything possible to avoid developing services in smaller communities (villages). We now know that, for some older residents, moving into a larger town may be more traumatic than it is worth. The development of services in villages can actually increase the residents’ chances of integration if the community is smaller and more welcoming than a large town. The key here is balance – any new service developed in a village **MUST** have easy access (transportation) to larger towns where good supporting services such as Day Centres are located.”*

*Lindsay Saltsgiver*

- **Consider the community’s motivation to develop supporting services**

Any community which has the physical capacity to develop new supporting services to meet the needs of the residents, should also demonstrate a desire to do so. This should be made clear from the start – **residents should not be expected to have their needs met by the residential service alone.** Access to quality supportive services and the support of a progressive municipality are crucial parts of the closure of any institution for people with disabilities.

- **Choose your terrain very carefully**

Buildings for the new services ideally **should not be located on one single terrain.** Instead the terrain(s) of choice should allow for structural (not to mention social) integration into the surrounding community. Consider the problems that a municipality will face when it creates another institution, right in the middle of town – this does not benefit the municipality, the public, or the residents.

#### Architectural design for new structures and/or remodelling

- **Closely monitor the development of the architectural design**

Close monitoring is needed to ensure that all materials are as safe as possible (as in the case in Kyustendil, fewer glass sliding doors, complete non-slip surfaces on outdoor patios, etc.)

- **Complete separation of houses from one another**

While this created further tension in the Kyustendil service’s already-stretched staffing budget, a small-institution environment was avoided when the homes were not located next to one another.

- **Effective communication between architects, municipality and builders**

We at The Cedar Foundation acknowledge that as an NGO we should have been more actively involved in facilitating such communication. This would have prevented some of the problems which eventually arose due to miscommunication, for example:

- Questions regarding type of building and Expert Council progress;
- Inaccurate geographical survey information provided to architects by municipality which caused major problems during construction;
- Concerns of the municipality that the architects are not active enough in consulting builders after plans are provided (during construction).

- **Visual integration of buildings into their surroundings**

*“While they are modern and handsome by European standards, the new buildings in Kyustendil do not “match” well the surrounding neighbourhood – they are almost too European and not enough Bulgarian. While this point has been debated many times within and outside our team, care should be taken in any case to consider how the buildings themselves integrate into their surroundings. This will also affect how well the buildings and, subsequently, their residents, will be accepted into the surrounding community”*

*Lindsay Saltsgiver*

- **Safety first**

In developing the structural base for new services, attention should always be paid first to the safety of the residents.

- **Running costs second (especially heating systems)**

As a general rule, we have found that it is worth the investment to install solar energy systems for hot water heating and electric. Whatever method is chosen, Cedar has found that the cost of heating, after personnel salaries, remains its biggest expense, as it did in the institution. It would benefit municipalities and providers to plan to minimize these costs as much as possible.

- **Get advice from the right party, and avoid creating a sense of “disownership” within the municipality**

As an NGO, we at Cedar strongly recommend that, especially if a municipality plans on outsourcing its service management to an NGO, they should seek advice regarding the structural facility from one of the following:

- The NGO assisting with the closure of the Home;
- An NGO in Bulgaria with experience in running services for people with intellectual disabilities; or
- An NGO in the area which may eventually apply to become the outsourced provider.

The work required to serve people with intellectual disabilities, especially with residents who have lived their whole lives in institutions, is very specific. The structural facility of a service will be a key factor in determining the success of that service – the extent to which the service can meet the needs of the service users. Thus in every possible circumstance municipalities with little experience with this target group should seek the assistance of those who do have experience.

The phenomenon of creating a dysfunctional service within the municipality, then outsourcing the service provision, with the expectation that an NGO will turn this dysfunction into function should be avoided. If there is an NGO which is assisting with the closure, the municipality should let them consult on details regarding the structural base of the service.

## *Interview with Peter Paunov, Mayor of Kyustendil Municipality*

### *How did you decide to undertake this step, to help close the home in Gorna Koznitsa?*

*There's nothing more normal, more human. Even before the facts about the condition of the home in Gorna Koznitsa were made public, I was already informed that the situation there was very difficult. We had a discussion with the deputy-minister at the time, Ivanka Hristova, who shared her concerns that the colleagues from Bobov dol didn't have the necessary capacity to help the children. And then the idea to accept the young children and to provide a terrain, together with the colleagues from the Municipal Council, was born. And despite the incidental difficulties which came up, they were more political games... you see that things were brought to a good end so that the children feel good. I don't see more human and more normal reaction from giving a helping hand. Furthermore, we have had numerous examples and in our partnership with The Cedar Foundation and work with European experience. And that's why we are very grateful that children are with people who have the experience and know how to look after them.*

### *Didn't you have concerns about how the community might react – that there might be resistance?*

*The motivation to help a child excludes all similar concerns. We set up a goal; we walked the road in the best possible and proper way. Of course, the community itself was informed. We didn't let room for any speculation. For us it's clear that all children should feel in the best possible way together with their peers and among all people, and that's why there wasn't any dissent. There was a moment of speculation at the very beginning after the moving, as there was with Mogilino, but we didn't give anyone any reason to think that we would compromise the future of these children in any form and now I see that everyone is very happy. Not to mention that we also managed to cultivate a terrain which was in very bad condition. I don't have time for such concerns because of the extremely strong motivation. Children take the first place, and then comes everything else.*

### *What difficulties and challenges did you face during the process?*

*The main challenge was to create conditions which are really the best for the children. We ourselves didn't have experience, and concern only was not enough. That's why I'm glad that we were lucky to have people who are specialists, apart from the specialists in the Home, who loved the children very much. The partnership with Cedar was very valuable be-*

cause they have the necessary experience. I had the opportunity to witness the love Cedar and people around Cedar have for children. The numerous celebrations I have attended justified that. That's why it was a chance that life met us with them and since the moment they took over we can only learn from their experience. Such solicitude... With Mark we have partnered several times as well as with the other representatives of the foundation. It's good that the capacity of the community becomes bigger so that we can take more and more children and help them feel secure in a normal environment.

**What message would you send to other colleagues of yours where there's forthcoming deinstitutionalisation? Would you give them some advice?**

The only thing I could say is: love children. When you love children, you don't need advice. Your intuition leads you on the right way. Then look for the right people with whom you could partner. If you don't have it inside, then it's difficult for someone to advise you. And this is now a fact – we have the experience of such partnership and things can happen. However, you should have the love inside, so love children.

**Two of the young women from the Small group home "Siyanie" are already working in the municipal sweet shop "Champions". Would you say something about that?**

They are fantastic. At the moment, when they receive their chance in life, equal with everybody else, they use it in the best possible way and show how they give everything from themselves, how good and dedicated they are. They are amazing. That's why you can't draw a line. They are surrounded by love.

**What lies ahead with regard to deinstitutionalisation in Kyustendil?**

We continue with the homes in "Hisarlaka" – for children to 3 and from 3 to 6 years old. We will start building a protected home of the same type. We are already working on two social projects – building protected housing and in the same neighbourhood we are building a centre for work with all children to up to 7 years old. Apart from that, there will be also a strong social focus for children in disadvantaged situation, especially of Roma origin. To be together with their peers in the educational process so that they can receive the necessary social and health culture. The leading thing for us in terms of motivation is: the children.

**I suppose your aim is not only to develop services but also achieving the end goal – social inclusion?**

Certainly. That's exactly what I mean. Using every opportunity so that they may live in the best possible way, to be among their peers, to realize themselves on the labour market. Not a single chance should be missed.

**Would you like to add anything?**

I hope that we are as respectable as the children. They show what extreme potential they have. I hope, we the adults also are at their level and that's why we work and give everything of ourselves. So that we are able to protect their interests in the best possible way.

## 2. Considering the Details: Creating the Service Framework

A great difficulty is the lack of adequate legislation regarding the character, the type and the requirements which Cedar has to meet at the creation of the SGHs for adults. At this very moment, in a parallel to the process of the service creation, another process is going on - the creation of a state Methodology for SGHs homes for adults. The only guidance which Cedar has is the Methodology for SGHs for children so the Foundation has to find the best way of solving many issues on its own.

### 2.1 Negotiations regarding type of buildings

One of the key moments in the project creation is the task of convincing the Regional Health Inspection that the building should be categorized as residential public. This means that the sanitation regulations applied to institutions should not apply, as institutional environments are significantly different than the home environment. For example, in the institutional regulations, food must by law be delivered to the institution by outsourced providers. This prevents the service user from any opportunity to go to the store and buy food supplies, as he would in a family household. In institutions, food is to be prepared by a cook in a kitchen, inaccessible to the service users. This

denies the service user the right to even remotely become familiar with a kitchen and all its parts. Clearly the institutional regulations do not apply to the new service structure, but how to get around them?

After a number of successful meetings with sanitary inspectors and directors of the Inspectorate in 2009, Cedar manages to convince them that the building has to be approached as a residential one.

*“The main argument was the comparison with our own homes in which we live and the future home for the children. The purpose and the idea for the creation of a community based family type service was to make it look more like our own home, not only in terms of relation, upbringing and care but also in terms of division of the different areas and rooms. We had to defend this understanding in a few meetings of the technical expert council in the municipality but at the end our strong conviction and persistency managed to make the experts to believe in its rightness. Otherwise we would be doing nothing to change things or even create a family-type environment in our houses.”*

*Margarita Parmakova*

## 2.2 Negotiations regarding type of services

During the planning phase Cedar is obliged to continue using the broad term “alternative services” without strictly defining the type of service into which the Gorna Koznitsa Home residents would relocate. It is clear that, again, the legislation and social policy of the Bulgarian government lagged far behind the needs of service users exiting institutional care. The Cedar Foundation, parallel to closing the Home in Gorna Koznitsa, participates in discussions on methodology and legislation in Bulgaria as much as possible; however, it isn’t until several months before closure of the Home that legislation is updated to allow for the appropriate types of services necessary.

Regarding the Children: When Cedar starts the creation of the small group homes, the methodology for Small group homes for Children in Bulgaria is still being written. Thus at that time there is no official methodology to be followed. Questions remain as to whether the methodology would pertain also to children with disabilities (and, whether it would extend also to include adults with intellectual disabilities).

*“This had its charm though since we felt free to use the other countries’ experience and good practices and we felt satisfied with the fact that we create something new and unknown.”*

*Margarita Parmakova*

Regarding the Young Adults: While some of Cedar’s residents are potentially appropriate candidates for the only currently-existing service type, “Protected Home”, it is clear that the majority will not receive sufficient care and support in the framework defined as this type of service. Until 2010, the term “Small Group Home for Adults”, with funding equal to an SGH for Children, simply does not exist.

All new services opened as a result of the closure of the Home in Gorna Koznitsa are defined as SGHs – distinguished between SGHs for children and SGHs for adults.

Until distinct residential services for people with behavioural disorders are established in Bulgaria, staff of SGHs should be thoroughly trained in procedures such as physical restraint and behavioural management. While the SGH service type is the most suitable environment which is offered in Bulgaria today, it is clear that state funding is inadequate to meet not only the basic needs of SGH services, but also the needs of the most troubled residents exiting institutions.

## 2.3 Negotiations regarding the number of service users

The number of residents is one of the most essential factors Cedar considers. In general the smaller the group living in a residence, the more:

- capable the staff will be in meeting their individual needs;
- calm and composed the residents will feel;
- residents will be able to acquire skills for independent living;
- able staff and residents will be to develop positive and trusting relationships.

Originally the municipalities suggest grouping all residents together into one building, creating what Cedar considered to be a 'small institution'. This is a natural evolution of thought in Bulgaria at the time, as the country has never seen residential services with small numbers of residents grouped together. In addition, funding provided by the state is too minimal to allow for smaller group numbers. The Cedar Foundation faces perhaps one of its biggest challenges in convincing authorities that 28 residents in one building does not represent "alternative" services.

In Kyustendil, Cedar succeeds in negotiating plans to house 16 residents in two different buildings, each divided into two separate living spaces for four residents each. This represents a compromise – acknowledging that current funding will not allow for groups of four residents with separate staff, but with the expectation that funding levels will be increased to allow proper care to be provided in the future.

In Bobov dol, Cedar has less involvement in decisions regarding the number of residents to be housed, as the municipality is responsible for commissioning architectural plans. However the compromise reached is for the housing of 20 residents in two different buildings.

## ! LOOKING BACK, LESSONS LEARNT:

Here we share our recommendations regarding developing the framework of any new social residential service:

### • Determine the number of residents well in advance

This is one of the most important factors influencing the success of any service. Anyone seeking to develop new services should use caution in deciding how many clients will live together in one setting. We observe that the smaller the number, the more effective the service will be, but the more staff will need to be hired. At the time of publication of this booklet, funds provided by the state (and suggested staff-to-client ratios) are insufficient by *up to 100%*<sup>11</sup> for the provision of minimally effective services for clients with moderate to severe intellectual disability. Therefore co-financing on the part of the NGO-service provider or municipality will be inevitable if the institutional model is to be avoided. When determining numbers of service users, other factors should be taken into account, including:

- The individual needs and risk assessments of clients and potential behavioural problems or resistance to moving into the community;
- The location of the residence (will the apartments be dispersed around the community or will all residences be grouped into one spot?);
- How much personal space will be allotted in each residency, per service user
- The age of residents and availability of support services or schools in the area
- The staffing and shifts schedule – for example, will there be a "meal shift", to lessen the burden and chaos during mealtimes if larger numbers of clients must eat together? How will morning and bedtimes be covered, to ensure that clients are provided with individual opportunities to learn independent living skills?

### • Clarify your cause to the institutions in charge.

Service providers may have to do a fair amount of explaining to other local authorities (health inspection authorities, municipal technical councils, etc.) about the type of buildings which will house the residents and their distinction as *residential* buildings which house wards of the state. Regulations on internal policies regarding structural details are still not updated appropriately and providers may need to lobby or negotiate, coming to a compromise, to ensure that the service is not treated as an institution and that clients receive support in a setting which resembles a regular home.

<sup>11</sup> Problem areas in service provision of Small Group Homes (SGHs) and recommendation for corrections in financial standards, Bulgaria, National Network for Children, 2012

## 3. Reaching out: Analysis of existing services and Development of Partnerships

### 3.1 Analysing existing services in the community

Before analysing how well services in a community will meet the needs of potential clients, it is necessary to conduct an analysis of what those needs are. The community service needs of clients may include:

- Community services which directly respond to the disability. This includes supporting services such as:
  - Day care centres
  - Rehabilitation and integration centres
  - Resource teachers
  - Specialised psychiatric facilities (in the case of accompanying psychiatric disorder)
  - Accessible buildings and transportation (in the case of accompanying physical disorder)
  - Employment services (job coaches, sheltered workshops etc.)
- General public services, on which the disability has no bearing:
  - Medical services: (General practitioners, specialists and emergency medical care)
  - Psychological care services
  - Dental and Eye services
  - Educational services: (schools, kindergartens, higher education)
  - Public transportation
  - Employment opportunities
  - Civil participation opportunities
  - Sport and leisure opportunities

In many communities one will find all services offered in the second category, but few or none offered in the first. This should be used as an opportunity to develop the community to become hospitable to those with disabilities, whether that means implementing projects for the building of wheelchair ramps, or creating whole new social services in the community to meet the needs of the incoming residents.

Cedar invites expert groups to visit the Home in Gorna Koznitsa to conduct assessments, and hires a group of local Bulgarian experts to conduct individual assessments.

Using a combination of both assessments for each client, Cedar gets a comprehensive picture of the following:

- History of the resident and diagnoses
- Assessment of Skills Development
- Recommendations regarding type of residential service appropriate for client and his/her needs for staffing or specialists within or outside of said service
- Developmental goals
- Medical and psychiatric needs
- Recommendations on improving quality of life within the institutional setting

Cedar also begins working on a tool with which it can monitor development of each client without the need for highly-specialized evaluators – a tool which can be used on a regular basis within the service, by care workers who do not have specialized degrees but are trained in how to conduct the assessments using the tool. The organizations ARK Bulgaria shares an instrument, co-developed with Hope and Homes for Children, which Cedar modifies to reflect the realities of the lives of institutionalised children with disabilities.

Using the results from these assessments, especially regarding specialists needed, the Foundation then set out to analyse the availability of supporting services or specialists in the communities of Bobov dol and Kyustendil.

*“The availability of services was not the deciding factor in determining whether a community was appropriate for our clients; though it did provide a starting point for our negotiations with municipalities for the development of appropriate supporting services”*

*Lindsay Saltgiver, Operations Manager, The Cedar Foundation*

- Analysis (through meetings with leadership) should include:
- Capacity, willingness and openness to working with clients who do not live with their families;
- Types of services offered and specialists present
- Possibility of developing joint programs for new clients
- Internal policies regarding individual planning and monitoring of skills development

## 3.2 Developing Partnerships with other stakeholders

As all of these types of public services will be involved in serving the clients in some way, it is important that these services be seen as partners and that a common understanding is expressed, formally or informally, that deinstitutionalisation is good and that all involved will work for the good of the clients. Collaboration with different institutions and organisations is essential for the process of planning. It is a necessary condition for facilitating change in public attitude to ensure equal participation of the users in the life of the local community. Supporting a good quality of life including developing psycho-emotional and cognitive skills in the users is impossible without social inclusion.

*“First public reactions were negative. A big part of the community thought that the place of the children and young adults was not in the community. We saw unfriendly looks, we heard unpleasant statements and we didn’t get a lot of support from others in the neighbourhood. Our efforts had to be directed towards not only the local institutions and organisations but also towards the people who were, naturally, curious – our neighbours, the salespeople in the local shop, the cafe owners next to the houses, the people working in the nearby school and kindergarten. By creating contacts and relationships with the local community and trying to get them on our side we were aiming to promote friendliness, tolerance and understanding and to identify our partners for the future. Our attention was also focused on young adults, public figures and volunteers interested in the problems of children and young adults with disabilities.”*

*Margarita Parmakova*

An important partner for informing and engaging the community is the local and national media. Cedar doesn’t miss an opportunity to appear in media, to inform and to invite the community to its events. This way it tries to change the attitude of the community towards its newest members.

The foremost partners in the process are the municipalities of Kyustendil and Bobov dol, with which The Cedar Foundation signs formal partnership agreements. These agreements define roles and responsibilities and affirm the common goal of creating a good model of care in Kyustendil which can then be included in the national standards and applied in the whole country as an important part of the decentralisation of services for people with disabilities. Ideally, partnerships should be realised at all different levels – with supportive services and technical experts, Deputy Mayors and Mayors, Directorates and Regional Units for Social Assistance, and experts from the Agency for Social Assistance, the State Agency for Child Protection and the Ministry of Labour and Social Policy.



### LOOKING BACK, LESSONS LEARNT:

Here we share our recommendations regarding how to explore local services and establish partnerships within the community:

- **Start with individual assessment of the needs of the clients**

It is important to begin with *comprehensive* individual assessments of the needs of the clients leaving the institution. Assessors should be aware of the impact their assessment may have on the future of the individual. It is also useful if the initial assessments are the first step in the utilization of a comprehensive skills development monitoring system (such as the tool Cedar created).

- **Analyse all types of community services**

*“In hindsight we now know that it would have been useful to analyse all community services, not just those who cater to people with disabilities – health and dental, schools and kindergartens, educational centres and other extracurricular services for children/youth. Some of our biggest challenges, after moving into the community, came about because we had not properly identified or prepared professionals from all of the services with which our clients would have contact”*

*Lindsay Saltsgiver*

See Chapter 3 for more information.

- **Start right away to develop partnerships with other services in the community**

This analysis is an opportunity to begin forging very important partnerships with other services in the community, and to communicate the necessity of and benefits to deinstitutionalisation from the very start. Providers should work to get public services on board with the process.

*“We have been confronted many times by stubborn resistance from specialists working in the community (even those who work directly with people with disabilities) who were not in favour of deinstitutionalisation before we moved into the community. This reflects negatively on their work with our clients”*

*Lindsay Saltsgiver*

- **Talk about missing services**

When a particular service is missing, it is key that discussions regarding the future development of said service begin right away. The success of the residential service will very much rely on the availability of good supporting community services.

- **Think outside the box**

Be creative when identifying potential partners. For example, the salespeople in the shops in the neighbourhood, the nearby café owners, the children in the neighbourhood, local athletes or other role models, etc. Partners from the local community are your future ambassadors in the larger community.

## ***Interview with Lindsay Saltsgiver, Operations Manager, The Cedar Foundation***

### ***How did you get involved with The Cedar Foundation?***

*I was still a U.S. Peace Corps volunteer when I first got involved with The Cedar Foundation. The Foundation’s then-Marketing Manager, Lincoln Frager, a friend from the Peace Corps, told me about the work that Cedar was hoping to do with the Home in Gorna Koznitsa. I was fascinated, to say the least. As a volunteer I had managed an orphan sponsorship program and witnessed first-hand the negative consequences of the old “deinstitutionalisation” policies in Bulgaria – when the government was closing down or restructuring institutions with no reasonable alternative and no regard for the effects it would have on the children involved. So I was excited when I was invited to help out, and I wholeheartedly believed that we could really make a positive impact. I started out as a volunteer, but it soon became clear that the Project Manager position was a great fit for me. My responsibilities have grown since.*

### ***What was your role during the closure of the Gorna Koznitsa institution?***

*I played several roles in the project, actually; though thankfully we had a small but great team of dedicated people working toward the same goal! First and foremost I was responsible for planning out the project and managing each different stage of the closure. This was no simple task, and as deinstitutionalisation hadn’t really begun full-swing in Bulgaria, this required a lot of research and communication with our advisors, who shared their experiences. I also led the team in the design of the new services, and I directed the development of the training programs that we offered. I worked very closely with Margarita Parmakova and the municipalities, and I was closely involved in each activity undertaken by the Foundation, every step of the way.*

### **What struck you most when you first visited the institution?**

*That list is quite long! Gorna Koznitsa wasn't the first institution I'd seen in Bulgaria, but it was the first one for people with intellectual disability. I think I was most taken aback by what appeared to be a complete lack of activity – just a lot of people bunched into one yard and a few classrooms, with absolutely nothing to do and no one to help them do it. Everyone was just sitting around, and staff was more like counting heads rather than actually engaging them. I worked as a special educator in the US, where we designed activities to help the child reach developmental goals, and every step was carefully calculated; thus I was shocked to see that they were completely left to fend for themselves. Also I couldn't believe there were grown men and women inhabiting the same space as small, vulnerable children. And everyone's clothes were ill-fitting, pants falling down, men wearing skin-tight pink women's blouses, nothing seemed to fit anyone. It all just seemed, at first, like complete chaos.*

### **Which were the biggest challenges you faced during the closure and immediately after?**

*There were times when I really couldn't believe how little understanding there was toward what we were trying to do. I understand that change is difficult and that there will always be resistance to the unknown, but we heard so many negative comments, even from educated, professional people. It was a difficult mentality to contend with. We had to deal with a lot of inflexibility in the Bulgarian system, so we were also making decisions that pushed the limits of how social services were perceived by authorities in Bulgaria – thankfully, slowly lawmakers are also beginning to modernize the framework in which community-based services will operate. And we were, of course, challenged by the lack of funding available in Bulgaria for the operation of quality social services which actually meet the needs of the client. We are still contending with this!*

### **How did you overcome them?**

*Well, I think regarding the mentality towards accepting and supporting people with disability in the community, we just kept right on with what we were doing, despite the resistance. Our philosophy has always been that people will never accept these children if they are not given the chance to accept them. Nothing in Bulgaria is going to change unless someone instigates that change. That kept us going. This also helped us deal with the inflexibility of the current system. Though we carefully worked with authorities to make sure that they understood why we were pushing the envelope and what we felt needed to change. As for the financial strain of trying to run a decent social service, we meet that challenge with lots of fundraising. Though we won't be able to keep it up forever; for several years now we have also been lobbying the government, to help them realize what a huge task they're undertaking with deinstitutionalisation and to make them see that current funding levels are seriously inadequate.*

### **When you look back now, what was your (Cedar's) biggest success?**

*When I think back to that last day when the last group of young adults left the Home in Gorna Koznitsa, I still get chills. It was a dark, overcast day, and we were all so weary, so exhausted. But it was one of the best days of my life. I think we all felt the same profound relief and joy that never again would anyone be forced to live in that horrible place. I'm so proud to be able to say that we were a big factor in making that happen. Sentiment aside, this in itself was a huge success. I also am proud of the fact that in Kyustendil we have one of the highest caregiver-client ratios in Bulgaria. For a long time I couldn't sleep at night wondering how we were going to cover the shifts needed without being forced to put the clients back together in groups of 16 with one caregiver. We worked really hard to find people to sponsor the caregivers necessary, and our service would be a much different, more institutional and impersonal place without such support. Of course, we still worry about keeping the sponsorships going and still don't feel it's enough – but we are making the nearly impossible possible.*

### **What do you wish you knew then, before starting the process?**

*I wish I would have been more aware of the potential ways in which some of the clients could react to these life changes; we would have done even more thorough risk assessments and implemented more effective transition activities before the clients moved into the new residencies. I also wish that I had known just how long some of the project steps would have taken, before we began. In many cases tasks took twice, three times longer than we planned. Knowing this would have decreased some of the confusion we experienced and would have helped everyone make a smoother transition. More importantly, I wish I had known just how possible this would be, before we started! I came into this with little specific experience with deinstitutionalisation. So, before we began and also many times during the project, to me our task just seemed so huge and the obstacles so insurmountable. I think that I could have saved myself a lot of worrying along the way – Are we going to succeed? Can this really be done? Are we on the right track? – had I been more confident that all this would be achievable. Now I am just so glad to see the incredible change in the children and young adults who benefited from all our hard work.*

# Phase Three: Preparing for Change

The preparatory phase for closure should be well-planned and should *never* be rushed. While time will, in most cases, be of the essence and authorities will most likely want to complete the closure as soon as possible, the best interests of the client should guide all decisions during preparation for the big day, especially:

- Each client's emotional and psychological readiness for the event
- In all possible cases the wishes, preferences and input of the client themselves
- The psychological preparedness of staff and their thorough understanding of the basic principles of quality care.

Notice that among these factors are **not** listed:

- Availability of funding for the new services (timelines for switching funding between the institution and the new services)
- Politically-motivated timelines
- The modernization of legislative and policy regulations.

While each of these will play a role in the process, they should never be the sole factors which dictate any step of the process. Most of all, The Cedar Foundation recommends that all stakeholders view the clients as people, not objects which simply need to be moved from one location to another. No matter how non-verbal the client is or what the level of disability, he will be very sensitive to his surroundings and will be deeply affected by every decision made in his interest. It is all too easy to forget this in the face of so many decisions and such complex factors, but the power is within the authorities and service providers to make this a smooth life transition rather than a traumatic event for each and every individual client.

In this chapter we chronicle the events surrounding the planning phase of the Gorna Koznitsa project:

- Contracting, construction, and furnishing of the buildings and handover to the service provider;
- How we made efforts to prepare the community for our clients' arrival;
- Our successes and failures in preparing the children and young adults for this change in their lives;
- What we did to help prepare the staff, and how we handled the administrative details of personnel changes upon the closure of the institution.

*"In deinstitutionalisation, do not mistake 'construction' as being synonymous with 'preparation'. There are many other activities which should be conducted parallel to the building process, in order to ensure a smooth transition."*

*Lindsay Saltsgiver, Operations Manager, The Cedar Foundation*

## 1. Construction and handover

The municipalities of Kyustendil and Bobov Dol handle all aspects of the construction process, as state funding is directly managed through municipal accounts. This step can be broken down into several phases:

### 1.1 Tender procedure

As required by law, all construction of buildings for public use must be contracted out to a construction company through tender procedure. In Kyustendil, the call for proposals includes landscaping, building, finishing and furnishing; in Bobov dol, separate tender procedures are undertaken for building/landscaping and finishing/furnishing. In response, Kyustendil receives a bid from only one candidate and Bobov Dol receives several bids. This process takes much longer than expected in Kyustendil, as the municipality, with its already strained resources, struggles to prepare the paperwork required for the tender – perhaps due to the fact that the architectural plans themselves are outsourced. In Bobov Dol, the procedures go quite quickly and

smoothly. Cedar works to try to keep both municipalities on a parallel track, so that closure of the Home can occur in the same month both for residents moving to Bobov Dol and for those moving to Kyustendil. In both municipalities, the construction company is contracted to complete all phases of the construction, including landscaping and furnishing.



## 1.2 Construction of buildings

Both municipalities hold ground-breaking ceremonies during August of 2009, attended by at least 100 guests from the media, residents and staff from the Home in Gorna Koznitsa, The Cedar Foundation, and local neighbours, including neighbourhood children who are curious about the new children who will be moving in. For many, this is the first time the public is meeting the residents from the Home in person, and there are mixed reactions. However the ceremonies are a success, and all celebrate this important milestone together.

As always in construction, obstacles must be overcome regularly during the building of the new homes in each community. However some of the key issues Cedar faces are as follows:

### Bobov Dol

- The basements of the buildings are leaking moisture from groundwater due to a poor drainage system. This in fact nearly threatens the entire building/remodelling process.
- Construction of the SGH and reconstruction of the Centre for Social Rehabilitation and Integration is delayed.

### Kyustendil

- The geological survey information provided from the municipality to the architect is inaccurate. As a result, the layout of the terrain and building locations has to be changed mid-construction, as digging for the building foundations unexpectedly hits an underground spring. This, in turn, creates several areas of the terrain which cannot be effectively utilized by the residents. It also takes a financial toll on the building company.
- As the architectural planning is done off-site and the builders are not involved in developing the architectural plans, facilitating communication between the architects and builders becomes critical (especially when the above-stated problems arise). This ultimately becomes the duty of the Cedar Foundation, who organizes meetings between the architects, builders and municipality to iron out major issues which develop during the construction process.
- While the municipality contracts the company to complete construction in 120 days, this proves to be an ultimately impossible timeframe. As a result the building process enters the winter months, during which little can be completed; the construction ends up taking nearly ten months instead of four.

## 1.3 Finishing and furnishing

Details regarding the finishing, furnishing and equipping of the new buildings raise many new questions. The answers to these questions ultimately reflect the philosophy of the service and individual needs of the clients, and have a significant effect on the longevity and quality of the service provided. While not going into every detail, the following Question and Answer should serve to summarize some of the main 'grey areas' in the finishing and furnishing of new SGH services:

### ***Do the houses need equipment for medical sterilisation?***

In an ideal SGH service for people with intellectual disabilities, the answer would be no, as there should be no requirement that medical procedures be conducted on-site, and vulnerability to bacterial infection would not be of significant concern. However one should be aware that there will be incoming residents who have not received appropriate care their entire lives, and/or residents with multiple disabilities, leaving them vulnerable to even ordinary household germs. Thus it is best that this equipment be on hand in case it is needed, and that individual service providers use their best judgment as to the scope of need for such equipment.

### ***What kind of furniture should we use?***

While, again, this is individual, some of Cedar's recommendations are:

- Sturdy furniture is a must!
- Furniture should have no sharp edges, if possible (round tables should be used instead of square, for example);
- Cabinet handles should be "embedded" in cabinet doors if possible; also hinges should not be located on the outside of cabinet doors as this poses a safety risk;
- Furniture should be comfortable but easily cleanable, including seat cushions, etc. Incontinence will be a common occurrence, at least until residents can learn to use the toilet properly
- Glass doors on furniture should be avoided
- Care should be taken to provide enough seating spaces for all residents PLUS staff (in living room and around kitchen table)

### ***Do we need clothes dryers?***

The Cedar Foundation initially tried to work without clothes dryers (as Bulgarian households usually hang clothes to dry) but ended up having to purchase them in the end. Clothes dryers are highly recommend, if possible, to help staff and clients keep up with laundry needs.

### ***What kind of flooring is best for an SGH?***

Non-slip, durable, easy to clean flooring is essential. Non-slip tiling is especially essential on outdoor patios, etc.

### ***What about window dressings?***

In Kyustendil there was quite a bit of debate about whether to install external roll-down shades or use normal, indoor shades and curtains. Cedar opted for the latter and, while regular replacement of shades was necessary while teaching the children to stop bending them, ultimately this was the right decision. The curtains and shades very effectively give the houses and apartments the feeling of 'home'.

### ***Plastic, ceramic or metal dinnerware?***

While it may be tempting to buy all plastic or metal ware, it is also important that such everyday household items do not constantly remind one of an institution. Additionally clients should ultimately be taught how to handle dishware, breakable or not. Cedar recommends using plastic at first, then once residents learn how to handle dishware, switching to ceramic. High-quality plastic drinking ware is more practical than glass.



### **What kitchen appliances are needed?**

The staff and residents in Kyustendil most frequently use:

- microwave oven
- juicer
- stick blender, especially where there are residents who need their food pureed
- electric kettle

### **What about security systems – are they necessary?**

Guided by methodological recommendations, Cedar installed silent security, human-response (SOT) systems in the SGHs in Kyustendil. While there has never been a need for them, they have helped staff feel safer during overnight shifts. Should a client exit the premises unannounced, such a system will alert the staff member on duty. However there are cost factors to be considered and providers should make a judgment call on whether to install security systems in their buildings.

## **1.4 Legalisation and handover**

All buildings must obtain Act 15 and 16 for public use in order to be brought into public domain. In Kyustendil, once the construction is completed the municipality guards the property until the contract is signed with external service provider and residents move into their new homes.



### **LOOKING BACK, LESSONS LEARNT:**

Here we share our recommendations regarding construction of new buildings to house SGHs for people with disabilities:

- **Allow sufficient time for all phases of the construction**

When planning the closure of a home parallel with the construction or remodelling of buildings for new services, it is best to plan as much time as possible for this phase. This way providers avoid the situation where the closure of the institution is immediately imminent but the construction is lagging behind, leaving nowhere for the clients to relocate.

- **Be thoughtful to what deinstitutionalisation means for the client**

When working with the construction company, the following should be priorities:

- client safety and security;
- giving the SGH a feel of 'home';
- providing opportunities for clients to learn independent living skills;
- hygiene of the facility;
- operational costs (will an item help cut down on running costs, or increase them?).

- **Get the construction company on board**

It is helpful also to get the contractor and project managers on board with what the buildings will be used for, and the above priorities which should set the tone for all decisions made during the building process.

- **Maintain good relations with the builder**

New builds or renovations will always present different structural issues. Municipalities and service providers will very likely need to contact the builder after move-in for minor repairs to the build. It is essential that this is set into the contract with the builder, and that it is clear that the service provider can contact the builder (through the municipality if necessary) for repairs, for a limited time after the opening of the new services.

<sup>12</sup> See "Medical model for disability" in the Glossary section.

## 2. Preparing the Community

Having identified the partners it is important to start building productive relationships with them. Once agreements have been signed defining the rights, obligations and responsibilities of all the parties involved, every productive meeting with local and national partners serves to strengthen the relationship and increase trust and mutual support.

### 2.1 Identifying medical specialists for the new clients in Kyustendil

Finding good medical care for persons with disabilities is a significant and often disenchanting challenge facing both institutions and community-based residential services. Persons with disabilities are often perceived to be hopelessly ill because of the widely-accepted, yet outdated, medical model for disability<sup>12</sup>; spending too much effort on these patients has, in the past, been considered pointless. The General Practitioners (GPs) who serve children with disabilities sometimes give up quickly due to a number of common misconceptions:

- children and adults with disabilities represent a challenging group, complicating the work of the doctor and
- burdening him with unnecessary and immeasurable risk;
- a higher number of specialist referrals due to the potential instability of the patients' health might be required, which in the Bulgarian healthcare system is problematic;
- a wide array of specific medications might need to be prescribed, which requires a special regime and additional examinations and observations;
- more thorough examinations may be required to observe the effects of the medicines on all the organs and systems;
- details and the specific characteristics of a disease may be unfamiliar, which requires a lot of time and research;
- there is a lot of pressure involved in working with children with severe disabilities;
- as they may not fully understand what is happening to their bodies, patients with intellectual disability react to the fear and pain they may be experiencing and are less cooperative during examinations.

Cedar receives many refusals from doctors in Kyustendil but finally finds a talented doctor willing to provide the clients with compassion, adequate help and timely treatment.

Another necessity which arises is that of finding a child psychiatrist who will meet the needs of Cedar's clients for regular observation, home visits in the residence, and systematic consultation regarding medications. The Foundation contacts the only child psychiatrist in Kyustendil and attempts to prepare her for her future work with the service users.

Most dentists decline Cedar's requests to use their services, and it takes nearly six months after the children move into the community to find a dentist to care for the residents' teeth. Service users also travel to Sofia to visit oral surgeons.

### 2.2 Ensuring educational opportunities

In the institution in Gorna Koznitsa, several days a week, all children attend regular educational sessions with specialized teachers from the School for children with intellectual disabilities in village Stob. These teachers follow the children and continue educating them in the Kyustendil residencies. However, the Foundation values social integration as much as educational opportunity and envisions integrated education for all of its clients.

For this reason service employees begin a series of meetings with the Director of the 6<sup>th</sup> Primary School in Kyustendil. The school is in proximity to the Day Care Centre attended by the children, which makes it a convenient option. However enrolling children with disability into a mainstream school turns out to be more difficult than anticipated:

The children have to be examined by a special commission of experts who meet at certain times during the year. This commission assesses the child's capability to study in a mainstream class with a resource teacher. The respective school has to check how many children with disabilities are already in attendance and whether there are enough resource teachers available to take more.



Finally, the Resource Centre must decide whether they can provide enough teachers to work with Cedar's clients in a mainstream school.

During the first year of service operation, Cedar does not manage to enrol a single child in a mainstream school. Meanwhile, the teachers from Stob continue their work with the remainder of the children but instead of schooling them at home they conduct their studies in a room provided by the 7<sup>th</sup> elementary school.

### 2.3 Attending the Day Care Centre and Rehabilitation Centre

Several of the residents in the Home in Gorna Koznitsa visit the Centre for Social Integration and Rehabilitation twice per week. In 2008 Cedar meets with the managers of the Rehabilitation Centre and the Day Care Centre "Faith, Hope, Love" in Kyustendil, to ensure access to more children and young adults, to work with qualified professionals such as a speech therapists, psychologists and specialized teachers. The Foundation also hopes to get the support of professionals for the preparation of the children and young adults for their relocation.

The Cedar Foundation is impressed by the conditions in the Centres and by the wonderful opportunity it presents to the children and young adults from the Home. The Foundation lobbies to increase the number of clients attending the services, once the children and young adults are settled into their new home in Kyustendil, but with little result. The children simply are not considered to be the ideal clients for either centre and only several are accepted to attend. By 2012, five children attend the Day Centre and eight children attend the Rehabilitation Centre.

### 2.4 Visiting other services which exercise good practices

An important element of the preparation for the Home closure is the opportunity for stakeholders to visit a similar service in Stara Zagora. The service is planned, created and developed by ARK, which becomes Cedar's partner, supporter and a source of good practices in the process of closing the institution and opening of new residential services.

The visit is organised in the autumn of 2008 with the main goal of demonstrating that good practices can exist in Bulgaria and to provide an example of what Cedar hopes to create in Kyustendil and Bobov dol. A small delegation visits the SGHs managed by ARK and the protected home managed by Stara Zagora Municipality. The service in Stara Zagora becomes a model for the planning and organization of the new services in Kyustendil.

## 2.5 Work with the community

Cedar concedes that its efforts in preparing the community of Kyustendil are perhaps insufficient. Nevertheless Cedar tries to spread the word about the new services and to create a positive attitude in the future neighbours with the support of relatives and friends of the people involved in the process of institution closing.

*“One of the ways in which we were able to attract community attention to our cause was by getting involved in a charity concert, organized by the pupils from the Natural Sciences and Mathematics high school in Kyustendil, at which they select a ‘Miss’ and ‘Mr of their high school. This was actually the initiative of the students themselves. We attended, with some of our residents in the Home. They devoted a special portion of the concert to recognize our residents and the work of The Cedar Foundation.”*

*Margarita Parmakova, Manager of the SGHs “Siyanie”*

## 2.6 Reaching out to parents and family members

Most children and young adults in institutions – especially in institutions for people with disabilities – have long been abandoned by their birth families. Before considering a small group home as an alternative to institutionalisation, organisers are obliged to attempt to contact the family and explore the option of reintegration into the family home. Locating the birth family also serves to help organise the relocation to the new services in a way in which users may be closer to their birthplaces, and in the hope that relatives may show more interest in them in the future, even if reintegration is not possible.

At this time, the guardianship council (the body responsible for assigning an abandoned child or adult with disability with an appropriate legal guardian) prepares all of the paperwork necessary for transferring a child or vulnerable adult to a new location.

*“The Directorate for Social Assistance and the Department of Child Protection Bobov Dol researched and located all of the parents and close relatives of the children and young adults in the institution in Gorna Koznitsa. They tried to establish contact with them in order to revive the lost relationships. But only two families expressed a desire to re-establish contact: One family brought their daughter home, and one father now regularly visits his daughter in the Protected Home in Ardino.”*

*Margarita Parmakova*



### LOOKING BACK, LESSONS LEARNT:

Here we share what we have learned as we reached out to the community in Kyustendil:

- **Conduct stakeholders’ analyses**

Map out all of the involved parties and key players in the reform, clarifying their roles and interests. Then identify yourself (organization) on this map and try to see through how you connect to the others, what your interests are, what sort of information and support you need.

- **Don’t underestimate the role of your partners**

The role of the partners should never be underestimated no matter whether they are directly involved with the deinstitutionalisation process or are part of the larger community. Everyone has their unique and special role.

- **Work with the official institutions**

The official institutions and a productive relationship with them are important conditions for plans and projects to be supported by the state structures and to become a base for innovative changes and thinking.

- **Supporting services must be prepared for change as well**

The residents of alternative residential services have the right to receive the same specialist support in the community (physical rehabilitation, speech therapy, psychological services) which is provided to children who live with their families. This can be difficult for support service staff to recognize, as the common misconception is that children living in a residential service should get all the care they need in the Small Group Home. We continue to meet with resistance from specialist support services in Kyustendil, who are not well-trained to meet the needs of our specific client group. Supportive services in the community must be well-prepared to work with the incoming children and young adults; they should be included in training whenever possible, and should administratively increase their capacities to accept the incoming children and young adults.

- **Show off good practices**

Provide an opportunity for people to see a good practice, a good model of what you are aiming for, in order to convince them that nothing is impossible.

### 3. Preparatory work with children and young adults

An important element in moving residents into a new service is their preparation. This includes preparing them mentally and emotionally for the move and helping them get ready to acquire certain skills and habits needed in community life.

Cedar invites a team of professionals who are well aware of the deep waters of the process, including Francis Ma and Anna Tylor, both key players in the deinstitutionalisation process in England.

#### 3.1 Implementing adaptation program

The first visit of the UK partners is in the summer of 2008. Their main goal is to assess the situation and offer an effective strategy for how to prepare the children and young adults for the new services. The plan includes a number of main directives:

- Changes in the buildings:
  - installing doors to the bedrooms and creating separate rooms for the girls and boys;
  - installing lockers in the bedrooms and living rooms and creating spaces where private possessions can be placed;
  - renovating many of the rooms.
- Changes in the organisation of work:
  - decreasing the number of children per group;
  - increasing the number of staff;
  - changing the existing daily agenda;
  - changing the distribution of children in the bedrooms;
  - changing staff's attitude towards users and their roles in working with them;
  - preparing individual assessment of the users in order to define their individual needs and create short term transition plans and long term plans for development;
  - ensuring a possibility for all the users to visit the social services in the town of Kyustendil – Day Care Centre and Centre for Social Rehabilitation and Integration;
  - increasing qualification of the staff;
  - changing the educational – vocational process, while putting the focus on the individual and his/her abilities and needs;
  - changing the work methods;
  - creating individual programmes for development into which development of skills for independent living is integrated.

Cedar succeeds in fulfilling part of the recommendations, as follows:

- the number of the classrooms is increased
- the number of children and young adults in the separate groups is decreased
- children and young adults are divided into separate groups, which diminishes the risk of the younger ones being victimised in crisis situations of challenging behaviour;
- separate rooms are created for different activities – speech development, getting to know the environment, domestic labour, basic learning;
- the classrooms are refurbished, as well as the bedrooms and the kitchen with the dining room, in order to create a more home-like atmosphere;
- the number of children eating together is decreased (consequently the atmosphere and the environment during eating times is also improved);
- wardrobes for personal belongings are installed;
- there is an attempt to divide the bedrooms for girls and boys but this happens only for a small number of the residents – 3 boys and 10 girls – due to the structure of the buildings and lack of space.

## Ani's Story

Ani<sup>13</sup>, who has always wanted to have her own room with a wardrobe, own toilet articles, perfumes and cosmetics, is very happy that this has finally happened and that she is the “boss” of this room for girls. She starts teaching the other girls in the room how to dress, how to wash themselves, how to make their beds and fold their clothes, when and how to change their bedclothes. Each time when there is a visit from donors or volunteers, she always insists on showing them her room of which she is very proud. With her interest in cosmetics she gives the service the idea of creating a “female club”. The girls put on makeup, do each other's' hair, and give each other manicures. Ani tries to keep certain rules for hand and face hygiene and no female visitor leaves the place without a freshly done manicure. For her this is her dream fulfilled, a way to feel part of the female community and at the same time – to show her skills, desires and aims.

The changes in the environment and the way in which residents' time is re-organised have a significant effect on the development of many of the children and young adults.

## 3.2 Summer camps

One of the tasks in the period of preparation is for the residents to gain hygienic domestic skills and habits for more independent living – to learn to eat quietly and calmly, to not grab food from one another, to be able to serve food, wash themselves, dress themselves, to behave in society and other skills and habits which we all learn subconsciously, imitating our parents and relatives already in our childhood. Institutionalised children, especially those with intellectual disabilities, miss this opportunity in their development and never get the chance to learn these skills. Even exposure to well trained professionals who have the knowledge, skills, strong will and big hearts doesn't always help them to compensate the loss.

*“We organized summer camps in 2010, with the help of volunteers. Pupils and teachers from a private Catholic high school in England, together with staff from the Home and representatives of the Foundation, organized a variety of activities. They were not held in the Home but in the community of the town, which was to soon accept them – Kyustendil. Visits to cafes, shops, restaurants, games and entertaining places, painting in the classrooms and around the 3<sup>rd</sup> Primary School were organized. In addition they visited the group homes which were still under construction and established contact with the people who were building their future home”.*

*Margarita Parmakova*

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<sup>13</sup> All names of the service clients have been changed in order to ensure confidentiality.



Two volunteers from England – Alan and Jennifer Watters – contribute significantly to the preparation of children and young adults for the transition. In 2008 – 2009 they devote several visits to Bulgaria to the residents of the Home in Gorna Koznitsa. Their attention is focused not only on training of staff but also on direct work with the children and young adults. They participate in the daily activities of the Home. They organise a gardening class through which the young adults gain labour skills and self-confidence, besides a few tomatoes, carrots, courgettes and parsley. They develop a temporary sensory room and spend significant amounts of time with the staff, trying to teach them how to use a person-centred approach in their work. They also take the children and the young adults to the town and for those of them who have more challenging behaviour this is the first time out of the Home.

### 3.3 Talking about moving

Staff in the institution speaks openly with the residents about the upcoming move, as much as possible.

*“The goal was, of course, to help the residents understand what was happening and to help ease them into the idea as early as possible. Ideally, we would have taken it one step further and gotten the residents more involved in deciding where they wanted to live, in what kind of setting, and with whom – thus transforming what has been a passive experience into something in which the client is actively making decisions for himself. Where this was possible, we did involve residents. Unfortunately in this situation that was not possible with the majority of the clients, as they had never made choices even regarding what they wanted to wear, let alone what community they feel would be most appropriate for them. This ultimately was one of the biggest weaknesses of the project – not enough self-determination for the clients themselves. We did, however, make every attempt to help the government and other authorities see the clients as people, not ‘sacks of potatoes’ as we say, who can be moved at the whim of the authority without regard for the wishes or input of the client”.*

*Lindsay Saltsgiver*

### 3.4 Grouping Residents: Multi-disciplinary team decisions

During the spring of 2010, the Cedar Foundation holds a multidisciplinary team meeting to decide which residents would move to Kyustendil and which to Bobov dol. Present are:

- The Kyustendil Regional Directorate for Social Assistance;
- Bobov dol municipal representatives (Social Assistance);
- Cedar Foundation representatives;
- 4 staff members with different specializations, plus the director, from the Home in Gorna Koznitsa, which includes the legal guardian(s) of all of the residents in question.

During the meeting the case files of each of the 48 residents in question are reviewed, and the best option for residency is discussed among the team. The criteria which Cedar uses to determine placements (as always, using what is in the best interest of the resident as a guide), are as follows, in general order of priority:

- type and capacity of new service provided in each community;
- family relations, keeping siblings together;

- the wishes of the client, where expressed – this can be very difficult to ascertain, not only due to the lack of exposure of the client to the world outside the institution, but also because Cedar does catch staff trying to manipulate the opinions of the clients by “teaching” them which community they would say when asked;
- family relations, location of any known relatives of the client – locating client as closely as possible so as to promote rebuilding of relationship in future, where possible;
- support services present in the community – will they meet the needs of the client?;
- client-client relationships, both adverse and positive. Ensuring that clients are placed safely but keeping friends together where possible;
- client-staff relationships – this is not wholly possible as at the time staff has not been hired yet for the new services

Unfortunately, the capacity of the new services in Kyustendil and Bobov dol is five less than the total number of remaining residents. The Cedar Foundation notifies authorities of this problem many times to no avail, before resorting to having to choose which five residents would be relocated elsewhere. As a multidisciplinary team, this issue is discussed thoroughly and five residents tentatively chosen for residency outside of the new services.

*“There were many arguments about the type of services in which to place the young adults. There was an opinion that if they don’t have certain habits and skills and haven’t reached a certain level of their development and ability to manage with different life situations, they shouldn’t be placed in community-based services. The community based and residential services up until now had been kept only for the young adults with lighter disabilities and for the rest the only suitable form of care was considered to be the institution. The appropriate service simply did not exist. Our big regret is that initially two and later on one more young adults were situated in institutions – two young men in the Home for adults with intellectual disabilities in the village of Kudelin, Vidin district, and a young woman - in the Home for adults with disabilities in the village of Kachulka, Sliven Municipality.”*

*Margarita Parmakova*

As no alternative options are presented by authorities, the Cedar Foundation travels throughout the country in search of appropriate existing services for five young adults. Most services in Bulgaria are full to capacity or in terrible shape, and there are no appropriate services for the people with the most complex multiple disabilities and challenging behaviour. After several months of searching, and on the figurative eve of the closure of the Home, two clients are assigned to SGHs for people with intellectual disabilities, and three are most unfortunately assigned to institutions for people with intellectual disabilities.

### 3.5 The First Residents Exit the Home: Moving into Marchevo and Ardino

The Cedar Foundation has very little time – one month – to prepare the 10 residents for moving into the Protected Homes in Marchevo and Ardino in October 2009. The Foundation manages to make transition plans and to organise visits in the services together with the clients so that they can meet the staff, the service and the place and adjust to the idea of moving. The staff of the services also pays a two-day visit to the Home in Gorna Koznitsa where they have the chance to communicate with the users and to see their documents. However the rushed process took its toll on the ease with which the young people accepted their circumstances.

*“There was something that really bothered us. Initially we got a visit from the service management where the main purpose was to see the residents of the Home, to try to communicate with them if possible and to “cherry pick” them – to choose those who were meeting their requirements without any preliminary in-depth assessment of their abilities and needs. We were initially told that on that very day that those who were chosen would be transferred into their services. We managed to make an agreement with the Agency for Social Assistance to prolong this period to a month, which gave us the possibility to prepare them for the move. The time was inadequate, but we tried to enable the transfer to happen in a smooth and painless way because we expected the young adults would not accept it calmly, which is exactly what happened. At our first visit to the new group home there was no problem and they felt fine, taking it as a trip, but when the final move came, they were constantly searching with their eyes for people from the staff in Gorna Koznitsa who were accompanying them and repeating that it was time to go home.”*

*Margarita Parmakova*

Maria, Svetla and Vasil also show how the changes reflect the development of the users. All of them become calmer, more communicative, feel more independent and significant, become persons.

## **Vasil's Story**

*Vasil is part of the first group who leaves the Home in October 2009. He is very independent, quiet and calm. In the institution he lives in a room together with two more boys. Cedar repairs this room and turns it into a multifunctional room – living room, bedroom, entertainment room. In the beginning he doesn't feel responsible for keeping it in order, often does not make his bed, doesn't put his clothes together and doesn't clean it but after many conversations, reminders and demonstrations from the staff on how to do all this, he has changed positively. He feels proud of having his own space, wardrobe and belongings. He has changed and his behaviour has formed as one of an individual with his own preferences and opinions. He shows interest in the guests to the Home who bring cameras.*

*After his first meeting with the camera and after he finds out what he can make with it, he doesn't stop looking through the lens and rediscovering the world by making pictures. In the last days before moving to the group home in the village of Marchevo he has made his own pictures - and very good ones - of his friends in the Home, the guests and staff. During the transition period the purpose of which is to adapt to his new home – the group home - Vasil demonstrates his newly acquired abilities to make sandwiches, serving, house work as well as fast adaptation to the new environment, but nevertheless this doesn't decrease the stress and tension he experiences from the separation from his closest friends – his roommates, the staff and some of the other users.*

### **3.6 Final 'pre-moving' assessments of the residents, in the Home**

A realistic and in-depth assessment of the abilities of the children and young adults is necessary before they relocate, so that their development can be followed and future planning can meet their needs. A number of instruments are needed for this process – clear and precise criteria by which development will be judged, systematic checks to be used for following their development. In this way a whole assessment system is created. The first stage of its implementation takes place in September, a month before the final move. There is a short introductory training on the instruments, which teachers in the Home use to assess the children and the young adults before their move to the new services.

*"This however was not enough and the results from the assessments left all of us doubtful about their reliability and exactness. Nevertheless we took that risk and that is how we put into place and began the systemized and detailed assessment which we were about to use in the future."*

*Margarita Parmakova*

## **Interview with Peter Hristov, Social Work Coordinator, The Cedar Foundation, December 2010 to March 2011**

### **How did you start working for The Cedar Foundation?**

*I found out that the foundation was working on the closure of the Gorna Koznitsa home and that they were looking for a person who had experience in deinstitutionalization. I applied and they offered me the job. I worked for The Cedar Foundation a year and three months, until March 2011.*

### **What were your responsibilities?**

*I participated in the closure process, in the users' assessment, identification of their needs, and preparation of the old institutional staff so that they were less concerned about the closure of the home. We planned the transition process together with the Home director and other Cedar staff, focusing on the placement process for the young adults, training for the new staff, training and supervision of the staff in Marchevo and Ardino, as well as in Kyustendil and Bobov dol. I identified and prepared another NGO to run the services in Bobov dol, and helped develop and implement rehabilitation programmes. People talk about deinstitutionalization but we should not forget that this is a very complex process and it spans a lot of social prejudice. Without knowing, most people commit social exclusion, not social inclusion. And this was a problem in all localities where we worked, to varying degrees.*

### *And what were your findings from the children's assessments?*

*Basically what I expected. The users functioned far below their real levels of abilities, given that they had lived in a home and that the psychiatric deprivation there depleted their potential considerably. First, they communicated far below their true abilities because they hadn't communicated. They were neglected. The second thing which was observed, typical for an institution, was that many suffered from concomitant conditions such as incontinence. This was largely because of the social defenses of the staff, who were conscientious, but at the same time isolated from these people. They used diapers as there wasn't anyone to take them to the toilet.*

*On an institutional level, other main deficits were that the assessments they used previously in the institution weren't accurate. They weren't accurate for the simple reason that the medical documentation kept in the Home was inaccurate. For some residents the documentation said that they functioned very well, which wasn't the case; for others, according to the documentation they shouldn't have even been alive yet they were vital, smiling people. There was a big discrepancy between documentation and reality. Also, the diagnoses of most users didn't correspond to their actual conditions. If the international classification of diseases had been used, and it was indicated that they had severe learning disabilities, other concomitant conditions should also have been identified.*

*Another thing which they had because of their life in an institution is that they functioned socially at a very low level, they acted purely on instinct, demonstrating knee-jerk reactions – they lacked the ability to function in a group, to observe personal and other borders...this was a very disturbing thing which was difficult to handle in 2010. I don't blame anyone, simply this was the reality. Some of the users had long-term illnesses, such as hepatitis. Also, because many of the users were given various medications without full blood analysis, it turned out that they had damaged livers. Other serious conditions were evident, not resulting from their disabilities, but resulting from the way of life they led. Some of the users were unable to identify themselves sexually, people who were over 18. There was a boy who wore women's clothes and carried a purse.*

### *How should assessments be conducted?*

*The assessment should be based on skills – whether they can talk, what they can do. The assessments we conducted took a lot of time, but I must admit that that I continue observing them. This is an on-going process. It also included an assessment of the needs and the deficits of the staff in order to see what they should build upon so that they could work with children and young people more effectively.*

### *Is there something else you see as a problem in the deinstitutionalization process?*

*Many new services risk failure because of the problem with the lack of leadership which is prevalent in Bulgaria. Especially in small localities, social prejudices could lead to failure of the services. That's why there should be on-going supervision and training of the staff. Another problem is the lack of supportive services. They should be developed – the services should be structured around the personality rather than the personality around the services.*



## **LOOKING BACK, LESSONS LEARNT:**

Here we share what we learned, as we worked to prepare the children for their new placements:

- **Allow enough time for preparation**

*“Moving the children and the young adults from the Home to the new services took a few hours but the preparation for it required a lot of time, work and other resources. Such a turning point in the life of every person requires preliminary psychological preparation, acquired and formed basic skills and habits, essential for one's survival. And for this a well-organized and planned transition period is needed in which skills for independent living are created via different activities. The users get to know their new home and the community. It is important that this transition is smooth and painless and to create a feeling of security instead of fear of the unknown”.*

*Margarita Parmakova*

- **Use old connections for facilitating a painless transit**

Separation from people who have been with and supported one for years is painful for everyone involved. Despite the poor conditions in the Home and the inadequate, outdated work methods used there, the majority of the residents and staff in Gorna Koznitsa had developed a relationship of attachment, which the children and young adults relied on. By cutting this connection they felt completely abandoned and helpless. These relationships shouldn't be underestimated but instead should be analysed and used for the painless transit to the new stage of their lives.

- **See the client's best interest as the main priority**

It is crucial that decisions are made with the client's best interest as the priority – **not** the interests of the municipality, service, staff, etc., except where they parallel the best interest of the client.

- **Involve the clients when deciding about their placement**

It is also very important for all involved to remember that all clients have the right to participate in the decisions made regarding their placement, as much as is possible. Cedar has found that, especially for many people who have worked with the institutional system for years, it is difficult to view the residents as people with the right to determine their own destiny. We should always treat each client – and all discussions or decisions regarding that client – with the utmost respect for the human rights with which he/she is endowed. They can be included in a number of ways:

- insist on the client's presence in every meeting where he/she will be discussed;
- take the client to visit several possible communities/residential services *before* deciding where they should be placed, and find a way to let them express to you their preference;
- explain at every step of the way what is going on and what their future may hold – they may or may not understand or respond, but this is their right!

- **Enable the clients to express their preferences and consider them**

Always be very observant of the personal preferences of each client, and make sure they are noted in their individual care/support plan. When these preferences are noted, it will be easier to form and discuss decisions which are more based on the individuality of the client (not viewing him as an object):

- pay very close attention to the relationships which the client holds dear, with clients, community members, or staff. Do whatever possible to keep those relationships intact.
- make note of any and all personal preferences the client may have – does he/she feel better in a smaller, more enclosed space, or does he/she need lots of room? Is he/she comfortable surrounded by others or will he/she need somewhere where he can be alone? And do whatever possible to meet those individual needs.

- **Get everyone on board who is involved with client's support**

Make sure that all meetings, in which major decisions will be made regarding placements, are attended by a multidisciplinary group who know the client well. This should include, if possible, all specialists who work with the client, his/her guardian, any staff who know the client and his/her preferences well, NGO representatives if any and local authorities. Discuss each case individually and thoroughly before coming to a decision.

- **Build in a sufficient transition period**

It is very important to build in a transition period for any relocation process, with a transition plan and risk assessment conducted for each and every individual. This is not only for the good of the client (and his/her acclimation to new surroundings), but also for the benefit of staff and services who will be welcoming the new client, as it can mean the difference between preventing and causing future problems, especially with behaviour.

- **Have in mind the long-term consequences of your decisions**

When making decisions regarding placement, keep also in mind the long-term consequences of these decisions – will the service be a suitable place in which the resident can reach his/her full potential? Will the client's family members be given an opportunity to reconnect in the long-run? Will the community in question offer opportunities for the client once he/she turns 18 years old?

- **Use consistent criteria for all users**

Use the same set of criteria for deciding placements for each and every individual. Make sure that the criteria are determined before the individuals are discussed.

- **Determine placements well in advance**

Determine placements as far in advance as possible, so as to provide the opportunity for a thorough transition process.

## 4. Preparing the staff

The Cedar Foundation has a regular presence in the Home, from the moment the closure is definite. With permission from the Municipality of Bobov Dol, Foundation representatives are present at all-staff meetings. This provides the opportunity to communicate with staff members consistently.

Great care is taken in how the closure is presented to the staff in the Home in Gorna Koznitsa, as reactions of the staff to the imminent closure of the Home vary greatly. Some staff members view it as an end to their employment, automatically assuming that they will lose their job and income. Some staff members assume that they would automatically be transferred to the new services, without needing to go through a hiring process. Cedar is very honest about what staff could expect by discussing:

- The inevitability of complete Home closure (staff had gotten used to NGOs working temporarily within the Home, then “disappearing”);
- Anticipated time frames for closure;
- Transparent hiring process for new services, open to all Kyustendil and Bobov Dol community members;
- Complete change from current methods used, and the expectations of them during the transition time in the Home:
- Staff presence at all mandatory meetings and trainings;
- The acceptance of upcoming changes with an open mind whenever possible;
- The hospitable treatment of foreign trainers and experts (some problems with this do initially arise).

At the same time Cedar also tries to focus on the benefits which these changes will bring to staff members in the workplace. The Foundation regards as very important the concept that providing better, person-centred care will give more job satisfaction; it reminds them of this frequently, at every opportunity. More importantly, however, it tries to give staff members as much opportunity as possible to see the upcoming changes as a way to improve themselves professionally.

*“It was essential for us to maintain a balance of sorts – to give staff every chance to prove their dedication and desire to adapt to higher expectations, but also to ensure that those who would be hired for the new services would provide quality care to the clients. In the end, all were treated as new applicants for new job openings, who came to the table with the slight advantage of already knowing the clients (depending on how willing they were to become “deinstitutionalised” themselves. Eventually some were hired, some not, for the new services.”*

*Lindsay Saltsgiver*

A total of 21 staff members apply and are invited to an interview for the new services. Twelve of them are hired initially in the following positions: service manager, accountant, 3 team leads, and 7 social assistants. Later, two more ex-staff members from the institution are hired.

### 4.1 Preliminary training in the institution

As soon as the decision is made to fully close the Home, Cedar recognizes that it is best to start working with the staff as soon as possible, in the institutional setting.

*“We knew that we would need to begin the transition process in the Home, before the relocation, and began ‘retraining’ the staff in person-centred care long before the changes were to*

take place. We aimed to start building the foundation of the philosophy upon which we felt the new services should be based, to give staff a head start in learning new methods and philosophy, and to begin assessing which staff members would be able to accept such a big change in the way they work with the clients. This also gave us an excellent opportunity to be as transparent as possible in the process, in front of the staff – to demonstrate to them that we intended to change not only the location of the residents, but the whole way in which Bulgaria works with people with disabilities. We wanted to show to them that willingness to change, openness to accepting new ways of working, and hard work, would ultimately work in staff members' favour when it came time to hire for the new services".

Lindsay Saltsgiver



Utilising help from various volunteers (Erin Smith, Jennifer Watters, and later Mary Crane and the Greenfields group), Cedar devises and implements a training program, mandatory for all staff of the Home. Topics include:

- Effects of institutionalisation;
- Person-centred care;
- Privacy, Dignity and Principles of care;
- Trust and Communication;
- Teaching strategies;
- Behaviour management (multiple sessions);
- Occupational Therapy overview.

### **Assessment**

After several phases of training, the Foundation attempts to assess the staff's understanding of the topics learnt through a comprehensive test. While it is clear that this method will give only cursory information on how much the staff had learned, it is the only way possible considering the environment of the institution.

*"What we didn't expect to find is that many of the staff members had not taken an exam in years and had no test-taking skills; we also gave them the option of taking the exam orally. The majority of the staff demonstrated varying degrees of willingness to change their practices for the better of the clients; a small handful resisted change to the point where it became clear that they had no desire to move on into the new services, with its different philosophy."*

Lindsay Saltsgiver

### **Supervision**

Cedar also attempts to implement a short-term 'supervisory' program led by Jennifer Watters, a professional in the field in UK and Cedar Foundation volunteer. Despite the fact that supervisory programs had been mandatory throughout Bulgaria for years, staff in the Home have never been properly supervised and in general are wary of having another professional, especially a foreigner, accompany or observe them during their

work duties. While the Foundation focuses heavily on the benefits of such a program on the professional development of the staff, only a handful of staff members utilize their sessions adequately, and since at that point there was not enough professional manpower available the program had to be suspended until a later point in time.

*“The biggest challenge we met while training the staff was that it constantly seemed as though the institutional model would prevent implementation of new methods; for example, when discussing teaching methods and ways to break down a simple independent living task into its multiple steps, it was clear that no one in the institution would have the time to help individual residents learn these skills during their normal daily routine.”*

*Lindsay Saltsgiver*

Despite the many obstacles, however, Cedar does consider the training programme a success. The staff at the very least is introduced to best practices reflecting the philosophy upon which the new services would be based. Many of the staff members make sincere attempts at changing the way they work, albeit with great difficulty in the institutional environment. For example, instead of changing a client's diapers in front of all the other clients in the room, most caretakers attempt to complete such a task in the privacy of another room or behind a curtain, where possible (to maintain the privacy and dignity of the client).

This experience also makes it very clear to Cedar that all training which will be conducted with staff of the new services needs to “start at the beginning” – to completely overhaul the way in which they view work with people with disabilities.

*“Nothing demonstrated to us more clearly the fact that **staff also becomes institutionalised after years working in an institutional system**. They had, for the most part, stopped seeing the clients as individuals with individual needs, and had given up on the idea that the clients can learn new skills or take care of themselves to any degree. We heard many times from staff, even dedicated staff that clearly cared for the clients, the argument that any given client cannot dress himself or learn how to use the toilet because he is with intellectual disability. We understood at this point just how much re-training everyone would need.”*

*Lindsay Saltsgiver*

## 4.2 Administrative obligations: Hiring and dismissal of personnel

The dismissal of staff from the Home in Gorna Koznitsa begins a few months after the transfer of the first young adults to the protected homes in October 2009. With the decrease in the number of residents, the number of staff must decrease as well. In March 2010, a Commission for Dismissal is created in the Home and a full staff assessment procedure is undertaken using clear and precise criteria – staff members receiving the lowest number of points are released first. Staff members' presence at and results in the preliminary training stages are both considered, and are included in the factors measured in the point system. The assessment and dismissal process, administrative and paperwork procedures and the division of responsibility among remaining staff members is approved by the Labour Inspectorate, the Employment office and the Commission for dismissals.

The procedure for hiring new staff in the SGHs begins at the end of May 2010. The first stage is the creation of job descriptions for the different positions for which interviews are to be announced. This is very important not only for providing more information to people who wished to apply but also for distinguishing the difference between candidates' hitherto understanding about care staff in the institutions (hygienist, baby-sitter, teacher, etc.) and the new position (social therapist). Hundreds of packets of documents are printed and distributed for this purpose, containing a list with the necessary documents for application, job descriptions for the separate positions, information about the philosophy of the new service, directions where the documents can be filed, the deadline, and contact information. The information is advertised in the local cable television and newspapers and packets are placed in the municipality and the local labour office.

Nearly 200 CVs are submitted, and processing them takes one week. The open positions are for a manager, key social worker, team leaders, social therapists, rehabilitators and accountant. The first interviews for service manager begin in June 2010. Participating in the Commission are representatives of the Cedar Foundation and one representative of the Social Activities department of the Kustendil Municipality. Cedar selects the Service Manager first, so that he/she can participate in the Commission for the remainder of the positions. Seven highly-qual-

ified persons are interviewed, but after careful consideration the Foundation selects Margarita Parmakova, the current Director of the Home in Gorna Koznitsa.

*“Choosing the Service Manager was the most difficult of all of the positions, and we thought long and hard about our selection – we wanted to hire someone who had a very good knowledge of the social service sector in Bulgaria, but were not so entrenched in the system that they couldn’t be open to change. We were looking for someone who would work hard and love what they do, who had strong ties somewhere in their life to vulnerable groups, and who would be open to and capable of helping us make very big changes in the sector. We needed someone who could delegate, handle staff issues with a strong hand, but still be progressive, nurturing and demonstrate good leadership skills. We did not hire Margarita because we knew her, nor because she knew the children. We hired her because she fit the description best, out of all the candidates.”*

*Lindsay Saltsgiver*

The next stage brings the interviews for a Key Social Worker. Following these are interviews for Team Leaders, Social Therapists, Rehabilitator and Accountant/Administrator.

*“The interviews for social therapist were the longest and most demanding because of the large number of applicants for this position. The interviews lasted for days and were starting at 9:00 am, sometimes at 8:30 and continued until 6 pm. We had a list with our interview questions and the list was different for the different positions”*

*Margarita Parmakova*

Unfortunately only the manager participates in the selection of new staff because of the large number of qualified candidates for team leads, of whom only three are to be selected. Since this decision takes some time, it is not possible to have team leads represented in the jury panel.

*“We had a very difficult task since we wanted our new staff to be the best people – to have the capacity, an innovative look towards persons with disabilities, to be positive towards change and most of all to be people with big souls, ready to share the pain and the joy of the children and young adults in the service, to support them, to respect and stand for their rights.”*

*Margarita Parmakova*

## ***Interview with Anna Philipova Team Leader, SGH 2***

### ***What is the role of the Team Leader?***

*I fulfil the role of the person who should be everywhere and be connected with everything and everyone. I am also the person who supervises the social therapists, who is part of the Central Management Unit and has the main responsibility towards the children. The person who takes them to the doctor when their case manager is not on shift, and is the key contact point for everyone. I also have administrative duties.*

### ***What does your day look like?***

*I like to say I am a very happy person since every morning when I come to work I see a playful child’s face and hear the words: “Good morning girl!”. That is how my day starts. Elena meets me every morning at the door with a hug and a kiss and these words. Then she shares with me what she did the previous evening. Whether she behaved, whether there were problems... Then I read the report book. If there have been incidents, we need to see how to fix what has happened. If there are sick children, I go to the doctor... Then we have lunch and do all the other tasks. I go to the shop every day to buy yogurt and bread for the dinner. Georgi almost always comes with me. He insists on that. Also he likes to help me take the products out of the storeroom.*

### ***What is your shift?***

*I work from 8:30 am to 4 pm but I never leave then. There is always something more to do. I always come when I am needed. The team knows that when a doctor is coming, I am the first person to call, even before the doctor, so that I can*

be here when they come. I also take shifts if one of the social therapists is on sick leave. I take the children to the Day Care Centre, now – with the driver; before, I was driving the bus myself.

#### **You have a lot of administrative work...What does it consist of?**

Making the food menu and shopping lists, preparation of a monthly shift schedule, filling in the presence form...Also I am the person who distributes the medication. We have a child with heart problems and it is essential for him to be given the medicines on time.

#### **Are all these reports needed?**

Probably. That required by the law. At home I don't make reports to anyone on the type and quantity of the ingredients I put in the meal...And I think they are too detailed. The schedule is ok. But the host book, where the grams of each ingredient are described, in my opinion, is something that is not suitable for this type of service. At home I do what everyone else does – if I want an apple, I just have it.

#### **How many people comprise your team?**

Eight, including me. We have team meetings every two weeks. We discuss the work and the forthcoming activities and events...My team is very varied. Everyone is very different as an individual but they all support one another. Every shift tries to help the next one so that there is more time for the children left.

#### **Which are the main challenges in front of the Team Leader?**

It is very difficult. If I am too fast, the other team members will stop me. The work won't be moving ahead. We need to walk in one speed, together.

#### **Is there something else you would like to add?**

To me it is great that I have been given the opportunity to work here. In Bulgaria it is hard for a young adult who has just graduated to get the job they want doing. There is always someone with more connection, the "right" friends... Whereas I was given this opportunity here and not only this but also to develop. I started as a social therapist – I really wanted to do this job. And five months later I was already a Team Leader. I have been in this position for a year now.

## **4.3 Induction training and Orientation**

Once hiring for the new services in Kyustendil is complete and Cedar signs the contract for service provision with the Municipality of Kyustendil, it moves on to the phase of Induction Training for all staff members who are to work in the new services. Induction training and orientation is a common mandatory practice in established European services. It is meant to:

- provide the foundations upon which new staff members' practice is based;
- provide new staff with essential safety and security training before they have any hands-on practice with the clients;
- introduce staff members to the client base safely and gently; and to
- provide employers with the opportunity to assess the strengths and weaknesses of the staff member and needs for further / on-going training.

#### **Induction Training:**

Peter Hristov (a clinical psychologist working for The Cedar Foundation and temporarily sponsored by the British-based organization TBACT) works with the Foundation during the transition period. He designs a training program, which includes all of the sessions conducted in the Home, as well as others such as:

- Clinical aspects of Intellectual Difficulty
- Therapeutic community (creating a family-like community within the service, which interacts with the outside community)
- Teams and teamwork
- Case management
- Documentation and confidentiality
- Individual care planning

- Ergotherapeutic assessment
- First Aid and CPR (through off-site training at the Bulgarian Red Cross base in Sofia, paid for by the Cedar Foundation)

There is a strong focus on discussion and case study during training, and Cedar succeeds at creating a very positive atmosphere within the training group. Attendance at all induction training sessions is, of course, mandatory. Due to time constraints, training takes place during one full-time week, several weeks before the opening of the new services.

*“Our biggest challenge during this phase was the lack of time – many of these training sessions should have been expanded to provide more thorough information; unfortunately, however, several factors limited the time we had available. Political and financial pressure to close the Home by late September gave authorities the impetus to demand immediate closure; we were unsuccessful in our attempts to lobby for two more weeks for training purposes. Additionally, staff was asked to give their time, without pay, to complete training (though we did provide pay, at half salary, for the time spent during training, after successful completion of three months’ work and continuation with the service.)”*

*Lindsay Saltsgiver*

### Observation and team formation

Cedar carefully observes staff during the induction training so as to be able to form effective teams for the new services. The Foundation team bases their decisions on the following factors:

- preferences of staff member – target group (youth or children), location, team leader;
- children with which staff member felt close;
- productive / positive relations between staff members;
- variety in each group, based on most outstanding characteristics of staff members – artistic creativity, athletic ability/interest, leaders/followers, mild-mannered/boisterous, etc. We tried to create well-rounded teams for each group of clients.

*“I must admit I was pleasantly surprised with the initial trainings. The good news was that the staff that wasn’t from the home wasn’t burdened by the system itself. Some gave up, others not. We used the experience and the confidence of some of the people who had worked at the home to bolster the others’ confidence. We worked with the staff on accepting and embracing the idea about the rehabilitation of the person, to continue looking at these users and clients as human beings and to start treating them as they might treat their own children. It’s a complex process and to be only conscientious is not always enough. Many things are written, but are not practiced. We had to be very subtle so that the staff members from the home didn’t lock themselves into institutional thought any further. The staff came from different experiences and education, and with different attitudes, and we had to use their positive qualities in different ways so that the things could move forward.”*

*Peter Hristov, Social Work Coordinator, The Cedar Foundation,  
December 2010 – March 2011*

### Orientation

During two orientation weeks, Cedar holds a summer day camp with the help of youth volunteers from the UK, and staff teams are given the opportunity to work together to prepare the houses for the arrival of their clients. The goals of orientation are as follows:

- to give the staff the opportunity to meet the residents in as positive an atmosphere as possible, without the pressure of being directly responsible for their well-being;
- to help the clients slowly get acquainted with the new staff and new surroundings of the services;
- to make the experience as positive as possible for all involved (staff and clients), through a series of pre-organized activities and outings;
- to observe teams in action in order to make final adjustments to groupings if necessary;
- to promote team-building through completion of tasks in anticipation of clients’ arrival (purchase of small household items, preparation of team schedules, etc.)

During the first week of orientation, staff works with their assigned groups of clients on organized camp-like activities (tie-dyeing t-shirts, taking picnics, etc.) This gives them a chance to meet the groups, with

which they will work, and they are encouraged to develop personal relationships with individual residents – this would later be developed into the case management program – as much as possible. During the second week of orientation, teams work again with their residents but more closely in the setting of the houses/apartments themselves. They are provided with small budgets and assigned the task of creating opportunities to decorate the houses according to the tastes of the residents, wherever possible. They also work to complete a varied list of tasks within their teams – assigning different roles to different team members, adjusting the upcoming schedules for the first month of work, and taking breaks together to get to know one another better.

*“We hired and trained three more staff than we actually needed, assuming that at least one or two staff would drop out or need to be reconsidered after orientation. Our contingency plan, should all staff members stay on, was to openly inform them from the outset that several members of staff may need to play the role of substitute caretaker (for sick leaves, etc.), at least during the first several months of the service, until it was clear who would continue and who would not. As expected, reaction to the target group was mixed among those staff members who had no previous experience with people with intellectual disability, and two staff members decided during orientation that they no longer felt the job was right for them. The third (extra) staff member became a substitute but eventually took the job full-time when one more staff member resigned after three months’ work”*

Lindsay Saltsgiver



## LOOKING BACK, LESSONS LEARNT:

Here we share what we learned, as we worked to prepare the staff for what lay ahead.

- **Treat the ‘old’ staff with respect**

It is really essential that staff who have worked in the institution for years are treated with the respect they deserve – they, too, have often survived horrible working conditions in a thankless job with little pay – just another side effect of the institutional system. Thus openness and honesty about upcoming changes, which will inevitably affect their lives is the least we can do when working with staff. Giving them a chance to prove themselves is the only respectful thing we can do. ‘Old’ staff who are hired to work in new services can also help new staff learn about the clients.

- **Put clients’ interest first**

At no time should intolerance toward the clients, a negative attitude toward changes or the people implementing them, or the inability or unwillingness to work to improve the lives of the clients (to say nothing of abuse or neglect) ever be tolerated. Every decision made at every stage of the project should be made *in the clients’ best interest*, and if staff, authorities, or other experts are unwilling to accept this then they should have no place moving on into the new services, or being involved with the project at all. Expectations for staff should not be lowered for the sake of convenience or to save someone’s job.

- **Put in place assessment and supervision**

When implementing a theory-based training program before the Home is closed, be sure to put into place a simple but effective form of assessment and supervision. It is best if the supervisor(s) are available on a regular basis and can form positive relationships with the staff in the institution. This will give staff the support they need to transition into a completely different style of work, as well as improve the chances that residents will be included in key decisions during the process.

- **Do not rely only on the experience of the old staff**

Staff members working in an institution are also themselves highly institutionalised, with no exception. It is important to realize that when beginning to work with staff they will need a complete overhaul regarding principles of care and methods for working with people with disabilities. Do not neglect this and assume that it will come automatically from staff members who have experience in the Home.

- **Be open-minded when interviewing staff for the new services**

We have in many cases been surprised about which hired staff have been successful and which have not been so effective. It is very important to have creative, energetic people on staff, people who will try to improve or build upon the systems already set up in the service. However the number one most important quality a good staff member should have is a heart for the job – the patience and caring personality required to work with such a difficult target group on a day-to-day basis. The most ambitious, educated, or intelligent person isn't always the right fit for the job.

- **Avoid “I know this person” criteria**

Make sure you avoid falling into the trap of hiring people because they know you, or know someone else of importance. We continue to be surprised by the prevalence of this practice in Bulgaria. While you may inadvertently find quality staff through such channels, your top priority is the quality of the service provided. This means giving all potential staff members equal opportunity to be quality staff members. The clients don't know, and don't care, who knows whom – their best interests should always be at the heart of every decision you make.

- **Be prepared for changes**

Most people, when they apply for this type of job, unless they have already worked with people with intellectual disability, really have no conception of what they are getting into.

Be prepared to deal with a certain level of shock on the part of new staff, and always plan for the inevitable few who won't want to continue, or who should not be taking a spot among the staff.

- **Use the preparatory work as team-building**

Cedar has found that the best team-building (at the beginning of a service) can take place during the collaborative efforts of the team to prepare for the upcoming arrival of their clients. We also suggest providing team members with a bit of autonomy and an opportunity to be creative, which can lead to more effective teams with more of a sense of ownership over the work that they do (see Chapter 5).

- **Train the staff in new policies and procedures early enough**

We made the mistake of not thoroughly training the staff in all of the new policies and procedures before the services opens (we were still developing them at that time, and conducted training in these at a later date). While such documents should not be the be-all, end-all of a service, they do help form the framework in which staff will be asked to conduct their duties, and due attention should be paid to this framework in a more timely manner.

# Phase Four: Moving and Adaptation



Moving out of a familiar place and into a new environment can be a stressful event for anyone. If the steps are planned out correctly, however, in the process of discharging vulnerable people out of institutions and placing them in new facilities, one can avoid creating chaos and trauma in the lives of service users.

In this chapter we chronicle the move itself, both physical and administrative, different reactions of the children and young adults, and the steps Cedar took to help everyone adjust to the dramatic changes that were taking place.

## 1. Logistics of transition and moving

### 1.1 The first residents leave the Home: Marchevo and Ardino

During October of 2009, the first ten residents move out of the Home in Gorna Koznitsa, into Protected Home services for adults with intellectual disability in the communities of Marchevo and Ardino. As mentioned in Chapter 3, Cedar designs and implements transition plans around this time, and convince the authorities to allow a one-month transition period before the move would take place. The transition period, in more detail, consists of the following:

- Two “getting to know you” visitations to the new services, accompanied by Gorna Koznitsa staff, during which:
  - Gorna Koznitsa staff holds individual care meetings with each resident and new service staff;
  - Clients participate in organized activities with the clients already living in the service, including eating in the dining room;
  - Clients take walks and tours to become more familiar with the new facilities and surrounding community;
  - Each Gorna Koznitsa client has individual time with the staff of the new services;
  - Cedar conducts assessments on the needs of the new services, for further support;
  - Cedar shares and organizes the necessary paperwork – care plans / client files, etc.
- Conduction of risk assessments, individual for each client
- Recording and discussion of observations – reactions to new environment, potential first friendships, potential pitfalls during the moving process.

Moving itself takes a total of three days, again a method utilised to help the residents cope with the adjustment as smoothly as possible. Gorna Koznitsa staff travels with residents to the new services and stays for two nights. They spend time with the clients and their new caretakers, and help the residents decorate and organize their new rooms, before saying their final farewells and returning to Gorna Koznitsa. Staff also uses the opportunity to pass on appropriate final documentation as needed.

See Cedar Foundation sample Transition Plan in Appendix 4.

## 1.2 Timing and phases of moving – the Home empties out

The closure of an institution and the synonymous creation of new social services in the community consist of many different stages and phases which need to be implemented in parallel. Thus, as is the case with the Gorna Koznitsa project, planning the timing for everything – ‘the big event’ – to happen during a small window of time needs to be as precise as possible. Authorities originally expect the closure of the institution in Gorna Koznitsa to occur during the spring of 2010. However, due to construction delays and delays in the issuance of the necessary Act 16 documentation for bringing the new structures into use, relocation is pushed back to the fall of 2010.

By that time, pressure to close the home has grown considerably, and the final phases before relocation are ultimately rushed. Authorities state that the primary reason for this accelerated deadline is financial – the difficult situation in which the municipality of Bobov dol would find itself, if the Home does not close as quickly as possible. The “heating season” is fast approaching, and there are no funds allotted for coal for heating the institution. On top of this, technically the money allotted for each client is scheduled to move with that client (see Section 2 of this chapter on financial aspects of moving). Thus the municipality of Bobov dol also would be left without finances to continue paying staff in the Home should the moving process be drawn out much longer. Therefore Cedar has to react quickly and re-plan the phases for moving the residents.

Physically conducting the move of 48 people is complicated, and if not organized properly can cause more trauma than is necessary to such a sensitive target group. The Foundation, and the Municipality of Bobov dol, organise the move out of Gorna Koznitsa into Kyustendil services to occur in the following fashion:

### Kyustendil

PHASE ONE – 7 children, Kyustendil – House / Staff team #1:

- 1 moving day + 6 days adjustment period.
- Staff from Team 2 alternates between assisting Team 1 with daily activities in the House (cleaning, cooking), and covering shifts in the Home in Gorna Koznitsa.
- Team 3 alternates between completing decorations/renovations on apartments, and covering shifts in the Home in Gorna Koznitsa.

PHASE TWO – 8 children, Kyustendil – House / Staff team #2:

- 1 moving day + 3 days adjustment period.
- Staff from Team 3 alternate between assisting Team 2 with daily activities in the House and covering shifts in the Home in Gorna Koznitsa.

PHASE THREE – 8 young adults, Kyustendil – Apartments / Staff team #3:

- Final moving day out of the Home in Gorna Koznitsa.
- Team 3 begins work with clients (all teams now working with clients in new services).

### Bobov dol

PHASE ONE – 10 young adults – SGH 1:

- 1 moving day + approximately 10 day adjustment period.

PHASE TWO – 10 young adults – SGH 2:

Final moving day out of the Home in Gorna Koznitsa.

Staff in the Home in Gorna Koznitsa work with the new service staff and the clients themselves to pack personal effects and prepare for their respective moving days. The physical move is conducted as quickly and qui-

etly as possible, without long goodbyes or drawn-out packing, so as to lessen the potential trauma of the experience for the residents. Clients are included as much as possible, and most of them carry their own possessions to the waiting vans and cars to take the ride to their new home.

### 1.3 Financial aspects of moving: Does the money follow the child?

During the move the principle “Money follows the child”, though officially true, is not entirely practicable. The Home in Gorna Koznitsa has financial shortages already before the closure. The Bobov Dol Municipality is also in a difficult financial situation. Despite the fact that federal funds for the institution legally should not be utilized by the municipality for other purposes, and special funds were paid into the municipal account to compensate for the closure of the Home, the Bobov dol municipality has spent the money intended for the institution and their financial problems spill over into the institution budget. In reality the money is not reaching the Home, which puts it in debt to the water and electrical companies and the suppliers of food and medications for the residents.

The largest debt is towards the staff in the form of unpaid salaries and compensations, some of which are, at the time of this publication, still unpaid (June 2012).

Even more difficulties arise. A new compensated budget is created, by which remaining institution funds are to be transferred to the new services in Bobov dol, to be used to pay for building maintenance from October to December 2010. This gives the municipality great incentive to cut further the financial means for the Home so that more money is kept for the new service in Bobov dol.

No problems are encountered with the funding of a new service in Kyustendil, integrated in the municipal budget and after submitting a request for funding to the state, the necessary means are ensured from the moment of its opening.

### 1.4 Layoffs

The first staff cuts occur after the young adults are moved to the Small Group Homes in Ardino and Marchevo. They begin in March 2010 – half a year after the decrease in the residents’ number and the official decrease of the Home capacity.

On 27<sup>th</sup> September 2010, eight children move into the small group home No.1. Simultaneously, seven young adults move into the SGH in Bobov dol. This marks the beginning of the final staff cuts, which in all will take several weeks.

On 1<sup>st</sup> October 2010 the second group of 7 children move into the SGH No.2 in Kyustendil and seven young adults into the SGH in Bobov dol. At this point the second group of staff members is dismissed.

In the morning of 4<sup>th</sup> October 2010, two young adults leave for the institution for men with intellectual disabilities in Kudelin. Despite Cedar’s many attempts, it has not been possible to find a suitable alternative service for them due to challenging behaviour.

Later that day, two more groups leave the Home, eight to move to Kyustendil and six to move to Bobov dol. The last staff members go with them. Part of the staff will later start working in the SGHs. For the rest, it is the final working day.

The organization and planning of these moves is, at all times, guided by calculating the number of staff needed. Their responsibility is to ensure proper care and prevention of risk situations which could threaten the life and the health of the children and young adults. At the same time, it is difficult to organize as there must be staff present in both the new services and the institution. Part of the trained staff who will soon begin work in the SGHs is still working in the Home. Thus it is very difficult for them to be present in the two services. The preparation of the rooms, purchase of products and materials, food preparation and many other important preparatory details – clothing, personal accessories, medicines, documents, hygienic procedures before leaving – all of this happens simultaneously and is a responsibility of all the same people.



## LOOKING BACK, LESSONS LEARNT:

Here we share what we learned, when we moved the residents out of the Home and into their new services.

- **Prepare a detailed transition plan**

If at all possible, the transition out of the institution and into new services should be guided by a very specific transition plan, which favours client input during every phase. Transition plans should include plenty of time for the client to get to know the new surroundings, new staff members and other clients in the service *before the move takes place*. The whole process should be planned carefully to allow time for the client to take “baby steps” toward his/her new life – first several hours spent in the new environment, then perhaps a meal there, then perhaps spending one night, etc. If time allows, the client should be accompanied to spend a lot of free time in the new community before the move.

- **Take into account client’s choices**

Successful transition also means taking into account the choices made by the client, and giving him/her the opportunity to make these choices. The paint colour of a user’s room, the position of his/her bed in the new bedroom, the pictures which decorate the walls, these are all aspects of the new environment which can include the choice of the client and therefore ease the transition anxiety which so often accompanies a move.

- **Phase up the move**

Whenever possible, we recommend that any move be conducted in phases – again, planned out very carefully – so as not to cause too much alarm in the clients, or too much confusion or chaos in the actual move.

- **The money does not always follow the child**

Due to the complicated procedures related to funding social services it is often the case that the child or the adult leaves the respective institution whereas the state funding remains, until a decision is made for ceasing the funding. Situations can also occur in which a new service is opened and state money is given for its full capacity, before those clients actually living there.

- **The “money follows the child” system is not fully effective**

The money used for the opening of different social services becomes the priority, the main factor which defines the service whereas the role and the significance of the child or the adult who enters that service is diminished.

## 2. Adjusting to the new environment

### 2.1 Personnel

*“We were very impressed with the way in which staff handled the first several weeks of work in the new services. Most of them worked overtime in order to help get the houses in order and running smoothly, or to handle situations with individual clients as they arose. For the most part in the groups a very strong sense of teamwork was present, as staff members supported one another and shared the experience together. There were, of course, a great many growing pains as the first few days became weeks, and the first weeks turned into months.”*

*Lindsay Salts giver, Operations Manager, The Cedar Foundation*

Among the challenges Cedar faces are:

- Questions regarding schedules and shift hours, especially night shifts

- Learning curve on managing/handling the cooking in the service – during the first few weeks more is spent on food than was necessary, as teams adjusted to having to measure quantities and follow cookbook portions
- Lack of confidence in how to handle crisis situations with clients, and worries about being alone during night shifts
- Concerns about how to handle the medication distribution process in the groups
- Adjustments and finalizations of service policy documentation
- Initial reservations about using community medical services – staff are not used to calling emergency services or having such close access to doctors and specialists
- Indecision about what to do with the clients during the day, to meet goals of individual care plans

#### Easing Transition Anxiety: Staff

Of the utmost importance during training and orientation is the openness of Cedar to communication with staff members.

*“This was a very exciting, stressful, thrilling, and exhausting time, for all staff, and we made it our priority to be available and approachable for staff who were having a difficult time. Management staff and Cedar Foundation representatives were on call, at all hours of the day, and we did everything possible to support staff during this tenuous time. We also tried to encourage staff to develop a sense of ownership over their teams and residencies. They were still working with small budgets to make final adjustments to routines and features in the houses/apartments, which gave them more freedom to develop a sense of responsibility toward their work and their ‘family-style’ group.”*

*Lindsay Saltsgiver*

A few weeks after the opening of the service, the Foundation is visited by a group of experts from the Greenfields School in England, led by special educator and long-time Cedar volunteer Mary Crane, who assist staff in developing daily routines and activities for the children and young adults. The training is mandatory and staff members work with the volunteers in groups, focusing on individual residents. Caretakers are introduced to many new types of activities in which they can engage the clients, and the volunteers demonstrate effective methods for organizing the groups’ days and handling difficult behaviour. While staff finds this helpful and reacts positively to the visit, the management realizes that it is too early in the adjustment period for staff – both Cedar and service staff – to utilize the visit as efficiently as was needed. The volunteer group returns a year later, after staff and clients are much more settled in the service, and the training is much more productive.

The first few months after the service opening is also a time for observation of what kind of on-going training will be needed for staff. Cedar notices an immediate need for the following types of follow-up/on-going training:

- Handling challenging behaviours – prevention and reaction
- Conducting assessments
- Teaching independent living skills
- Working with service documentation
- Teamwork and leadership (especially for those in leadership positions)

## ***Interview with Dimitrina Stoilkova, Social Therapist in SGH “Siyanie”***

### ***What was your first working day like?***

*At the beginning I was a little bit stressed when I met the users. I wasn’t used to the children and the team. The beginning was difficult. The children would go into mass hysteria. For example, Ivan wouldn’t make contact with anyone, he isolated himself in his own world...while now he talks all the time, get involved in activities and this is incredible. The clinical meetings where we discussed cases on how to approach and deal with the different children and to solve the problems related to them were really helpful. I think we did very well with many problems.*

### *How did you overcome these feelings and how did you manage with the difficult situations at the beginning?*

*I observed children a lot. Started to get to know them. I also had information from the colleagues but as a whole I managed on my own. It was very busy and you had to react immediately. There were many team meetings and discussions and with the decisions taken by the team we overcame the problems. The most striking example for me remains Ivan who recently danced at one of the events. This was unthinkable at the beginning. Even, when I was on a business trip, he cried that I wouldn't be with him. Bonds are created. I'm stricter and at the beginning some of the children pulled back but later they themselves understood that this is for their own good. Everyone says that Ivan doesn't want to get involved in activities and I make him do it. I give him a potato to wash, or an onion and that's how.....step by step.*

### *What do you think is the biggest achievement of the service so far and how do you see the future development?*

*A centre for social rehabilitation and integration should be set up as soon as possible so that there are more possibilities for the children and young adults' therapy and activities in the community. The progress of children is our biggest achievement until now.*

## **2.2 Clients**

It is not realistic to think that with the closure of the Home and the placement of its former residents in the new services the problems are over and the easy part has come.

These are the most difficult two weeks for the children and the whole team. On the first and the second day the children are happy, taken by the euphoria of the new experience but on the third day they start asking when they will return to Gorna Koznitsa. The short transition and adjustment period is not enough for them to realize that:

- they have left the old Home in Gorna Koznitsa forever, and cannot go back;
- the new building will be their new home;
- a very small part of the people who have surrounded them for so long will be in the new home; and
- part of their friends won't be around anymore.

*"Imagine that all of a sudden you happen to be in an almost completely unfamiliar place with strange people passing by on the street, looking at you in an unfriendly or even hostile manner. Imagine that you are surrounded by many tall buildings, whose windows are lit up in the evenings like a Christmas tree and all of this makes you feel as though you are exposed all the time and that it prevents you from being on your own or closing your eyes. Imagine the sound of the children playing in the neighbouring schoolyard, and the noise of the engine of huge trucks passing by and at the same time you are feeling the loneliness of a lost child, a child who till yesterday had accepted the world in one way and today everything familiar is in ruins... That child, you, doesn't know where he is or what is happening. If we can look through the eyes of this child we may be able to begin to understand this horror, fear and panic which is hard to describe."*

*Margarita Parmakova, Manager of SGH "Siyanie"*

Cedar imagines that these are the feelings of all of the residents, both the children and the young adults. Many of them ask constantly about Gorna Koznitsa and when they can return because for them this is the only place of security, related to their hitherto life - their childhood. It takes a lot of time until they start seeing the good things in what they have received and begin to see the new houses as their home.

They have also lost many of the people upon whom they have relied for so long, people with whom they have established an emotional connection, who have been their friends and have supported them in difficult moments.

The environment in the building is also unfamiliar. The numerous, large rooms, the multiple entrances and exits, the glass doors, the access to different kitchen appliances and electrical equipment, which they have never before been close enough to touch, all of this confuses and puzzles them.

*“They touched unknown and never-before-seen objects and surfaces, and even though they felt like Alice in the wonderland this more likely puzzled them and made them feel nervous, which sometimes resulted in emotional breakdowns. At times the users displayed challenging behaviour and/or self-aggression due to their difficulty to accept the changes around them and the impossibility to fully understand what was happening.”*

Margarita Parmakova

## **Interview with Milena Dertlijska, Team lead of SGH 1**

### **What was your attitude towards closing the Home?**

*I was very positive and full of enthusiasm. I thought this was great for everyone and was happy that we were leaving this hell.*

### **Was this the general attitude?**

*Some were against moving the children, thinking that if something is created in the Home the premises would be better. To improve the conditions there. But it is a question of opinion and my opinion was that we had to move.*

### **How was the preparation happening? What do you remember from it?**

*There was very little time for preparation. It all happened very fast. We didn't expect things to develop in such a speed since this step had been postponed for months and years. And we didn't believe that it will actually happen till the last moment when we all of a sudden were in town... We always thought that the things might stop. So all happened very fast. But the staff has been preparing with the trainings, organized by Cedar, which had been taking place in the last two years, also with the presence of other British organizations providing training to us. So we still had some time to adjust ourselves to the idea whereas for the children and the young adults it was a shock.*

### **You participated in a competition and were selected for your current position. How did it go?**

*I always feel nervous at competitions... But it went well. The faces were familiar which was reassuring.*

### **How did you feel after the moving?**

*It was confusing for me. I imagined things differently.*

### **In which way?**

*I thought that only because I liked it, the children would like it too. That only because I was quickly getting used to the new situation, it would be the same for them. But it was exactly the opposite. Even now there are children who still need time. But then it was... hard to describe. There was even a moment when I thought I would give up. I didn't imagine the things this way. But as we got mobilized, step by step things started coming to their places.*

### **How did you help them with the adaptation?**

*I don't know whether we were very helpful in the beginning. The team was new and children were seeing them for the first time. There were only two familiar faces one of which was mine. It was a big shock for them. The new team was not able to handle the situation and the children couldn't get used to the new environment. It was very difficult. I didn't expect it at all.*

### **How did they get adapted?**

*Some adapted faster. It was easier for the younger ones. The older ones understand more. Teodor was most problematic. He has a difficult time dealing with changes, even today. He notices the slightest change and the open space makes him feel discomfort. He doesn't feel protected. In Gorna Koznitsa they were all staying in a small room and there was no space at all. And the space around him in the new home stressed him a lot as well as the daylight.*

### *Do you think more time is needed for preparation?*

*Definitely. We took them here three-four times before the move but for them these were trips. At least half a year is needed for gradual transition. It depends on the individual child or young adult as well. It is very individual. For some this was not a problem.*

#### Easing Transition Anxiety: Clients

The first two weeks are very difficult, but staff learns to help ease transition anxiety in their clients by any number of means:

- For staff, the first priority is to establish a connection with each child or young adult so that he feels supported. The members of the Central Management Unit (CMU)<sup>14</sup> sometimes spend hours trying to reassure a client. At these moments most children draw into themselves and don't allow anyone to approach them. Only people whom they know are able to reach them.
- Even the contact with a familiar person does not help with some residents. Sometimes a walk outside, or a game, is more effective than allowing the child to be drawn into loneliness and isolation. Small and seemingly insignificant factors are able to change their emotional condition, their sense of freedom; the opportunity to engage in their favourite activities or to hold a favourite object calms them down.
- The next step is making a contact with a GP, psychiatrist or psychologist. The psychiatrist who had cared for the children while they were in the institution visits the new residencies two or three times to see their living conditions but this is not adequate. She is often contacted by phone by the staff for advice and change of their medical treatment. For the most difficult cases the therapy is changed a few times per month.
- If things get out of control and nothing helps to alleviate the problem, the local emergency medical unit is called. The ambulance comes often during the first few weeks, to provide support, but clearly the medications they administer are only a temporary solution.

The adaptation process manifests itself differently in each child and they respond in different ways.

*Maria, 13, who has severe intellectual disability, has already gone through many different emotional states. In the institution she is neglected by the staff and is sometimes abused by the other users; she stays locked within herself and does not seek out contact with others. She often displays self-aggression, hurting herself by making big wounds on her head. She also shrieks, causes haemorrhages to her eyes. But in the last 1-2 months before the moving she seems calmer. After the first days in the new service however her behaviour dramatically changes. Maria has unlocked not only auto-aggression but also aggressive behaviour towards the staff. If someone – another child or staff member – is around her when she feels threatened or insecure and doesn't know how to react, she attacks them, trying to scratch them. Her screams sometimes continue all day long. She throws herself on the bed, kicks, lying on the ground, pushes chairs. All attempts of the staff members to console her fail. Maria often has episodes including severe shaking of her limbs and a strong desire to hit her head with her fist or against walls, doors and cupboards.*

*Staff slowly learn that sometimes she calms down if she lies in the bedroom and covers her head with a blanket, falling asleep like that and feeling protected. The blanket becomes a way for her to isolate herself from the surrounding world. Sometimes this doesn't help and consultation with a child psychiatrist is needed in order to change her therapy but often also the emergency centre is contacted and she gets a sedative injection. Staff continues to work on finding ways to help Maria calm herself.*

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*Rumyana, 12, always carries small objects with her – parts of toys, pieces of cloth and paper. This is her treasure from which she is never apart. No matter how much the staff tries to convince her to leave them in order to wash her hands or take a shower, she refuses and brings them with her everywhere – when sleeping, when changing clothes, when eating, walking, in the toilet, in the bathroom. She also holds her belongings close while lying in the foetal position and sits on the floor in the same corner in one of the dining rooms. She sits without moving or changing her position. She reacts very strongly if someone tries to move her or take something of her treasure, or if she loses something. She becomes very angry and behaves aggressively towards objects and people – kicks people next*

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<sup>14</sup> For more information about the CMU see Chapter 5, Section 3.1, "Staffing", subheading "Management".

to her, pushes and breaks chairs, pulls the window blinds...Once she roared for 24 hours. Attempts to change this behaviour only set off major crises.

A lot of time is needed for things to change and for the ice to break. Eventually the trust of both Maria and Romyana is gained.

## 2.3 Community

*"We will never forget this first reaction of some of the people from the neighbourhood who came to the opening of the houses. There was a small children's slide on which children from the community were playing and their parents were standing next to them watching. At the moment when our children approached the slide and tried to play with the other children, the parents pulled their children aside telling them: "Come here, leave them alone". It sounded rude and cruel; they were looking at the disabled children in a way as if they were lower quality people, as if they had a virus which could start an infection. And we didn't blame these people for their reaction because it was not their fault – rather we blame the state and its policies which for years had kept children and adults with disabilities hidden and didn't provide enough information on their existence and capabilities. We were determined to change this and started right there, right then with exactly these people. We conversed with them politely, simultaneously supporting the children in their attempts to contact other children in the spontaneous games."*

*Margarita Parmakova*

There are complaints from the neighbours that the children start screaming early in the morning and wake them up. Others clearly and categorically express their disagreement with the presence of the children and young adults in the area and raise the question of how the Foundation hasn't found some more suitable place for them, more remote and isolated.

### Easing Transition Anxiety: the Community

The first thing Cedar does is to try, through conversation, to provide quality information to the neighbours in the nearby shop and café. The aim is to help them understand that these are children and young adults like everybody else with their strengths and weaknesses, individual capabilities and needs.

Simultaneously Cedar discusses with the staff in the service how to provide information about the users without violating the rules of confidentiality or revealing personal information. They are advised to focus on the positive side of their clients' behaviour, their good qualities, what they like doing, what they do well and on their need for being understood and receiving human warmth.

Cedar takes every opportunity to invite people who are interested in the service and the users, to visit the building, to look around and to meet their residents. The Foundation doesn't miss a chance to invite the children from the neighbourhood to come and mix with the children from the service. And when the residents are taken out for a walk, Cedar tries to establish contact with the people around, to greet them, to start a chat and to call the residents by their names.

*"By identifying their personality we took them out of the common faceless mass and underlined their identity, significance and uniqueness."*

*Margarita Parmakova*

Some people show a vivid interest in what is going on in the houses and the yard, in the children and the young adults who walk in the streets. They often stop to greet the users and to express interest in what they are doing, where they are going and even to offer their help.

One such person is the owner of the café next door. He is interested in the life and destiny of the children. He develops a particular sympathy and attachment towards one child, Kamen. He wants to know about his health problems, what he likes and how he can help him. Sometimes he gives him sweets (with staff permission). And when Kamen disappears from the house, everyone knows where to find him – around the fence which separates the complex from the café. This person continues to support Cedar to date, never misses an opportunity to make gifts to the children and is always ready to provide the service with help when something is needed.

There are also children who are friends of the children in the service. When they enter the complex with their bikes for the first time, they are shy and insecure; some of them even ask their parents to allow them to enter but the shared laughter overtakes their fear of the unknown. The giant parachute they raise over their heads together in a circle with the service residents, looking up with expressions of elation, somehow unites them in the joy and happiness they feel in the moment.



## LOOKING BACK, LESSONS LEARNT:

Here we share what we learned, as we helped the staff, children and community overcome their anxiety associated with the transition:

- **Give the staff autonomy**

Personnel teams should be given as much autonomy as possible in the development of their individual residencies, so as to create a feeling of ownership over their work with the clients.

- **Support your staff**

Personnel need to know that they are supported by the management and municipality, and that an atmosphere of “we’re all in this together” is fostered during the transition phase for personnel. This is traumatic not only for clients, but also for staff, and the more they feel included and important in the process, the better they will adjust and the more calm and effective they will be when working with the clients.

- **Assess the needs of your staff carefully**

Careful observation should be conducted to assess the needs of the personnel during the first three months, to avoid burnout (or eventual resignation) due to the change, and to nurture good practices and goodwill among team members.

- **Expect the unexpected**

In the first days after the move of the children and young adults to the new services, expect the unexpected. Many unanticipated things can happen – total breakdowns, unlocking of behavioural problems, aggression, auto-aggression and other challenging behaviours, some of which you have may never seen before from the client. This is a normal defence mechanism in some individuals who in every way possible are trying to resist the changes, to deal with the unknown which all of a sudden is all around them. They themselves don’t know how to respond to these changes or how to accept them and what is expected from them.

- **Be patient**

The only cure for these situations is patience and an understanding of the problem. Have a good crisis plan in place before moving children into the new residencies and regularly update this plan. Give the children and young adults time to get used to the changes and to start accepting them.

- **Don’t blame the community**

In the same way the users are traumatised in the period of adjustment to the new environment and neighbours, the community also goes through its own period of trauma. It’s our obligation to help them to overcome their fears, artificially fed for years, to give them time in order for the prejudices to disappear.

- **Constantly work to raise awareness**

We should not forget our role in this process of healing, the key is in our hands and it depends on us when and how we will provide the correct information and how we will structure it. We are the new messengers of the users to the community, those who will create the new image of and attitude towards people with intellectual disabilities. The way they will be accepted depends also on us.

## 2.4 First round of assessments

Despite the wide range of individual client reactions to living in a new, drastically better environment, on the whole the effect is immediate and overwhelmingly positive.

*“At the beginning the focus was more upon the adaptation. Now, you can feel that there’s some level of integration but the first year was all about adaptation. Everything was new for them. [The clients] needed time to accept the world we wanted to provide for them. I was very impressed by the change in many of them – they literally blossomed in the new service. Before that their development was suppressed, even at physical level. And now, the attention they receive is of huge importance. They are part of our community network, and they live truly among us.”*

*Jenya Petrova, Services and Volunteer Coordinator, The Cedar Foundation*

Eager to track and document these results, for the first year of the service operation, Cedar collects data about the residents’ development every three months, so as to follow more carefully where more effort is needed and to keep up with the rapid changes that it is witnessing. After that, it collects data every six months.

The data after the first three months reflects, in general, an increase in skills development and an average decrease in difficult behaviours. See the table below for three-month data. The results are slightly distorted for the first two 3-month periods, because baseline data is taken by staff still working in the Home with minimum of experience and training in observation and assessment. However, as time passes and the same staff members gain experience in assessment, Cedar for the most part continues to see an average increase in skills and decrease in behaviour problems.

### Assessment Results, SGH “Siyanie”, Sept – Dec 2010

<u>Skill / Category</u>	<u>Children</u>
1. Independent Living Skills	+ 8,5 %
2. Mobility and Coordination in time and space	+ 4,1 %
3. Language and communication	- 1,5 %
4. Social-emotional development	+ 0,2 %
5. Behaviour	+ 6,7 %
6. Height	+ 1,6 cm
7. Weight	+ 1,9 kg



## LOOKING BACK, LESSONS LEARNT:

Here we share what we learned as we began the process of conducting assessments:

- **Train the staff in assessment before you begin**

Take care to thoroughly train staff in assessment **before** conducting baseline assessments, to ensure good quality data. Baseline data should be taken **before** the closure of the institution.

- **Make frequent assessment**

During the first year or so of the service (after closure of the institution) the changes observed in the clients will generally be fast-paced – it is a good idea to make assessments frequently during that year, in order to keep up with those changes and make adjustments to the individual care plans as necessary.

- **Share the results with staff**

Especially when there is progress made in some area of a client's development, staff should be openly congratulated and encouraged. Results could be posted in different areas of the residence. As always, results should also be used in the development of individual care plans.

# Phase Five:

## The new service: A Case Study of Cedar's SGH "Siyanie"

Every small group home service will be different, depending on the individual needs of its clients, the structure of the facilities, the surrounding community, and the service provider. However all services should be working toward the same goal – to provide its clients the opportunity to learn skills for life to the best of their ability, and to support them in being included in society to the greatest extent possible.

In this chapter we outline the specific features of the SGH service (named "Siyanie" by its staff), such as:

- Philosophy and goals
- Administrative structure and financing
- Staff job descriptions
- Policies and procedures, and
- Internal programmes designed to meet the service goals.

### 1. Management Outsourcing

In most cases, Cedar would highly recommend any municipality to outsource the management of the new SGH service to a competent NGO operating in the area. The exception would be when there is no NGO working with people with disability in the region, or when there is a specially-commissioned department in the municipality. This department should have the human resources available to effectively protect the rights of children and young adults with disability and work towards building *quality* services. This is no easy task. NGOs often exist for this sole purpose, and have access to specialists and volunteers who otherwise operate independently of the municipality. NGOs can commit their full efforts to the work in the service, whereas the social service department in the municipality is often overloaded with many different responsibilities and cannot afford to spend adequate time on developing one service.

#### 1.1 Procedures

The procedure for choosing an NGO to manage the services is just like any other tender procedure – the interested parties submit proposals to the municipality, which are reviewed on the basis of criteria defined before the procedure begins. When Cedar applies to manage the services in Kyustendil, its proposal includes the following:

- Copies of all legal documentation proving the existence and legal condition of the organization, *including all licenses necessary to legally manage services for children and adults with disability*;
- Information about Cedar's experience with managing projects or services, and recommendations commenting on our capacity to manage a social service;
- Documentation outlining the material and financial status of the organization
- A detailed plan for the service, including:
  - Description of the target group;
  - Short- and long-term goals and activities for the service;
  - Expected results, which can be effectively measured;
  - Plan for the organization of the service personnel, including their training, meeting schedules and supervision;
  - Activity schedules;
  - Budget (on the basis of the state allowances plus in-kind contribution), including the salary fund and expected expenses;
  - Strategy for sustainability of the service.

Cedar is well aware that for many municipalities, the categories regarding financing of the service will be among the most important in choosing a service provider. In fact, one requirement of the Kyustendil Municipality is the contribution of 20% of the budget to be in-kind, from the NGO. Considering the current condition of the Bulgarian state allowance, this factor is indeed very important in the decision. However, the Foundation stresses that **even more crucial in the effective management of a SGH is a good plan for the development of the service, and the pledge that the service will be based on a solid philosophy for working with people with disabilities – one which upholds their rights as full members of a community and which strives to help them reach their potential, through the continual development of the service itself.**

## 1.2 Contract between the municipality and the service provider

The Cedar Foundation signs a contract with the Municipality of Kyustendil on September 17, 2010 – two weeks before the clients move into the service – marking the beginning of the service itself and the start of service financing. The contract outlines the following major agreements:

- The service development program (as an inseparable part of the contract itself);
- The term of the contract (3 years, in Cedar’s case);
- The rights and responsibilities of each party – including financial – and procedures through which these responsibilities will be carried out;
- The conditions under which the contract can be interrupted or cancelled;
- The procedures through which disagreements or disputes are to be settled.



### LOOKING BACK, LESSONS LEARNT:

Here we share our recommendations on finding suitable management for the service:

- **Outsource the service management to a capable NGO.**

Management of the service should be outsourced to a capable NGO whenever possible. Municipalities should take great care and thoroughly consider their expectations for the development of the service *before* making the call for proposals. The process should be completely transparent from start to finish.

- **Meet the quality standards in the service.**

While the financial aspect of what an NGO can contribute to a service is important, more important is the organization’s commitment to developing and meeting quality standards in the service.

- **Get well acquainted with the contract before signing it.**

The contract between the municipality and NGO should serve both sides, and both parties should review, discuss and, if necessary, negotiate all points before signing.

## 2. Overview of “Siyanie” Philosophy and Goals

The SGH services managed by the Cedar Foundation in Kyustendil, for 16 children and 8 adults, are designed with the assistance of experts in the field, both in Bulgaria and from abroad. The Foundation is continually taking steps to improve the services and is flexible on its structure and programs in cases where progress can be more effectively achieved through different means. The service is defined by the framework in which Cedar operates:

- The priority is *always* to uphold the client’s rights, dignity, and self-determination;
- Regular assessment and improvement of service policies and programs is key to providing an effective service;

- The SGH is an integral part of the surrounding community, and our relationships with and reliance on other community services is integral to the service itself.

The aim of SGH “Siyanie” is to provide a true alternative to large-scale institutional care – 24-hour residential support in a small group setting, located in the community and closely resembling the family environment. There is an individual focus on the needs of every service user. There is also a therapeutic aspect, as its function is to create prerequisite skills for full social integration, including in the education and the employment spheres.

Quality service can exist only when it provides quality care which has two main aspects:

- Care and support within the service provided by the staff on the territory of the service;
- Care and support outside the service provided by the SGH staff and the partners from the community.

## 2.1 Quality daily care and support in a family-like environment

*“No matter how simple and elementary it sounds, this term includes a large amount of work. Starting with the daily hygienic activities – washing, cleaning and maintaining the premises in the building, going through the process of creating elementary skills and habits such as putting on and taking off clothes, putting your shoes on, choosing appropriate clothes, participation in the household, eating, shopping and cooking. All these activities are learned by all other people naturally in their childhood and day-to-day life; in the service they should be planned and purposeful given that some of them haven’t been undertaken properly in the institution or haven’t taken place at all. The other important thing is that the care of the staff in the institution had required the service users to be passive, in other words they were treated as people ‘who cannot look after themselves’. In the new service the role of the staff is not only to provide care but also to support children and young adults in their efforts to cope on their own in all type of activities. The care and support should be individual and aimed at every service user depending on their needs and wishes. Of course, the service doesn’t aim to replace the biological family but to create as much as possible a family-like environment.”*

*Margarita Parmakova, Manager of the SGHs “Siyanie”*

## 2.2 Care and support aimed at integration in the community

Community integration includes many aspects of life which we take for granted – education, health, rehabilitation, employment.

*“Despite the opportunity to have educational process in the services themselves where all children have the opportunity to be included, the idea for their education outside the service remains and is still on the agenda. How many children in the “normal” families are taught at home where they are visited by private teachers? Most of them attend mainstream schools and receive their education there. At the moment three of the children attend mainstream school with a resource teacher in certain days of the week. Our aim is for this number to be increased.”*

*Margarita Parmakova*

As discussed in Chapter 3, the clients of “Siyanie” need not only educational support in a mainstream school, but also other specialised social services in the community – day care centres, rehabilitation centres, resource centres where they can receive adequate support from a psychologist, speech therapist, rehabilitator.

While some progress has been made in enrolling the children in supporting services in Kyustendil, unfortunately Cedar has not been able to secure inclusion of the young adults into educational activities, or any community-based supporting service. No service for children will accept the young adults, and the service which does serve adults is not equipped to handle people who have been institutionalised. This means that there is a considerable lack of community services for adults with disability, a situation which Cedar hopes to help rectify in the next few years (see Chapter 6, Section 4.1).

*“The institutional care had deprived the service users to be part of a reality which existed outside the fence of the home – norms and rules for behaviour, understanding the meaning of money, knowing traffic rules, public places orientation, an ability for self-preservation, etc. And all of this was a task for the team in terms of social inclusion and creating opportunities for an adequate and significant social life of service-users.”*

*Margarita Parmakova*

A significant part of the social inclusion process is providing support for people to secure employment. Being employed is a main feature of creating feelings of dignity, adequacy and contribution to society and allows one to explore opportunities for life enrichment. Despite the issues related to communication and attachment, the children and young adults living in SGH “Siyanie” demonstrate a wide range of skills and potential for employment and it turns out that they can achieve significant progress when given adequate support (see Chapter 6, Section 4.5).

## 3. Administration, Management and Structure

### 3.1 Staffing (human resources)

A quality service is only possible when there is excellent caregiving provided; excellent caregiving is only possible when there are sufficient and qualified human resources. It’s important to distinguish both of these aspects of human resources – sufficient and qualified – as necessary for the normal functioning of the SGH Siyanie.

#### Number of Employees

The SGH has a state delegated annual budget in the amount of 174 120 BGN (89 292 EUR), from which the funds for staff salaries are provided in the amount of 101 000 BGN (51 795 EUR) for 17 members of staff. People working in the social sphere know all too well the methodology used for defining the number of staff in residential care services. Specifically for SGHs this coefficient is currently 0,9<sup>15</sup>. These are for two separate SGHs – one for children and one for young adults, spread around two houses and two apartments and requiring separate staff. Even without conducting man-hour calculations it is clear that the state funds are not sufficient for securing the minimum staff necessary to cover a 24-hour schedule.

The number of staff directly involved with service users is further reduced when in the number of 17 people are included a manager, social worker and accountant. Cedar refuses to hire additional administrative personnel (as per the governmental recommendations – this is a carryover from the institutional system), as the human resource capacity is already stretched to the limit.

To deal with this very serious problem, Cedar is forced to hire additional staff to double the amount funded by the state.

As the SGHs are separated geographically into four groups (one group per 8-child house and one group per 4-adult apartment), Cedar creates four teams who are separately responsible for their corresponding groups. Three leaders are assigned to manage these groups – each responsible for 8 children or young adults. Each team works exclusively with their 8 clients, and do not switch between SGHs, guided by the following rationale:

- This is a service which should be modelled on the family structure. Parents/caretakers in a family do not change on a daily, weekly, or monthly basis.
- This encourages and helps staff to develop very crucial relationships with their clients, based on trust, security and consistency.

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<sup>15</sup> In 2011, the Ministry of Labour and Social Policy increased this ratio coefficient recommendation from 0,7 to 0,9. However they did not increase the amount of funding provided to SGH services to pay for these additional staff members. Thus funds for additional staff member salaries must be taken out of the funds used for food, heating, clothing and other necessities for the children. This gives the appearance that services are being given adequate means to provide quality care when this, in fact, is simply not true.

- This gives staff incentive to feel a sense of responsibility to and ownership over their SGH and everything that happens there.
- This encourages staff members to bond more closely with their colleagues, when they are in smaller groups.

The main building unit of SGH Siyanie is its teams. A special place in the training process is dedicated to sessions about the essence of a team, the stages of forming a team, team work and communication and collective problem-solving.

*“The process of building and setting up the teams in the different homes or the different SGHs required a lot of time and energy. Each team had their own development path and ways of working, there were changes in the teams and some initial conflicts with the team leaders until they became more settled. This process hasn’t been completed yet and this is good because the moment when a team decides it’s formed forever and there aren’t different opinions and constructive criticism is a moment of deadlock and the team doesn’t function effectively.”*

*Margarita Parmakova*

In the beginning Cedar hires and trainees 21 people – the bare minimum it needed to keep the service functioning, with staff working overtime and not taking sick leave or vacation. 17 are paid through state funds and 4 through funds donated to Cedar: 1 Manager, 1 Key social worker, 1 Accountant/Administrator, 3 Team leaders and 15 Social therapists.

Following a very heavy period of adaptation on behalf of the service users and much exhausting overtime from the staff (who is now totally exhausted, physically and emotionally, and is quickly burning out), Cedar realizes the urgent need of securing additional funds for more staff.

This marks the beginning of the second stage for hiring additional staff. This is followed by new interviews, trainings, and orientation. Since November 2010, the number of the social therapists has gradually increased and, as of June 2012, reaches 34 people – 17 funded by the state and 17 funded with contributions from supporters of the Cedar Foundation. The distribution is as follows:

Service Manager	1
Key Social Worker	1
Accountant/Administrator	1
Team Leaders	3
Labour Therapists	2
Social Therapists (caretakers)	25
Driver / maintenance	1

#### Comparison with the Institutional Model

	Employees responsible for administration only		Employees working directly with clients	
	No.	%	No.	%
Institution (GORNA KOZNITSA)	13	<b>29%</b>	32	<b>71%</b>
SGH Siyanie	3	<b>9%</b>	31	<b>91%</b>

While the number of staff needed to cover shifts and support the clients in an SGH service is greater, the staffing structure is much more effective. Over 90% of staff is directly involved in working with the clients toward his/her goals. In the institutional model, this percentage is just above 70%; 30% of staff is responsible solely for administrative tasks!

For more details on comparing models, see Appendix 5.

*"It wasn't easy but fortunately we succeeded. During our ball in 2010, we made an appeal to our guests – an annual salary of a social therapist in Kyustendil cost 3600 euro and this person could contribute a lot to the life and the development of a certain child or young person. We presented the situation at the moment and the difficulties we were facing because there wasn't sufficient staff provided by the state. Our suggestion for partnership – because many companies use that as their own corporate responsibility – was very clear and concrete. And many companies decided to sponsor a social therapist – some on behalf of their company, others personally and there were some who did both."*

*Toni Stoykova, Marketing and Communications Coordinator, The Cedar Foundation*

### Staff roles and responsibilities

The following are brief descriptions of the roles and responsibilities of each staff member:

**Manager** – Responsible for the overall effective functioning of the service; manages all service employees; coordinates the work of all units and teams in the service; supports the team leaders, the key social worker and all team members; manages conflicts; delegates rights and responsibilities; is the service spokesperson to authorities, media and general public.

**Key social worker** – Supports both clients and staff; maintains close relationships with local schools, supporting services, the Child protection department, the Department for social assistance, and other professionals in the community; leads meetings for planning and reviewing the care and support to the clients; works directly with the clients on an individual basis; is responsible for managing and updating client files; manages the assessment and individual care planning of clients and the case management program.

**Accountant/Administrator** – Responsible for managing all aspects of the finances of the services, including in-kind contributions from the Cedar Foundation; conducts all accounting, banking, and payroll activities; provides regular reports to the Municipality of Kyustendil regarding financial activity; is responsible for maintaining the condition of the facilities.

**Driver/Maintenance** – Is responsible for the safe transportation of clients, goods and equipment; maintains service vehicles in good condition; maintains good conditions of service facilities.

**Labour therapists** – Work directly with the clients, developing and implementing individual labour therapy programmes; participate in multidisciplinary team meetings for discussion of individual care plans.

**Social therapists** – Work directly with clients in the residencies, supporting them in everyday activities; implement activities for the development of skills according to individual care plans, act as case manager to individual clients; undertake all activities in the home, including cooking and cleaning.

**Team leader** – *In addition to completing all tasks of Social therapist*, clarifies service goals and objectives related to the clients' development and everyday life to the teams; distributes responsibilities among the team members; supervises the implementation of group activities; supports the team members and help in resolving current issues.

For more information on the Management structure See Appendix 6. For detailed sample job descriptions, please contact Lindsay Saltsgiver at The Cedar Foundation.

### Management

The service doesn't have an officially appointed manager and accountant working full time from September 2010 to January 2011, as Margarita Parmakova and Guna Bojilova are responsible for completing the inventory and handover of the Gorna Koznitsa institution. They were released from employment with the Bobov dol municipality once the official documentation connected with the Home was complete. The activities of the administrative unit are managed by the Cedar Foundation team during this time.

The key social worker, the accountant and the manager are the central administrative staff for all SGHs. The Central Management Unit (CMU) consists of the administrative staff plus the Cedar Foundation project manager, Labour Therapists and Team Leaders. This body meets on a regular basis and is responsible for handling all aspects of the service.

### Communication

The weekly team meetings of the CMU, where issues related to the running of the service, staff and clients are discussed, play an important role in ensuring effective communication and smooth functioning of the service. Additionally, each separate caretaker team holds bi-weekly meetings led by the Team Leader, where different issues are discussed related to the organization of service activities or initiatives. Teams also hold clinical meetings where individual client cases are discussed. Each month general assemblies are held, at which all staff are required to be in attendance.

### 3.2 Service budget

Though The Cedar Foundation is required to contribute only 20% in-kind to the service budget, it in actuality contributes nearly 50% of the overall budget. This creates a great financial strain on the Foundation and is clearly not sustainable over time. However, Cedar has found that in order to provide a service which upholds *minimum* standards for meeting the needs of its clients, it has been necessary to almost double the amount of funding provided by the Bulgarian government. The Foundation manages this through year-round fundraising efforts, the most important of which is our Sponsor a Carer programme – in which donors sponsor the yearly salary, insurances and training costs of one member of staff.

Most notably in the budget of SGH “Siyanie”:

- Despite Cedar’s use of natural gas and solar power, heating and electric costs in the winter are, after Personnel, the biggest expense.
- Cedar utilises, whenever possible, donations from other parties (such as the Bulgarian Red Cross) for basic needs, such as food, clothing, or materials.
- The labour therapy program pays for itself – items made by the clients are sold at local craft fairs, the proceeds of which are re-fed into materials for the program.
- The state allowance per child as of June 2012 is 7255 BGN (3721 EUR). This amount is equal to nearly 20 BGN (10 EUR) per day. These funds are distributed in the following manner:

#### STATE FUNDING Expenditures, SGH “Siyanie”, 2011

Expense category	% of budget	expenditure per day, BGN	expenditure per day, EUR
Salaries and insurances - personnel	62 %	12,33	6,32
Energy and heating	14 %	2,78	1,43
Food	14 %	2,78	1,43
Materials and Services	6 %	1,19	0,61
Clothing	2 %	0,40	0,21
Medication	1 %	0,20	0,10
Taxes and Fees	1 %	0,20	0,10

The staff members needed to cover the minimum of shifts in the service, and other expenses such as training/supervision, donations, etc. are NOT represented by this percentage (in-kind staffing is not included in this breakdown). It is clear to see why co-financing, either by the municipality or the governing NGO, is necessary to provide services minimally adequate for the client, at least until the Bulgarian government raises the allowance for provision of services in a SGHs.

### 3.3 Service policies and procedures

Cedar designs entirely new policies and procedures for the service, striving to move away from the overly-bureaucratized Bulgarian regulatory model. It meets the minimum documentation standards required by law, but has added more policies where necessary and minimized others where appropriate. For a list of the policy and procedure documents utilized in Cedar’s service, please see Appendix 7.

For any service, it is crucial that policies and procedures are all connected to one main philosophy which guides the work of all people working in the service. In Cedar’s case, this philosophy is outlined in its documents, “Principles for Care and Support of SGH Service Users,” and “Philosophy and Obligations.” (See the document, “Philosophy and Obligations” in Appendix 8). For a copy of the “Principles for Care and Support” policy, please contact Lindsay Saltsgiver with The Cedar Foundation.

It is also very important that staff members are trained in all policies and procedures guiding their work in the SGHs. Frequent reference to this documentation during staff meetings and conversation reminds staff members that there is a set of 'rules' by which they must always abide. All staff members working in the SGHs "Siyanie" are required to provide their signature indicating that they have read and understand all documentation connected to the service. This helps to encourage them to read the documentation, and to prevent misunderstandings.

### 3.4 Internal programs

#### Case management

When the service is developed, it is decided that every service user will have a certain caretaker who will take personal responsibility for them and their integration and development. The Case manager should learn everything there is to know about the client and organize individual initiatives to help the client reach developmental goals and integrate into the community. The case manager is responsible for conducting the development assessments for his/her client and acts on his behalf during multi-disciplinary meetings to discuss care plans and other matters. Cedar is still developing this program in the service.

#### Labour therapy

The Foundation hires two Labour Therapists in February 2011, looking to create more opportunities and activities through which clients can develop their skills and find meaningful use of their time. Labour therapy is an active kinesis-therapeutic method where the labour activities, chosen carefully according to the development goals of the users, are systematically planned and used. Every craft produced requires a combination of physical and intellectual efforts. The programme is organized so that the client can see the worth and product in his/her work. Two separate labour therapy programs – recreational and functional – are created.

The **recreational therapy** programme in SGH "Siyanie" aims to promote communication with the clients through art including fine art, constructive activities and applied art. The end results are very positive – the children and the young adults have great fun in making jewellery, paintings, souvenirs, martenitsi (traditional Bulgarian ornaments), greeting cards and items for the home.

The **functional therapy programme** uses work in the garden, house work, and cooking, to help clients develop basic independent living skills. This is also a success – the clients do well in learning how to clean the premises, sort, fold and arrange their clothing, serve and wash up; some even start making part of their own meals. And they are proud to use the vegetables from their own garden. To some extent, the labour therapy programme temporarily alleviates the problem of lack of employment opportunities and serves well to help the young people develop good labour skills and habits.





## LOOKING BACK, LESSONS LEARNT:

Here we share what we learned as we have worked to develop the small group home services in Kyustendil:

- **Calculate man-hour needs before opening the service**

Before the service opens, it is helpful for the service provider to complete man-hour calculations in order to determine the appropriate number of staff needed to provide care in the service. Factors such as sick leave, vacation leave, shift times/breaks, and staffing overlaps (in order to pass on information from shift to shift) should be taken into account. We have provided a sample man-hour calculation table in Appendix 9, for reference. This is one of the most difficult aspects of starting a new service, as there are so many such factors to consider. However it is crucial to developing the service, to prevent gaps in coverage, discrepancies with Bulgarian labour law, and to avoid staff burnout.

- **Seek donations from reliable sources**

Whenever possible, seek out and utilize donations from reliable sources. Community members are usually eager to donate clothing or food supplies (though all foods must be packaged and within the expiration date – check with the local health department). Some community services may be willing to provide the service with a discount on certain services because it serves a public good.

- **Always refer back to your main principles**

All internal policies in any service should refer back to a set of principles upon which the service is based. Management should refer to this set of principles as frequently as possible with staff, and even post the principles in key areas in the residency or print them on frequently-used materials to remind staff regularly of the underlying philosophy of their work.

- **Review all policies and procedures during staff training**

Care should be taken during staff training to thoroughly review all policies and procedures with management and staff. Any time a policy is changed, added or becomes void staff should be notified.

- **Recognize that the educational system is unprepared**

The educational system is still unprepared regarding the process of integration of children with intellectual difficulties in mainstream schools due to a range of reasons – there is little understanding about disabilities and those who have them; lack of sufficient number of resource teachers; insufficient work with parents from the school with regard to tolerance and acceptance of the differences in others.

## 4. Longer-term results

As mentioned earlier in this chapter, The Cedar Foundation keeps close data regarding client progress in skills development and behaviour indicators. On average, the Foundation has seen progress in every category measured, and knows that the design of the service, the programs it has developed, and the social opportunities afforded the clients all have positively influenced the abilities of the children and young people. The Cedar Foundation recognizes that this data is not perfect and does not solely rely on these numbers to gather feedback on the success of its program. However, the Foundation does use this data to explore:

- areas where individual clients need improvement (goals for individual care/support plans);
- whether or not changes we make have a positive effect;
- where risk areas are, indicated by steady decline in results over time;
- where the focus of new programs should be in the service.

Below are two tables with **averaged percent improvement compared to baseline data** taken before the residents moved from the Home in Gorna Koznitsa:

Children and/or Profound to Severe Disability:

Category	Children / Profound to Severe ID		
	3-month	6-month	12-month
INDEPENDENT LIVING SKILLS	5,3%	8,5%	11,0%
MOBILITY AND TIME-SPACE COORDINATION	3,4%	3,5%	11,2%
LANGUAGE AND COMMUNICATION	-0,7%	-2,9%	3,8%
SOCIAL-EMOTIONAL DEVELOPMENT	0,8%	2,0%	5,5%
<b>Total, Skills Assessment</b>	2,9%	4,7%	9,4%
BEHAVIOUR	3,5%	2,5%	4,0%

Young Adults and/or Moderate to Mild Disability:

Category	Adults / Severe to Moderate ID		
	3-month	6-month	12-month
INDEPENDENT LIVING SKILLS	insufficient data	8,6%	8,7%
MOBILITY AND TIME-SPACE COORDINATION		4,0%	5,5%
LANGUAGE AND COMMUNICATION		0,0%	2,1%
SOCIAL-EMOTIONAL DEVELOPMENT		1,3%	-0,5%
<b>Total, Skills Assessment</b>		5,0%	5,6%
BEHAVIOUR		-2,9%	-0,5%



## LOOKING BACK, LESSONS LEARNT:

Here we share what we are learning as we continue to conduct assessments:

- **Ensure that the same person conducts all assessments of one client**

It is helpful if the same person conducts all assessments of one client each time – this will reduce the chances of data being incorrect and will give the assessor a sense of ownership over the task. In the “Siyanie” service in Kyustendil, case managers are responsible for the assessments for their client.

- **Do not refer to previous assessments when conducting a new one**

Assessors should not be given the opportunity to refer back to previous assessments when conducting an assessment with clients. For most staff members, it is very tempting to emphasize progress. Treating each assessment in isolation from other assessments helps keep data real.

- **All staff should be thoroughly trained in conducting assessments**

While knowledge in statistics or specialized assessment skills are not a prerequisite for collecting good data, it is important that staff members do receive training in good assessment methods. How to not let mood influence the assessment, giving the client multiple chances to prove a skill, how to set up the assessment atmosphere, these are all factors which will affect the outcome of the assessment and therefore the quality of the data collected. Good training can prevent sloppy data.

# Phase Six:

## Moving to the next level

When Cedar designs and opens its services in Kyustendil, there are very few other Bulgarian services which can be used as models upon which to establish its service design. For the most part the Foundation relies on a mix of different models, most of them foreign but some also Bulgarian, in order to form the core services which it wants to provide. Since opening the SGHs in Kyustendil in 2010 and undergoing its initial period of settlement, the Foundation has been taking measures to move to what it considers the next level – going beyond the minimum requirements of the law and fine-tuning to improve and expand the full range of services which we provide to our clients.

In this chapter we take a look at the different elements of quality of care and social inclusion, which The Cedar Foundation prioritise as the next steps to ensuring a better quality of life for its clients. We describe the programmes which currently serve our children and young people and offer a case study demonstrating the power of social inclusion.

### 1. Quality of care

#### 1.1 Defining Quality of Care

Quality of care is very difficult to define. There are various angles through which quality can be considered, in the field of social services:

- Quality as excellence
- Quality as value
- Quality as meeting user-expectations
- User-perceived quality
- Quality as management.

The choice of one of these perspectives will influence the way in which the quality standards/principles and respectively the quality indicators will be formulated<sup>16</sup>.

In its Guidelines, Handicap International (HI) concludes that the 21st century paradigm of quality takes into consideration a holistic approach on service provision and focuses simultaneously on:

- Human resource management
- Person centred approaches
- Users involvement in service provision
- Adaptability and responsiveness of the service.

It also suggests another approach - making a correlation between quality of social services and the quality of life in general, referring to the EASPD (The European Association of Service Providers for Persons with Disabilities) which promotes this approach: the fact that quality services should base their policies and practices on human rights related values:

- Persons with disabilities as individuals
- Focus on abilities
- Implication for families
- Equality, full participation, inclusion, empowerment, choice

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<sup>16</sup> Guidelines for the elaboration of quality standards for the Personal assistant service (PAS) within the Centre of Independent Living Serbia, Handicap International, 2007

HI continues that in the light of these values, social services should develop methods and tools in order to guarantee for each user:

- Emotional well-being
- Interpersonal relations
- Material well-being
- Personal development
- Physical well-being
- Self-determination
- Social inclusion
- Rights

These aspects are generally considered the elements that contribute to a good quality of life of a person.

Finally, HI acknowledges the main accents that are currently recognized in all European countries in this field:

- “User involvement, participation, and management;
- Consultation and participation mechanisms on policy design between services, providers and users and the creation of networks of local stakeholders, and the formulation of local action plans;
- Increased internal quality reviews. Monitoring, performance evaluation and sharing of best practice;
- Minimum standards (providing quality assurance for both social services and their users)
- Creating a learning environment. Training for professionals and volunteers; consultation of service users in the design and content of training;
- Coordinated and integrated services, requiring an effective communication system and mechanisms for cooperation between different branches of social service provision”.

#### Developing standards

Even if the concept of “quality care” were universal, in different countries and in different situations, the implementation of quality care will inevitably mean very different things. What is considered quality in Belgium or England or Australia, for example, in many ways is inapplicable in Bulgaria, due to differences in regulating structures, financial support from the government, available expertise and the stage which each country has reached in the process of mass deinstitutionalisation. Thus what is necessary is the development of a definition and strategy which suits the current situation in Bulgaria, and standards to which services can pragmatically aim to adhere, considering the circumstances. The Foundation feels very strongly that the government should continue working with experienced NGOs to develop an easily-navigable system for all SGH services to be able to meet specific criteria for provision of quality care.

The first steps have been taken in that direction, resulting in the Methodology for SGHs for Children and the Methodology for SGHs for Adults – essential documents for any organization or municipality tasked with establishing this type of service. In 2008, UNICEF began gathering service providers, NGOs, and representatives from the Ministry of Labour and Social Policy, Agency for Social Support and the State Agency for Child Protection, to hold a series of discussions and draft the methodology. In late 2011, the final draft was officially approved by the SACP and distributed to service providers around the country. While in legal terms it is not mandatory for service providers to follow the methodology, it is strongly intertwined with the Ordinance for Standards and Criteria for Social Services for Children, and Cedar considers the document an indispensable guide in the development and management of SGHs services.

The Methodology – and the legally-binding Ordinance for Standards and Criteria for Social Services for Children – sets out a minimum set of criteria for the development of an effective SGH service, and outlines indicators for achievement in different categories. These documents do not, however, fulfil the role of defining Quality of service, nor do they present a method through which different services can be measured in terms of quality, not minimum standards. The discussion must continue, in order to develop a set of standards *above* the minimum, so as to address the question of quality. Most stakeholders would probably agree that quality should be measured using a number of different indicators, not just those currently regulated through inspections. Based on the above information and its experience Cedar asserts that quality indicators should include:

#### **1. Focus on the client**

- Positive feedback from the client
- Confirmation that the human rights and dignity of the client are valued, upheld and protected

- A personal development approach for all clients, measured by regular assessments of achievements
- Proven track record of users participating in all decisions and choices which concern them.

## 2. Focus on the Staff

- A programme of skill acquisition and career development, underpinned by on-the-job training and qualified supervision
- High ratings of staff's job satisfaction and low turnover rates
- Staff reviews demonstrate improvement, and staff clearly benefit from a rich and varied set of professional development opportunities

## 3. Focus on the Community

- Wide scope of opportunities provided to clients for social inclusion and community involvement
- Opportunities for the wider community to engage with and support the client group and overall positive feedback from it
- Good upkeep and condition of facilities and grounds

## 4. Focus on the Home and Service Structure

- The home – relationships between service users and staff are designed to and demonstrate it is the service users home
- The facilities are appropriately designed and adaptable to meet changing needs.
- Activities are documented in ways which respect confidentiality, enable accountability and clearly reflect and support those activities
- All procedures are streamlined and operating smoothly, efficiently and in accordance with the law.

Internally, Cedar's next phase – through which it is moving at the time of the writing of this booklet – is to work on all of the areas above and improve the overall quality of the service it offers. The Foundation thinks that these quality standards should be formulated into a quality rating for every service in Bulgaria.



## LOOKING BACK, LESSONS LEARNT:

Here we share what we are learning as we explore quality of service:

- **Services must move to the next level.**

While the Methodology for SGHs for Children and for Adults are indispensable guides to creating services, service providers should not stop at providing the minimum requirements to their clients. Services should continually grow and develop to meet the needs of its individual clients, and should be open-minded and creative in developing ways to meet those needs.

- **Services should set annual goals for improvement.**

Until a universal system of measuring quality of care is developed in Bulgaria, individual services should set its own goals on an annual basis for improving services and quality of the care they provide their clients.

## 2. Social inclusion – the European and Bulgarian context

### 2.1 Social inclusion versus social exclusion

Social inclusion and respectively social exclusion have multiple definitions which vary significantly depending on the context, and have continually evolved over time. The European Union definition of social inclusion reads as follows:

“Social inclusion is a process which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life and to enjoy a standard of living and well-being that is considered normal in the society in which they live. It ensures that they have a greater participation in decision making which affects their lives and access to their fundamental rights.”

It is not possible to talk about social inclusion without focusing also on the other side of the coin - social exclusion. The two processes are connected and depend on each other.

Invention of the term “social exclusion”<sup>17</sup> is attributed to Rene Lenoir, the Secretary of state for social action in the Chirac government, and author of *Les Exclus*. The EU defines social exclusion as “a process whereby certain individuals are pushed to the edge of society and prevented from participating fully by virtue of their poverty, or lack of basic competencies and lifelong learning opportunities, or as a result of discrimination. This distances them from job, income and education and training opportunities, as well as social and community networks and activities. They have little access to power and decision making bodies and thus feel powerless and unable to take control over the decisions that affect their day to day lives”.<sup>18</sup>

A report made by the University of Bristol<sup>19</sup> gives the following definition for social exclusion:

“Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.”

## 2.2 Groups under risk of social exclusion

Based on the above mentioned definitions the Bristol University report derives a series of domains and sub-domains of potential exclusion:

- Resources
  - Material/economic resources
  - Access to public and private services
  - Social resources
- Participation
  - Economic participation
  - Social participation
  - Culture, education and skills
  - Political and civic participation
- Quality of life
  - Health and well-being
  - Living environment
  - Crime, harm and criminalization

There are certain groups who are either deprived from access or have limited access to one or more of these domains such as:

- Children without parental care
- Disabled people
- Single parents
- Older people

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<sup>17</sup> Social Exclusion and Social Solidarity: Three paradigms, Hilary Silver, *International Labour Review*, Vol. 133, 1994/5-6

<sup>18</sup> European Commission, *Joint Report on Social Inclusion 2004*

<sup>19</sup> *The Multi-dimensional analysis of the social exclusion*, Ruth Levitas, Christina Pantazis, Eldin Fahmy, David Gordon, Eva Lloyd and Demi Patsios, 2007

- Unemployed
- People with different ethnic origin
- Other depending on culture/society specifics.

The focus of this manual is, clearly, children and adults with disabilities. Therefore we will focus on the factors for overcoming their social exclusion and achieving inclusion in Bulgaria.

## 2.3 Implementing social inclusion in Bulgaria

### Legislative changes

Bulgaria ratified the UN Convention on the rights of persons with disabilities on 26<sup>th</sup> January 2012. This is an enormous step ahead towards enabling persons with disabilities to exercise their fundamental rights. The Ministry of Labour and Social Policy is responsible for developing a two year Action plan for its implementation. The next step however should be the ratification of the Optional Protocol to the Convention which establishes two procedures aimed at strengthening the implementation and monitoring of the Convention. The first is an individual communications procedure allowing individuals to bring petitions to the Committee claiming breaches of their rights; the second is an inquiry procedure giving the Committee authority to undertake inquiries of grave or systematic violations of the Convention. By ratifying the Optional Protocol Bulgaria would demonstrate a real commitment towards respecting the rights of persons with disabilities and ensuring their full social inclusion.

There are three issues in the Bulgarian legislation which are closely linked to the Convention and need to be changed in order to comply with it.

The first is the definition of disabled persons. The table below compares the definitions given in the Bulgarian Law for integration of Persons with disabilities and the UN Convention.

Law for integration of persons with disabilities , Additional regulations- §1,point 2	UN Convention on the rights of persons with disabilities
„ <b>A person with permanent disability</b> “ is a person who as a result of anatomical, physiologic or mental disability is with permanently reduced abilities to perform activities in a way and to a degree possible for the <b>healthy</b> person, and for whom the medical expertise bodies have established a degree of reduced capacity for work or have determined type and a degree of disability 50 and over 50 %.	Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

The definition in the Bulgarian law focuses on the disability and the lack of capacity, making a clear distinction between the disabled person and the healthy person. It is more in line with the medical model of disability than with the social model and is discriminative. Therefore it should be changed in order to reflect the rights-based approach, modelled by the definition in the Convention, which makes it clear that the problem is not in the lack of capacity and/or the deficits of the disabled person but in the “different barriers” they face in the environment.

One significant problem facing people with disabilities on the practical level is the legal status of persons with intellectual disabilities and the existence of the Bulgarian guardianship procedure. Currently persons with intellectual disabilities are not allowed to act as legal persons. As a result Cedar faces the following significant problem: its users who are over 16 are not able to access the part of their disability allowance which is transferred to their bank accounts. The bank does not consider their signature as valid and requires a signature from a guardian. Article 12 of the Convention however reaffirms that persons with disabilities have the right to recognition everywhere as persons before the law as well as to enjoy legal capacity on an equal basis with others in all aspects of life.

The third problem is related to the assessments made by the Labour-expert doctor commission (TELK). Once the Commission decides that someone is not capable to work, especially if the person is classified as 100%

lacking labour capacity, then the person is not allowed to work; if they are hired, the employer can be fined for breaching the law. Changing this label is a long and expensive process. Article 27 of the Convention prohibits “discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions”.

These are not the only changes which need to be made in the national legislation concerning persons with disabilities. While this is not an exhaustive list this is a description of some of the key problems we have faced in our day to day work.

#### Political engagement with the outcomes

Achieving sustainable growth and a stable macroeconomic environment are important preconditions for realizing the priorities of the social inclusion policy. This however on its own right does not lead to social inclusion. Additional measures for improving the quality of life of persons with disabilities, their social inclusion, need to be integrated in all state policies and – more importantly – a mechanism ensuring their implementation has to be introduced.

There are a number of strategic documents dealing with the rights of persons with disabilities including:

- Strategy for ensuring equal opportunities for persons with disabilities 2008 – 2015
- Strategy for corporate social responsibility 2009 – 2013 with annual Action plans to it
- Long term strategy for employment of persons with disabilities 2011 - 2020
- Draft national strategy “Vision for deinstitutionalisation of adults with mental health problems, intellectual disabilities and dementia”

If they are properly implemented with the respective monitoring, this would improve significantly the social inclusion of persons with disabilities.

#### Preparing the local community

As mentioned in previous chapters the local community is very important for achieving social inclusion of persons with disabilities. Together with the NGO sector, the government and the media have an important role to play for raising awareness of the rights and capacity of persons among the local community. There should be special programmes and/or strategy devoted to it on the governmental level. Then, of course, the service providers themselves should direct their efforts towards preparing the community and introducing its new members in a way which enables their acceptance and integration.

#### Improving the educational system

The access to mainstream schools for children with disabilities has significantly increased in the last few years. Still however some significant improvements are needed in order to achieve their full integration in school.

Ordinance No. 6 issued on 19 August 2002 on education of children with special educational needs and/or chronic diseases entitles children with multiple disabilities to be integrated in mainstream schools with a resource teacher. Following the completion of the class, they receive a certificate stating that they have learned the knowledge and skills envisaged in the individual plan. However this is without scores and only with words such as “successfully completed.” Children with severe intellectual disabilities who cannot learn the state general educational requirements are referred to special schools. After completion of eighth grade, irrespective whether in a mainstream school with resource support or in a special school, the students receive a certificate for completed class and if they would like to continue their education this may happen only in special classes for vocational occupation which exist in the special schools. The ordinance is not sufficiently clear whether children with severe intellectual disabilities can be enrolled in a mainstream school or only in special schools. The diagnostic commission at the Educational inspectorate decides what type of education the specific child needs and refers him or her to a helping school or mainstream one with a resource teacher.

The number of the resource teachers in the mainstream schools is not sufficient in order to support all children and persons with special educational needs and to provide quality and in accordance with their individual needs education. The number of classes spent in the mainstream class is also insufficient – Elena and Georgi attend school two or three times per week and attend mainstream class with the other children only in the music and sports subjects.

In addition, the school education takes place in a day form for children up to 16 years old. Following the completion of this age, irrespective of the grade reached by the child, it is necessary to receive a special permission from the Ministry of Education in order to be enrolled in the next class. Otherwise, he or she would automatically drop from the day form and should be enrolled in an individual form of education which however at this stage doesn't exist for children with intellectual difficulties.

For the young adults with disabilities who have turned 18 years old, and who hadn't attended any form of education, there isn't a possibility to make them literate despite that the Regulations for implementation of the Education Act says that "use their right to education in the educational system irrespective of their age" (art.2).

Another serious problem is that the textbooks and the educational materials as well as the programme/syllabus itself are not adapted for the needs of children with intellectual difficulties so that the educational material is offered in a way which is accessible to them.

### Health care

Access to adequate health care must be a priority of every strategy for social cohesion. The right to health care is a basic human right (Art. 35, Charter of Fundamental Rights of the European Union)<sup>20</sup> and no one should be deprived of it on the base of income or place of living. It is an obligation of the state to ensure equal access to quality services to all its citizens.

The health care reform led to significant financial pressure upon the already low level of incomes of the people with disabilities, which makes their access to quality health care very difficult. The funds provided from the National Health Insurance Office are extremely insufficient to cover the costs of the medicines. The problem with the medicines is extremely important for the children and people on daily and highly expensive therapy. The huge costs for medicines limit additionally the financial means which are necessary and could be used for more adequate social inclusion.

### Employment

Integrated employment is an expression of, and an opportunity for, social inclusion. Properly remunerated employment gives financial autonomy and inclusive opportunity. Thus employment is a direct expression of fundamental human rights.<sup>21</sup>

In order to provide a sustainable integration of the people with disabilities on the labour market it's necessary:

- public awareness raising of the capacity for work and talents of persons with disabilities with special accent on persons with intellectual disabilities and mental health problems for being the most stigmatised groups;
- cooperation with employers and awareness raising among them;
- support for the enterprising among people with disabilities;
- consultations and training which are adapted to the specific needs and interest of the people with disabilities;
- flexible labour market and working time in accordance with the needs of the concrete employees with disabilities;
- official introduction and implementation of the supported employment model;
- including labour integration in the priorities of the Partnership agreement of Republic of Bulgaria for programme period 2014 – 2020 for the EU Structural Funds.

A lot of this is already present under the form of different policy, legislative and financial instruments and benefits. There is still a lot more to be introduced and sustained in order to achieve labour integration of persons with disabilities and especially of persons with intellectual disabilities and mental health problems.

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<sup>20</sup> Charter of Fundamental Rights of the European Union, 2000/C, 364/01, Official Journal of the European Communities, 2000

<sup>21</sup> Good Practices of Labour Integration of Persons with Intellectual Disabilities in Belgium: Recommendations to Bulgaria, Irina Papancheva, 2008 (Masters thesis).

### 3. How Cedar works to promote inclusion – Internal programmes of the SGH “Siyanie”

Cedar considers the securing of a family-type environment as the first important condition and a necessary prerequisite for social inclusion. SGHs “Siyanie” are a good example of a mode of a residential care social service in which the work of the team and the lives of the users are organized in such a way so that they are as close as possible to the family environment. The atmosphere is supportive, based on care, patience and stimulation of the abilities and talents of the children and the young adults.

The work of the Foundation with regard to social inclusion is carried out through two plans, relying not only on a well-designed internal programme but also on a series of efforts to utilize external services to improve client inclusion in public life.

#### 3.1 Internal Programmes in SGH “Siyanie”

Cedar works within the service in the form of training of the staff in how to support the development of the potential and the independence of the children and the young adults. Cedar’s policy is to support the users to exercise their right of choice about everything which concerns them and their day-to-day life. The staff aims to understand what the wishes of every child and young adult are even if this is made difficult by the degree of the disability. Every month the team leaders gather two or three interesting cases which show how the social therapist was able to understand the wish of certain service user and to take this into account. Often these cases are related to what the children want to play with, what clothes they would like to put on, where they want to go, what the menu should be, etc. During the recruitment process of applicants for social therapists in the service, Cedar includes one of the girls from the SGH “Siyanie” in the recruitment panel. She has the opportunity to attend the interviews, to meet personally the applicants who might become part of the team in the service where she’s placed as well as for the applicants to be in first contact with some of the people they would support.

During the period 2007 through 2010, Cedar is visited five times by the British couple, Jennifer and Alan Waters, who train the staff to begin changing their mentality about the way they work. Jennifer, an experienced psychiatric nurse and Alan, a caretaker in several UK-based residential services, help entrench the philosophies of person-centred care, privacy, trust and dignity, in Cedar’s training programs, service philosophies and policy guidelines. They are also the first Cedar volunteers who began accompanying the children and young people on walks in the community.

In the beginning of March 2011 at the invitation of director Luc Verbeke, staff members from the Kyustendil SGHs pay a visit to Den Dries – residential social services for adults with disabilities in Evergem, Belgium. The visit is part of the EU Twinning Programme for professional exchange and is facilitated by The Cedar Foundation.

Luc Verbeke arranges for the Bulgarian staff to be introduced to a wide range of services. They visit Day Care centres, arts, technical and industrial workshops, sensopathic rooms, farms and fair trade shops where people with disabilities work. At every service the local staff deliver a lecture on the methods of individual work with the clients. They also discuss different models for working with challenging behaviour with the Den Dries team.

In mid-May 2011 staff members from Kyustendil SGHs and Day care centre Kazanlak for children and young adults with disabilities conduct a study trip to The United Kingdom to exchange experience and adopt best practices of work. The programme organised by a consistent Cedar volunteer, the physiotherapist Helen Baverstock, includes visits to various types of services in London and the area – supporting community teams, day care centres, consultation teams, a respite care centre, a hospice, etc. The trip gives the Bulgarian professionals a very broad view of the English system supporting people with disabilities and a chance to exchange ideas with their English counterparts on various topics regarding methods of work and good practices.

For four years in a row a team from Greenfields Specialized School, Newcastle visits The Cedar Foundation and conducts training with the staff members in Kyustendil. Mary Crane, Karen Dodds, Karen McElwee, Barbara Burton, Julie Boito, Sarah Knapper, Judith Anne Robson and Roisin Crane do theoretical and hands-on training sessions with the social therapists on various topics: Sensory Work and Sensory Stories, Managing Challenging Behaviour, Sex Education, Developmental Play Activities, etc. Mary Crane is an official advisor to Cedar and provides professional advice on regular basis through the year.

Other English professionals who join the Cedar team in Kyustendil in October 2011 as volunteers are Peter and Bridget Charlesworth. They are both special needs teachers who have experience working with young adults with mild, severe and profound learning needs. They have trained and worked at a special school in Essex, a model of good practice, previous to volunteering with The Cedar Foundation. During their time in Kyustendil they train staff on the topics of managing challenging behaviour, create a symbol system for communication with the users and train the staff on how to use it, a therapy room and a new system for document organisation, participate in team meetings in both the service and office in Sofia and provide their input. Based on a series of interviews with all the staff members conducted together with the Cedar Services and Volunteers Coordinator Jeni Petrova, the three of them produced a Strategic Development Plan for the Kyustendil service with proposed actions in 11 areas and a timetable for their implementation. Their advice to the new established social services in Bulgaria is as follows:

- Surround yourself with people who know more/have more experience than you in the given specialist field
- Have a clear, focused, structured vision for the service with clearly achievable goals that are communicated to all staff
- Guard against taking on more projects without achieving excellence in others
- Transitions from the Institution to the Small Group Home environment must be properly managed and facilitated.

One more step in this direction will be Cedar's project "Users' involvement in the decision making process – a step towards complete social integration" which has been approved for funding under the Human Resources Operational Programme by the Ministry of Labour and Social Policy and will be officially launched in the summer of 2012. Cedar's partners in the project are the Municipality of Kyustendil and the Welsh non-governmental organization Learning Disability Wales. The project involves the delivery of training by Welsh experts to the staff in the family-type homes "Siyanie" and the Municipality of Kyustendil as well as the creation of a municipal strategy on users' involvement and a guide with good practices.

Special attention is also paid to the planning of the users' day-to-day life so that it includes more activities in the community and communication with their peers as well as to be agreed with their wishes and needs.

Last but not least, the team is trained in how to present the service in the community in order to be advocate of the service users' interest, to protect their rights and at the same time to change the attitudes towards them through provoking of interest, understanding and a wish for involvement in their lives.

## *Interview with Jenya Petrova, Services and Volunteer Coordinator, The Cedar Foundation*

### *How long have you been working for "Cedar" foundation and what has been your role so far?*

*I've been working for "Cedar" foundation since June 2008, almost since the beginning of the deinstitutionalization process of the Gorna Koznitsa Home.*

*When there were foreign experts, I facilitated their visits and designed their programmes. I also coordinated our follow-up actions, based on their advice and recommendations. My role was also to coordinate the changes we made in the institution, and with the implementation of all training sessions – I've been an organizer, coordinator and translator at the same time. The biggest challenge and difficulty was to make people who had been working for 15-20 years in the institution, to believe that another care system could exist very soon, and that they would have the opportunity to be part of it if they are able to see this new way of support and change their attitude. I think this was the most difficult thing and we couldn't achieve it with a big part of the staff. To help the institution staff that has sufficient potential for change and to help enhance their professional capacity to perceive the modern methods of work and to use them, is invaluable.*

### *Where did you find the strength to face such big challenges?*

*At the time I had little experience with social work and I was like a blank page. My meetings with our foreign experts gave me the vision that things could happen in a much better way. I came to learn that to some extent that these better practices could exist in Bulgaria, even at the stage where we were at the time. This gave me a lot of enthusiasm and energy.*

### **What is the role of the volunteers in Cedar's work?**

*The work of the volunteers is very key. Our most stable volunteers are foreign experts – special pedagogues, physiotherapists, ergo-therapists. Their function is very important, as they transfer both their expertise and their attitude to the work and the service users. I think it's good from a moral point of view for a person who works with people with disabilities in Bulgaria to see the confidence of the foreign specialists and to be able to perceive himself in the same way, as a professional doing important work.*

### **What are you currently working on with Cedar, in even further developing the services?**

*A big part of my job in the upcoming months will be related to the management of our European Commission-funded project, which is aimed at increasing the capacity of the staff. We'll be working to improve the skills of the staff in directly involving the children and young people in making decisions which concern their own life, and in supporting the clients in following through with their decisions and learning how to express their own choices.*

### **You're also working on the service development plan?**

*Yes, the plan is being implemented at the moment. We are applying western European standards about the way such a service should function effectively. We made suggestions for changes which can improve the work of our staff so that we can offer more to our service users.*

*I think that in Bulgaria all newly set up services should go through such a process. The physical movement from one place to another, which offers better living conditions, is very important; however there are also other key factors to successful deinstitutionalization. These are connected with inclusion, mostly with the human attitude and the understanding about the value of the human being and to what extent this value depends on his intellectual development and the ability to express his will. The results of our strategy for development of the service are yet to be seen. It's important to think outside of the institutional framework – the human being and the quality of his experience should be paramount, rather than the system which serves him.*

## **4. How Cedar works to promote inclusion – Involving clients in external, public programmes**

The work outside the service is aimed at development of partnerships in the education, culture, employment and all other aspects of the community life.

### **4.1 Education**

Initially, the social therapists and special educators working with the clients in SGH "Siyanie" aim to help them develop basic skills and habits for independent living: Maintaining a decent appearance, arranging personal belongings and clothes, skills for hygienic eating, and maintaining good behaviour in the community. The Foundation encourages educators to take it one step further, to include them in mainstream schools and design lessons to help them learn reading, writing, arithmetic. Unfortunately in Bulgaria there are many who still subscribe to the notion that because they will not be able to learn, children with disabilities do not have the same basic right to education as every other child. The Foundation begins looking for ways to provide the children and young people in Kyustendil with an integrated, specialized education.

On 8<sup>th</sup> December 2011 two of the children – Elena and Georgi – attend mainstream school for the first time. The director of the Kyustendil 6<sup>th</sup> primary school Zdravka Taseva reacts cordially and is ready immediately to admit the children despite the fact that they already serve 23 children with disabilities.

*"The first school day for Elena and Georgi was one of the most exciting experiences I have ever had. Elena had been waiting for it for months and was constantly asking when she would go to school. For Christmas she asked for and received a school backpack. She was so enthusiastic about going to school. On the day itself her face was shining with happiness. Georgi was more quiet and puzzled about what was happening. The school bus came to pick them up and the filmmaker Tom Kirk, who shoots the key milestones in Cedar's history on volunteer basis, and*

*I accompanied them. Initially, they stayed in a room together with other children with disabilities. Afterwards the resource teacher took Elena to her future class and presented her to the children. She started introducing herself to them and they all reacted in a friendly and open way. This was the music class and at the next moment she already joined them in the dance they were performing, holding the hand of a girl whom, as it turned out, she knew from the previous visits to the school with the teachers from the Day Care Centre. And this big happy smile didn't go away from her face"*

*Irina Papancheva<sup>22</sup>, Acting Operations Manager, The Cedar Foundation*

## **Interview with Zdravka Taseva, Director of "Paisij Hilendarski" 6<sup>th</sup> primary school, Kyustendil**

### **How many children with disabilities are there at the school?**

*From 1st to 8th grade – 23 as well as 2 children in the pre-school group.*

### **How many of them are with intellectual difficulties?**

*I would say that about 50 percent of the children are with intellectual difficulties.*

### **Why are there so many children with disabilities?**

*We started working as partners on a project of the Centre for social activities with Mila Marinova in Sofia. That was the time when the term "resource teacher" was introduced. There wasn't even legislative framework for these children. The first children we had were from Lozen, following the closure of the school. They were 2-3 children and that's how today the number reached 23. I would say we have very good experience in admission and education of these children.*

### **What was the beginning like? Was it difficult?**

*The beginning was extremely difficult at first because the teachers were not prepared and not only the teachers but the parents too about the admission and education of these children. It turned out that a teacher could be required to work with children who have different problems – hearing, visual, intellectual difficulties. After the project launch, we attended many training sessions, sought ways to deal with the situation, but at the time there weren't ordinances, legislation, or guidance... we managed on the principle "trial and error". Unfortunately, that's how it was at the beginning. However, now with the existence of the Resource centre and the resource teachers, things are going better.*

### **What were the biggest challenges for you?**

*The most difficult was to help the teachers accept the children who are not in the norm in their classes, because they were not prepared and didn't know how to work with them. In general, we didn't have any problems with the other children. In other words, they could accept the children, as in our school there always have been children of Roma origin so haven't had problems with the children in the integration process. The problem was rather the adults who found it difficult to accept the different children.*

### **How did you change these attitudes?**

*Before all, with many discussions, conversations, with qualification of the teachers. We had meetings and trainings with associated professor Dr. Pelagia Terziiska from the Southwest university "Neofit Rilski" which really helped us. And our desire to seek a way to manage.*

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<sup>22</sup> Irina Papancheva replaces Lindsay Saltsgiver during her maternity leave from August 2011 until September 2012.

### **Do teachers receive training and support for the integration process?**

Teachers receive such support on behalf of the management because without this things won't work out. The colleagues from the Resource centre already have separate rooms and premises where children study and we partner all the time. Without a resource centre, without our joint work, things wouldn't happen. It was very difficult at the beginning, now we have other challenges.

### **What are they?**

In my opinion, it's normal for one resource teacher to work with one to two, up to three children while ours work with 10-12 which I think is absolutely unacceptable. In other words, I think the national government should secure more resource teachers and their salaries. Otherwise children are on schedule, they are taken out from class when they can so that the resource teachers could work with them but in my opinion the resource teacher should be in class rather than separate premises because such integration doesn't make sense.

### **Yes, this is not integration but a different form of segregation...**

Different form which we were satisfied with at the beginning as we didn't have experience. Now, however, we have experience and I think this is absolutely wrong.

### **Do you think that children with intellectual difficulties don't have capacity to attend general subjects with the other children?**

If the resource teacher is able to enter the class together with the child, then there won't be any problem. The child won't be just 'present'. The resource teacher will be with him/her and provide support. They really don't have capacity as they are only two people. We have two resource teachers for 22 children. That's why I think we should be pushing for more resource teachers. The state should commit to secure their salaries because money is really necessary for the integration to be successful.

### **Weren't you afraid to accept children with disabilities at the beginning?**

We had some concerns about what could happen, from the reaction of the parents, how they will accept these children, because they were grouped together in one educational establishment, isolated from the world and it was very scary at the beginning because there was a real exodus of children from our school. Even when we sought children for first grade, I was shocked by parents' words: "How are we going to allow our children to study at 6<sup>th</sup> school with the mad persons?". This is something which is on my mind even now as our society is a little bit hypocritical with regard to integration and both these children and children of Roma origin. I've experienced this and know it very well.

### **Have your fears transformed into confidence in the practice?**

Yes, I think that during these years things happened and we overcame these fears of the parents, of the children and the colleagues. It's another issue that we should find the optimum way for the integration to happen.

### **Would you send a message to the directors of other schools where there still aren't children with disabilities?**

We just shouldn't be afraid. We should look at things as a challenge, which are resolved more easily and I think that the sense of integration for children with special educational needs is their socialization. In other words, children in the norm get used to and accept, and love the different because in life they will meet such people and in my opinion this is the purpose of it all – to love and respect the different. I think our children are more sensitive towards the children who are different than them.

### **What is your vision for the school with regard to children with disabilities?**

We have always accepted and welcomed the different, the new, because at the end of the day the most important is the child. Whether the child will manage to socialize, whether the other children will accept him or her, as well as the colleagues and the society, this depends on the school. We should strike here while the iron is hot. So that, later on these children who communicated together, to have the same relationships as adults. Our teachers make maximum efforts to include them; we all do so that we can fulfil this task. I wouldn't say a mission because the mission is for the child to feel well and significant at school including these children who have difficulties as well as the children who have health problems.

## ***Interview with Siyana Spasova, Resource teacher for Elena***

### ***How does the integration of Elena take place?***

*At the beginning, we started working only her and me. She had to get used to the school, the new environment, the new people and situations. She stayed for a month in our resource room and after that we started going to her class. The children accepted her warmly. I was worried that there might be a moment of rejection or distance as this often happens. But they accepted her quickly. Maybe, because they are mostly girls and this was the reason. Even before New year after I had suggested them they gathered money and bought her a present – two fish. Now she stays in class with me and another resource teacher with the other children. I used to be with her in the class but since before the last time I let her on her own and then the other children bring her. She couldn't bear a whole class. I let her stay with the children in the music class because the teacher plays a piano. The live music impresses her a lot. Especially the first time when she heard the piano she was dazed. Maybe it was the first time she heard live music. When we go to the classes, they accept her warmly. The whole attitude of the Director and the teacher is also positive. My idea is to integrate her in the students' group. I'm far from the idea I could integrate her as teaching activities and knowledge because she has a moderate learning disability and we work mostly with social topics. Night, boy, girl....what does she do – cries, laughs....Her intellectual capacity is limited and she becomes exhausted very quickly.*



### ***How much time does she spend at school?***

*She comes three times per week for two teaching classes.*

### ***Are you on your own or with the group of children with disabilities?***

*She's with the group and feels very well with it. Recently she is feeling sympathy for a boy. She seeks him all the time, goes to him. She knows all the children and seeks them when she comes. She asks where is this one, where is the other one, when will he/she come?*

### ***She attends only music and sports classes?***

*Yes.*

### ***Doesn't she study general subjects?***

*There's no way for this to happen. As knowledge, she knows the vowels as morphemes. As graphemes she knows only three sounds. She knows the numbers up to 5 but can count to 10. She related the name with a figure to 5. They are now studying from 6 to 10.*

### **What are your aims for her?**

*To learn for all vowels to connect graphemes with morpheme and for the figures from 1 to 10. We are trying to count but only with illustrative examples – addition and subtraction. Possibly if she learns the numbers from 6 to 10. She doesn't know the colours. She should know at least the main ones. For other knowledge.....I can't see it happening. I don't think she has capacity for more. These are my aims for this year.*

### **And your long-term goals?**

*I can't say. I should see what would happen with the accomplishment of these so that I could build over them. If she doesn't accomplish them, we continue with them. This is the idea with us – repeated, on-going repetition.*

### **Don't you think that she however could learn other general subjects with pictures? For example history, geography...? With pictures and more simple language?**

*We have pictures with things from the home and she doesn't know most of them. Maybe next year we'll try for her to recognize certain historical persons. Vasil Levski, Hristo Botev....I can't say from now. I'll try.*

### **Do you think that next year she could start attending more classes?**

*I can't say again. I'll try. The work with her is maximum 10 minutes. She gets distracted very easily. Originally I tried to work only with her in a room but then I decided I deprive her from contact with the group. And decided she'll be part of it. But as I said, she gets distracted very easily. We could stay in a geography class, for example, but we could be only listeners. Because they are 6<sup>th</sup> grade and 6<sup>th</sup> and 7<sup>th</sup> grade are extremely difficult as subjects. For this year, my idea is for her to get used to the class, the children and possibly after that to build upon this.*

### **And with regard to integration?**

*I think it's going well. I think that integration for her is not related to the educational material but with the children, among her peers. In my opinion if the children from the whole school accept her, this will be a success for me. I think this is breaking the isolation. Because even if I teach her academic knowledge, I don't think it would be useful in her life. If I teach her the colours, what is this, when the sun is shining, what it is when the moon is shining, when the stars are – during the night or the day...These are things which are learned in early childhood. This is the result of her life in Koznitsa. She cannot make difference between a boy and a girl, man and a woman. Between the separate cutlery.*

### **Is there something else you would like to share?**

*The earlier you start the better. There are classes who don't accept these children. We have problems with parents too: why do you take these children to the other? You traumatize and frustrate them in this way. Elena is not the heaviest case. There are children in wheelchairs who I cannot take to the class. The teachers don't want them; the parents of children don't want them. Only for a child where the teacher is more open, we managed to get the wheelchair in the class. So the fact that Elena can go where she wants at school and her recognition by the other children is a success, in my opinion.*

### **But you think that the place of these children is in an integrated school?**

*I don't know. Especially recently with our problems that they want to close the special schools... I've been working 20 years in such a school and when it's said that these children go to a mainstream school, there's a big resistance. If it's first grade, it's much easier. Also for the other children because they too understand that there are such people who live among us and that unfortunately their number is increasing and these children see it's not only this home, not only the children from it, but that there are also other people and situations. The earlier it starts the better for all parties.*

## **4.2 Participation in local cultural life**

The residents of SGH "Siyanie" have participated in every public event in the Kyustendil since the service was opened in 2010. There are many initiatives on the calendar: The Cherry Festival, Earth Week, Easter, 1<sup>st</sup> of March (Baba Marta), Children's Day, and others. The SGHs' participation in bazaars and exhibitions is active. The team

never misses the opportunity to present the service, show off the clients' multiple talents, and give the children and young adults the opportunity to practice their social skills. The most recent significant participation was in the first Plovdiv fair for social enterprises, organized by the National Alliance for Social Responsibility, a membership organization in which Cedar participates.

The number of general community members who attend events organized on SGH property is also increasing. The children often hosts holiday parties, usually implemented in partnership with the 1<sup>st</sup> and 7<sup>th</sup> primary schools, "Zdravets" kindergarten, or the Fine arts club at the Municipal Children's Complex. They are attended by many guests, including children from the neighbourhood. Service staff report noticing a gradual change in public attitude towards the clients, sensing more tolerance, understanding and acceptance.

### 4.3 Leisure time and recreation



is not only sport but entertainment. Currently (June 2012) these activities have been suspended due to the absence of Coach Kostov from Kyustendil, but they will be renewed upon his return.

Fourteen-year-old Elena and eight-year-old Georgi take part in a camp for children's participation, organised by the National Children Network in Gergini village, Gabrovo district. The aim of the initiative is to teach children how to participate fully in the decision-making process, how to actively take part in public life and make their wishes be heard. This is the first time when Elena and Georgi are away from the environment in which they live. It is also the first case of participation of children with intellectual disabilities in a similar type of large-scale mainstream event. This is a challenge for the two children but they cope very well and become everybody's favourites. They manage to integrate very well among their peers and find many new friends.

In 2011 the young adults, six girls and three boys have the chance for the first time to go to a seaside vacation in the town of Kiten, Burgas district. Common activities such as shopping, walking and lounging on the beach, eating in a restaurant, and organising evening entertainments make users a part of the resort community. It is an unforgettable experience.

The Foundation negotiates for the children and young adults to attend, at no cost, the municipal swimming pool and weekly dance classes in the Municipal children's complex. They take clients to see the circus, a puppet theatre, make day excursions to nearby places of interest, and take nature walks.

From autumn 2011 through January 2012 eight young adults participate in athletics activities with track-and-field and Special Olympics coach Radoslav Kostov. The initiative comes entirely from him and he works with the young people free of charge. For the young adults this



## 4.4 Inclusion in Specialised services: Kyustendil Day Centre and Rehabilitation Centre

Children from “Siyanie” currently attend the Day Care Centre “Faith, Hope, Love” or the Centre for Social Rehabilitation and Integration managed by the foundation “The Institute for Social Policy and Social Work” in Kyustendil, for several hours a week. There they receive support from staff psychologists, rehabilitators and speech therapists and engage in activities such as:

- Psychological rehabilitation;
- Speech therapy rehabilitation;
- Labour therapy – daily living skills and habits such as cooking, cleaning, laundry and serving;
- Social-integration activities – walks in the community, discussion about different buildings and their uses, skills for safely crossing streets, shopping, etc.
- Music therapy
- Art therapy – drawing, gluing, pottery
- Development of study skills
- Conflict resolution

## 4.5 Employment

A significant challenge for Cedar is securing the labour employment for the young people from the SGHs for adults.

*“Employment is the best means for social inclusion and at the same time a source of income and opportunity for a decent living. For Cedar service users, it is also a way to feel like everybody else, as part of the community. It is hard for a person to feel complete, independent and free if he or she is not provided with equal access to labour. This is Cedar’s main task related to the young adults placed in the SGH – to help provide them with opportunities for employment.”*

*Margarita Parmakova, Manager of the SGHs “Siyanie”*

Cedar’s attempts to include the young adults in different programmes of the labour bureau are unsuccessful. They are ineligible to apply for these programmes due to the system used in Bulgaria for analysing the labour capacity of persons with disability. The clients have been labelled by the Labour-expert doctor commission (TELK) as being 90-100% unable to work due to their disability. This precludes them from being able to apply for employment.

One of the biggest achievements of Cedar regarding the social inclusion of the clients through employment comes from the initiative of Mrs. Radostina Nocheva, Director of “School nutrition” for the Municipality of Kyustendil, following a discussion with the Mayor Mr. Peter Paunov. In March 2012, two of the young women who live at the SGH “Siyanie” sign an agreement with the Kyustendil Municipality to work voluntarily as assistant hygienists in a café in town. One of the labour therapists in the SGH is provided with a research paper (Supported Employment: Creating a Working Model for Bulgaria, Irina Papancheva, 2009, Unpublished manuscript) about the supported employment model and receives guidance about the work of the job coach so that she can support the girls in their working place. At the time of writing this publication (June 2012), Petia and Ani work twice per week for two hours per shift. The goal is that if they are happy to continue working, a labour contract will be signed with them and they would switch to working full time.

*“The decisions regarding the choice of staff to carry out the whole activities of the organisation are always difficult and hide risks and fears. With Petia and Ani my fears were not in a direction that they wouldn’t manage with the given tasks but rather whether and when we will find the right way to support the potential they have. The support to people with intellectual disabilities is a process which requires commitment and in which the individual characteristics of every person should be considered and innovation and non-standard approaches must be allowed. This is the place to emphasize that without the support of the „Siyanie” team who are people with professional experience and knowledge of these issues, I wouldn’t have made this decision. The colleagues who work in the place where Petia and Ani work are acquainted with the disability of each of them and are aware of the difficulties and the need for support. The resulting communication is effective and appropriate for their level of understanding. They al-*

*ready participate in the preparation of the working schedule which encourages them and makes them more independent in their work."*

*Radostina Nocheva, Director, Municipal Enterprise "School nutrition"*

## **Interview with Maya Serafimova, Sales Coordinator, "Champions" confectionary**

### **How do the girls from SGH "Siyanie" manage?**

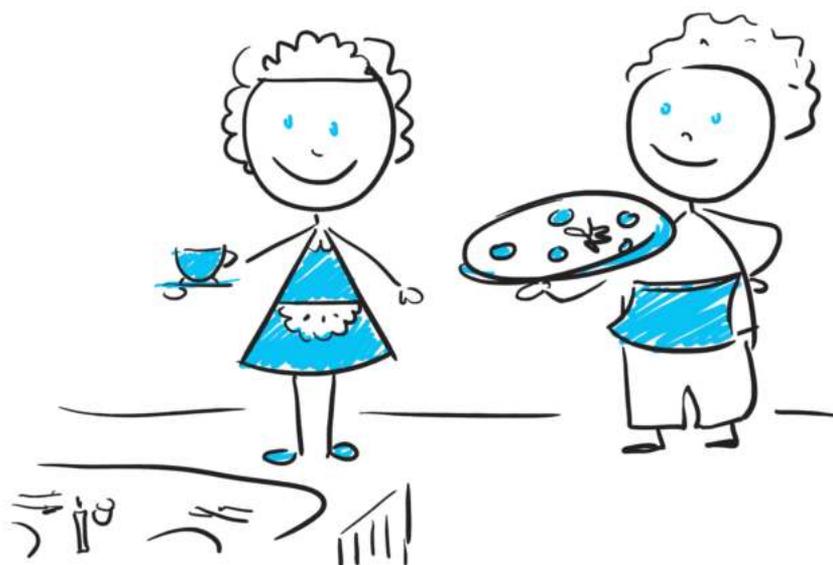
*They are very good girls. At the beginning it was a little bit difficult for them but after a month they started working on their own. Not completely but little by little. They are doing better during the last days. I noticed that they don't seek us to stand by them all the time, they get used to the tools they are given and start to differentiate them – what they are used for – and even there's sequence in the order of their use. Apart from becoming more independent, they communicate better with the whole team of the sweet shop.*

### **And do they integrate well?**

*Yes, absolutely everyone accepts them very well in the team, as well as they us. We think of them as our colleagues, as part of the team. At the beginning it was difficult to communicate with them, for the obvious reasons, but now we understand each other perfectly. Our communication is much better.*

### **And they have capacity for work?**

*Yes, they have such capacity.*



### **Would you send a message to the employers in Bulgaria who are still afraid to undertake similar step and to employ people with intellectual difficulties?**

*I would say to them to try. Not to be afraid, to try but there should be something in their hearts as well. To have the will and the patience and to give a hand to these people. We should have this mentality, without it things will be more difficult. There's something to gain from these children, they have capacity and I think they'll be pleased too and the employer will be satisfied. I'm glad this is happening. I'm very pleased with what I do. My colleagues too. We are also pleased with the work. Yesterday when I was on my own, I wouldn't have managed without them. The hygienist was off sick and the girls really helped me. They were perfect. Maybe because they were independent, without her, and were perfect. I was really amazed by them yesterday.*

*In May 2012 one more service user is employed with a part time contract. Ivan will be packaging the production for export to France at the “International Composite BG – AD” company, which produces sinks, three times per week for a couple of hours. He will have a contract and be paid for his work on the base of the minimal wage for the country. Ivan is very enthusiastic about this opportunity and has already been at his work place together with an SGH staff member who has been explained the basics of the work of the job coach. In addition, Cedar representatives, Margarita Parmakova and Levko Ochipalski, the job coach, hold a meeting with Ivan’s future colleagues in order to support his future integration in the team.*

*These are the first steps towards implementation of a supported employment model in Bulgaria before even there is an official methodology for this type of a service.*

## **Interview with Irina Papancheva, Acting Operations Manager, The Cedar Foundation**

### **What does supported employment mean?**

*Supported employment consists of services designed to enable people with disabilities to obtain and maintain employment on the open labour market. These services provide a range of assistance such as job finding and coaching, providing equipment to help the person carry out their tasks, specialized job training and individually tailored support and supervision. The concept behind supported employment states that anyone can work if they are provided with the right circumstances and the right job. A valid rule for the model implementation is to find a job in line with the preferences of the client focusing on their talents instead of the disability. Another essential formula for the model is the triangle: real job – real work – real salary. In most countries where supported employment is developed, it focuses mainly on persons with intellectual disabilities and mental health problems and enables them to work on the open labour market.*

### **What steps did Cedar take toward implementing the model?**

*I shared a study I wrote during my training, on supported employment, with the two persons whom we wanted to train for taking over job coach functions. After they read it, we discussed the role of the job coach. The next step was to talk with the future boss and colleagues of the potential employee. We stressed their abilities, positive sides and desire for work and asked the staff to include them socially and to treat them as any other colleague. Now we are constantly following their progress and advising the job coaches on next steps.*

### **What challenges are you facing?**

*Surprisingly, we haven’t faced any challenges so far. The two employers as well as the colleagues have been extremely open and supportive. And the two young women are very capable and are doing a very good job. The young man is now starting but has already had first experiences at the workplace and is also managing and is very enthusiastic about it. This is all very exciting since these are the first attempts of putting supported employment into practice in Bulgaria.*

### **What needs to be done in order for the model to be distributed in the country and more persons with intellectual disabilities to be hired on the open labour market?**

*The first step is the creation of a good practice which we are currently doing. Next this good practice needs to be shared so that more people start believing in and trusting the labour capacity of persons with intellectual disabilities and mental health problems. The ultimate goal should be the creation of a national methodology for the services comprising supported employment so that their establishment would be funded by the state.*

## **4.6 Policy work**

In 2011 Cedar significantly increases its presence on the Bulgarian and European social stage by developing more focused policy work. In October Cedar representatives pay a visit to Brussels and have a number of meetings with the key players in the area of deinstitutionalisation and children’s rights, including representatives of the European Commission, the Flemish authorities and the European NGO sector. One of the results of this visit is the creation of **The Cedar Foundation Position on the Action Plan to the National Deinstitutionalisation**

**Strategy and the Monitoring Report** in which Cedar outlines the main challenges in front of the reform in Bulgaria and makes recommendations for overcoming them. The Position is sent to the Directorate-General for Regional Policy and the Directorate-General for Employment, Social Affairs and Inclusion at the European Commission as well as to the Bulgarian Government and the National Association of the Municipalities. The Cedar Foundation holds meetings with Mrs Valentina Simeonova, Deputy Minister for Labour and Social Policy, Mrs Nadya Shabani, Chair of the National Agency for Child Protection and Ms Lili Tsonkova, Deputy Mayor of Kazanlak Municipality to discuss it.

The Cedar Foundation also contributes regularly to the Eurochild organization's policy documents and to all the relevant discussion and strategic/legislative documents in Bulgaria and Europe in the sector.

## 4.7 Communications

Cedar realises the importance of communication in raising public awareness regarding children and persons with disabilities and the deinstitutionalisation process and uses a variety of channels for this purpose.

The Foundation regularly updates its bilingual website with all new initiatives, reflected also in the monthly newsletter (again prepared in Bulgarian and English). The Foundation sends out press releases on all the events it carries out. The Facebook group is another important tool which Cedar uses in order to inform about its work and cause. In the beginning of 2012 Cedar organized for part of its staff one-day training on communications and contacts with the media. A result of this training is The Cedar Foundation Action Plan for Improving Communications.



### LOOKING BACK, LESSONS LEARNT:

Here we share what we are learning as we continue to promote social inclusion in Kyustendil and in Bulgaria:

- **Get all stakeholders on board**

Social inclusion cannot be achieved if all stakeholders are not cooperating toward this goal in their different positions and capacity. The state, the local authorities, the persons with disabilities themselves, their families, service providers and representative organizations and the local community – all of them have their role and function for ensuring social inclusion.

- **All areas of life are important**

Social inclusion is a complex process involving all areas of life. Educational integration ensures social inclusion for the children. In order for them to be included when they graduate however, they need to move to the next level, labour integration. Access to health care and treatment is essential for ensuring the well-being of disabled persons. Integration in the life of the community is social inclusion in day-to-day practice. These areas are all interconnected and interdependent and must be horizontally represented in every social inclusion policy.

- **Tackle social exclusion**

In order to achieve social inclusion start with tackling the obstacles which face it, which comprise the other side of the coin – the social exclusion. By clearly addressing the problems in all the above mentioned areas, the policy makers and actors are setting the scene for looking for creative and functional solutions.

- **Approach social inclusion as a cross-cutting issue**

Include social inclusion and the barriers facing it in all state, district and municipal policies and offer solutions and create action plans for overcoming them. Only when social inclusion becomes a well-structured and closely monitored policy will it be possible to achieve its complete and consistent realisation.

- **Focus on the individual**

There is no general case of social inclusion. It is always about the individual life of a human being with their own issues and ways of overcoming them. While the overall policy is essential for creating the conditions for achieving social inclusion, the individual work and the person-centred approach are the en-

gines driving it. The two go together and are interconnected. The policy gives the framework, whereas the individual support creates its content and ensures the best use of it.

- **Communicate your work and cause as much as possible**

By informing the society about your work and cause you are increasing the public awareness of the issues you deal with. In this way you influence the general attitude towards children and/or adults with disabilities, create better understanding of the challenges they face and their rights and contribute to paving the way to full social inclusion.

## 5. Challenges – children and young adults with challenging behaviours

### 5.1 Rumen's story

*"Rumen is a charmer. Always the first to greet visitors at the gate, always ready with a smile, Rumen was among the staff's favourite residents and was the one whose name guests always remembered after a visit."*

*Lindsay Saltsgiver, Operations Manager, The Cedar Foundation*

Rumen, 26 years old, spends the majority of his formative teenage and young adult years in the institution for Children with Intellectual disabilities in Gorna Koznitsa. Before that he lives in another similar institution, entering at the tender age of 6 months. He is high-functioning, verbal, mobile, and physically strong. He is diagnosed with moderate to severe mental retardation and epilepsy.

The Home in Gorna Koznitsa, in many ways, suits him quite well. Its location out in the country means fresh air and wide-open spaces, and he is provided by Cedar with his own room, which he shares with one to three other male residents at different times over the two years before the Home is closed. He can come and go as he pleases – no one holds him to the same schedule other residents are to follow – and he does not have to participate in his own care or any other activities if he doesn't feel up to it. He is at the very top of the hierarchy which rules the web of social interaction in the institution; his status gives him the pleasure of feeling that he rules over others, and gives him carte blanche in how he treats his fellow residents. He is, at the time, not particularly aggressive or violent. He is in fact quite well-liked by most – or at least it seems so – thus he is granted the freedom to feel as though he is in charge, with little to no interference from the staff.

Unfortunately, because he lives his entire life in an institution, Rumen's development falls far short of his potential. He has only attended school for brief periods during his life (and that, a "special school", meaning he is not responsible for himself academically), and he has learnt no skills or engaged in any activities which could be useful to him in his adult life.

*"He was famously lazy – staff often had to ask him to bathe, and joked about how he would never clean his room – but this also reflected a deep-set learned helplessness, or complete lack of motivation to take care of himself. He had learnt no social skills or boundary limits, and he often had to be asked to step away to give someone more personal space. Though he was well-liked, it was clear that he had not been given any opportunity to reach his potential. He was deemed fit for moving into an SGH for higher-functioning residents, with the goal of one day living more independently in a Supported Living environment."*

*Lindsay Saltsgiver*

Rumen is excited about moving into the newly-renovated apartment in the centre of Kyustendil. He has visited the town a multitude of times, seen the small houses being built, and taken part in activities specifically designed to help him positively adjust to a new community. Unfortunately (and in opposition to Cedar's recommendation), the Bulgarian government allows Rumen to be separated from his best friend Ivo, when Ivo is chosen to be one of the residents to move into the Protected Home in Marchevo. Also, due to delays in the renovation process of the apartment, he does not see his new residence until the day he moves in, an oversight which the Cedar Foundation would later regret. But Rumen is clearly looking forward to the big moving day, and he takes to his new life with a positive curiosity. Or so the Foundation thought.

*“We began to see signs that something was wrong about four months after Rumen moved to Kyustendil. During November 2010 Rumen complained several times of back pain and headaches but no medical cause was found and the symptoms disappeared. During February 2011 however Rumen began complaining again of a series of symptoms which often accompany epileptic seizures. Again, no physical cause was found despite a series of tests; the medical teams who attended to Rumen expressed their suspicion that he was faking the symptoms for sympathy. In reaction to these episodes his neurologist increased his dosage of epilepsy medication.”*

*Lindsay Saltsgiver*

Staff, on the other hand, begins to notice a distinct difference in Rumen. He is suddenly pale and seems much weaker. He also begins to weep frequently and stare into space. Staff reacts with compassion and gives him all the attention they think he needs to bring his health back. But Rumen begins reacting to others around him in a much different way.

In early March 2011, Rumen attacks one of the other residents of the apartment, nearly breaking her finger. This is to be the first in a series of episodes, occurring over a period of several months, during which Rumen breaks windows, furniture, and objects in his apartment, and physically attacks both staff and roommates. He often hurts himself in the process, cutting his hand on glass or banging his head against the floor. He has panic attacks, complaining about his new residency and demanding to be brought to the new houses to live with the children.

*“We were shocked. How could such a pleasant and outgoing young man so suddenly become an entirely different person? How did we not see this coming? And, most importantly, what was wrong and how could we fix it?”*

*Lindsay Saltsgiver*

Cedar turns to an array of experts to help solve this problem. The Foundation describes the situation to its advisors abroad, who give a lot of detailed feedback regarding behavioural analysis and possible triggers for Rumen’s strange behaviour. Quite insightfully, considering they were not in Bulgaria, they point out several reasons for this transformation:

- Rumen no longer feels the privilege of being at the top of the hierarchy; he is now living with three others who are close to him in age and ability;
- For the first time in many years he is being treated equally with others around him;
- He is no longer given free reign over his day’s activities – he is now expected to participate in his own care and in other activities with the apartment’s residents (walks, gardening, etc.);
- He is now confined to an apartment, much smaller than the institution and its grounds, and any time spent outside is now supervised by staff;
- He now sees many other people without disabilities in the centre of town and is reminded that he is ‘different’ – a fact which is very difficult for someone of such high cognitive ability to deal with.

Wanting the staff to come to similar insights as a team, Cedar holds a series of team meetings focused on Rumen’s situation and possible causes and solutions, and tasks them with describing what Rumen might be feeling. They come to the very same conclusions as the foreign advisors.

Cedar also turns to the psychiatrist in Kyustendil who has worked with Rumen before; she at first is categorical that it is a behaviour problem and not medical, then entertains the possibility of schizophrenia, then again determines that it is a behavioural issue. The Foundation visits another psychiatrist in Sofia, who diagnoses schizophrenia and prescribes additional medication. Cedar hires a local psychologist to work with Rumen and the staff; she blames the problem on the staff’s methods of working with Rumen. The Foundation works with his general practitioner and neurologist, who can find nothing physically wrong. Cedar’s attentions are torn in all directions and a comprehensive plan of action needs to be developed.

Cedar needs time, to plan its strategy and to repair the extensive damage that is done to the apartment, including replacing the windows with unbreakable glass. Rumen is admitted into the psychiatric ward of the Kyustendil hospital for 30 days, during which time:

- The windows are changed and the apartment is repaired;
- The psychologist works with the staff and discusses new methods which they are to use to deal with Rumen’s problem behaviour;
- Rumen’s medications and physical and psychiatric health are completely re-evaluated;

- Cedar develops strategies for helping Rumen feel more in control and adjust to his surroundings, without feeling the need to become destructive;
- Cedar slowly acclimates Rumen back into his apartment, through short visits.

Interestingly enough, Rumen at first claims that he enjoys the psychiatric ward. He is allowed to come and go as he pleases, and soon learns the routes to the children's houses and his own apartment. He meets others in the ward, though again occasionally displays aggression toward the other patients. It seems as though, because he has lived his whole life in an institution, he is most comfortable in an institutional environment. There, he is not expected to participate in any activities to contribute to his own care, and he is left to his own devices in all matters. However, by the end of his time in the ward he expresses a readiness to return to his apartment.

After Rumen returns, there follows a long period of readjustment. Rumen is given the opportunity to completely redecorate his bedroom (which he shares with one other resident). He is slowly brought back into the daily routine and activities, but not pressured to participate beyond his own initiative. He is allowed brief periods of freedom outside the apartment, and given small tasks outside which would allow him to independently function in the community. He is given an old laptop and taught how to use a drawing program and, feeling important, he often referred to himself as the 'boss'. Staff no longer caters to his every whim; they treat him with respect but do not allow him the opportunity to bully or dominate others around him. For many months Rumen responds positively to the small changes made and Cedar thinks the problem has been solved.

Unfortunately, it is wrong. In December 2011 Rumen begins exhibiting aggressive behaviour once again, this time causing injury to several staff members. The staff working with Rumen begins to quit their jobs, and with the help of British volunteers Peter and Bridget Charlesworth, Cedar develops a new behavioural plan and re-trains all staff in physical restraint and methods for dealing with Rumen's outbursts. Despite the training received and the relatively favourable staff ratio of 1:4, it is impossible for the staff to handle him when he is having his episodes.

*"Normally during the day we had one person per shift and the team leader. But the team leader in the case of the young adults is one for the two flats so she has to share her time between them. It was hard to believe that one person cannot keep Rumen under control, especially with him not being very physically big, until I experienced it myself. There were two women from the service staff holding him from the two sides but it was extremely difficult for them to calm and quiet him. He was turning sharply in the two directions and was trying to bite them. Then he started also kicking so two more persons, one of whom a man, held his legs. Even for four persons it was hard to keep him. It took two-three hours until he gradually calmed down and agreed to go out for a walk. It would have been absolutely unthinkable for one or two persons to cope with the situation. And this happens in a service with double as many staff as the numbers set in the national methodology. How would the other services which are hiring so much less staff manage persons with challenging behaviour then?"*

*Irina Papancheva, Acting Operations Manager, The Cedar Foundation*

In the end, to protect the other residents of the apartment the Foundation is forced to initiate court procedures to check Rumen into another psychiatric ward in Bulgaria, this time for six months. The doctors evaluating him there preliminarily diagnose him with schizophrenia, and Cedar is planning for two possible outcomes, depending on their final diagnosis: Providing more training to its staff in the SGHs in stricter procedures for dealing with problem behaviour, and exploring options for Rumen's transfer to a service which is better suited to his needs. Cedar is also considering opening a residential service for people with challenging behaviour, though this will take a considerable amount of time and will require a significant change in the contributions made by the Bulgarian government.

*"This is a heart-breaking story for all involved; Rumen is very close to the hearts of many who work with him, and we all feel as though we've failed him somehow, especially if he eventually needs to re-enter an institution in Bulgaria. However we also know that we are doing our absolute best with the resources on hand. Our current situation imposes limits on what we can handle. In an ideal situation, we would have three times the number of staff working in the apartment, which would make his outbursts manageable. In an ideal situation, we would have an extra room for the creation of a safe isolation space. In an ideal situation, our staff would include people who are highly qualified, well-paid behavioural management experts. But with such little support we are forced to weigh the consequences and do the best with what we've got, at least for the time being."*

*Lindsay Saltsgiver*

## 5.2 Maria's story

The story of Maria also reveals the challenges faced by the service team, and how they currently deal with them. At the same time it demonstrates what could be the reactions and behaviours of a child who is placed in a new and unfamiliar setting.

Maria spends her whole life in institutions without individual care, attention or love, without secured adequate specialized help. Maria is fifteen years old and is diagnosed with severe intellectual disability. She displays autistic and challenging behaviours, and has not developed speech communication skills.

Maria usually separates herself far from the other children in Gorna Koznitsa Home, looking fixedly at the ground and making no overtures to establish contact. Originally she didn't cope well with her move into the new service. Due to the short time for adaptation, orientation and getting used to the new environment, she becomes insecure which increases her crises. She shouts for hours, hurts herself and is aggressive to the staff and other children. Emergency services are contacted often in order to give her a sedative. She sees the child psychiatrist in Kyustendil and her therapy changes several times. She is also taken to Sofia for a consultation with a child psychiatrist there.

The treatment prescribed by Sofia doctors turns out to be successful. She significantly increases her height and weight, becomes calmer, stops hurting herself and starts smiling and seeks visual contact with other children. However, in January 2011 her condition changes again – she becomes restless and aggressive. The outbursts with shouting and self-aggression and isolation return. She is temporarily admitted to the psychiatric ward of the Kyustendil hospital. Her therapy is changed again. Maria is now calm, seeks contact with staff and no longer shows aggression to herself and other children and staff.

*"The constant changes in Maria's condition and the need for adequate care were a huge challenge for the service staff. At the beginning they were shocked by their own inability to deal with the situation, to help the girl, to calm her down. The staff wasn't able to deal with Maria's behaviour not because they didn't want to but because they hadn't really accepted that this could happen and that they could face this problem many more times".*

*Margarita Parmakova, Manager of Kyustendil SGH "Siyanie"*



### LOOKING BACK, LESSONS LEARNT:

Here we share what we are learning as we continue to learn better ways to work with challenging behaviour:

- **Conduct a thorough risk assessment for every resident**

It is crucial that a thorough risk assessment is conducted, by experienced professionals, for every single resident who will be moved into SGH services. Rumen had a risk assessment, but the assumption was made that he would be among those to most quickly adjust to the new setting. Not everything can be predicted, of course, but had we considered the matter more deeply we would have predicted several of the factors contributing to Rumen's stress. It is very important that this is completed beforehand so that these causes of stress can be avoided, if possible.

- **Train the staff in behaviour management procedures well in advance.**

No matter how passive or how aggressive residents are in the institution, staff of the new services should always be thoroughly trained in behaviour management procedures before the services open. This provides them with tools which give them confidence that they can handle any number of different situations, which once they arise can become frightening for staff.

*"Our staff was trained in the basic theories of behaviour management (behaviour always has a cause, safety is the most important priority during a crisis, using trust and communication to prevent challenging behaviours) and were introduced to physical restraint and calming methods, but not thoroughly enough. Frankly, we didn't think we would need this. But we did – and*

*we now know that Rumen will probably not be the last case in which we need to handle situations involving severe aggression"*

*Lindsay Saltsgiver*

- **Make the staff aware of the potential of challenging behaviour**

Staff should be informed well in advance that challenging behaviour will be in some cases unavoidable, and they should be prepared to have to handle it. This is one of the toughest problems Cedar faced – staff's complete disbelief that they would have to handle such behaviour. This in some cases caused them to resign the first moment problems arose. Even staff who had worked with the residents in the institution were baffled by the situation. Whereas before they could simply throw the client out of the classroom to let him be aggressive by himself on the institution grounds, now they no longer had that option and had to face the situation indoors using their own skills. For most of the staff this was too much to handle and they ended up resigning.

- **Encourage professionals to embrace deinstitutionalisation**

Service providers must make a serious effort to encourage professionals in the community to embrace deinstitutionalisation as a step forward for Bulgaria. One can imagine our disappointment when hearing from psychiatric professionals in Kyustendil that it was our mistake to even consider bringing these clients to live in the community. Whereas the Foundation thought that they would support the idea, they were in fact blaming Cedar for changing the status quo, and openly disapproved of the work Cedar has undertaken in the project. It was difficult to help professionals see that Rumen was everyone's responsibility, just as a regular patient is the responsibility of both the doctor and the patient, and this affected the quality of care he received.

- **Do not underestimate the effects of living in institutions on a person.**

Do not underestimate the effects that a lifetime of living in institutions can have on a person. Despite his outwardly social behaviour and high potential, Rumen was very damaged by institutionalisation and will need a lot of work in order to be able to live more independently.

- **Lobby the federal government to increase funding for staff numbers in SGHs.**

It is impossible for clients to receive individual support and care in a situation where one staff member is forced to work with 8-10 children or young adults with intellectual disabilities (this is not even possible for children without disability). Our practice shows that even a 1:4 ratio is not the best solution but is, at least, a starting point. Without the provision of high quality care and individual work with each user, it is impossible to achieve social inclusion.

- **Ensure there's a full range of community-based services available**

A full range of community-based services which meet the users' needs and their specific situation should be developed before total closure of the institutions. Services for people with challenging behaviour do not exist in Bulgaria and there are not enough trained professional capable of reacting appropriately and adequately. It is necessary to develop methodologies for the missing services and to secure their financing and the training of the staff.

## ***Interview with Ella Kobets, Kazanlak coordinator, The Cedar Foundation***

### ***How did you start working for the Cedar Foundation?***

*I started working for "Cedar" foundation in 2006 as a volunteer and a few months after that I began working full time. I think it was at the charity event in 2007 at the Army club, Mark shocked me with the following words: "I'm sick of making repairs at the institutions. I won't do it anymore." Then I thought that the Foundation would discontinue its activities. It was a shock for all in the room. His next words were: "We'll be closing institutions because life in an institution isn't worthy for any Bulgarian child". And then we understood that the direction of the foundation was changing and that we would be heading down a new road.*

### ***Did you participate in the process of closure of Gorna Koznitsa?***

*Our whole team participated in this process directly or indirectly. I visited the institution for the first time when the child assessments were done by Mary Crane's group. I supported Toni in coordinating the logistics of the visit. We arrived in*

Kyustendil, and during the first few days we waited for permission from the Bobov dol municipality to enter the institution. We didn't know until the end what would happen, but Mark was very persistent and this helped a lot so that we got the permission to continue our work.

Every time I go to Kyustendil, I remember this first time. What I felt was shock. It wasn't my first visit to an institution but I had never imagined it could be so horrible. The living conditions of the home where children live and the children themselves, they shocked me. They didn't know how to behave. They didn't react to what was happening around them. They didn't have any knowledge of how one should behave in public. I was afraid, as I neither knew how to react, nor where to look. I remember that Mary Crane held my hand and told me: "You're shocked at the moment and this is normal".

### **What did this experience give you regarding your activities in Kazanlak?**

The road we took to where we are now is significant. I thought that for the closure of this home at least five years would be necessary. I thought it was impossible to be achieved but the time necessary for things to happen was impressive. When I understood that we would be doing the groundbreaking for the services in Kyustendil, I couldn't believe it. The staff also changed a lot, thanks to the trainings; the children also changed beyond recognition...all that motivated me to keep working. Today, I feel much more confident and experienced, and wouldn't be at my wits' end as we all were that first time.

### **The living conditions in Buzovgrad, where you have done work, are much better. Do you think it should continue existing?**

I'll never accept the existence of institutions – neither for children, nor for adults. After the institution in Buzovgrad is closed, the building could be used to set up something like a hostel or a crisis centre, where people from different socially vulnerable groups could have temporary housing. But no closure could happen without sufficient alternative services and both processes should go in parallel. Kazanlak is privileged with the Municipal Day Care Centre which Cedar also helps support. The work they do there is very high-quality, and they adequately support their clients. Support services should provide care for the development of children according to individual programmes, otherwise these services turn into something else.

We had big hopes for the Day Centre in Buzovgrad. We supported them for a long time, and hoped that it would develop with the right methodologies and programmes, in which the staff would develop professionally and would be able to contribute to the deinstitutionalisation and alternative services development. We helped build the Centre, which worked successfully for a year with staff provided through funding from The Cedar Foundation. During this time we managed the structure of the work, and we did what we could to teach them about different programmes the staff could use for their work with the children. These are the programmes ABA (applied behavioral analysis) and PECS (Picture Exchange Communication System) for children who cannot communicate verbally. During that time it was encouraging to see what the children achieved, but unfortunately this relationship ended.

Similar methodologies could be applied in the whole country. We now provide staff, training opportunities and guidance to the municipal Day Care Centre in Kazanlak. The management of this Centre accepted our methodologies and continues working with them. These are very effective programmes because with ABA the staff analyses the behavior of the child and develops an individual plan according to the child's abilities and his or her behavior in the community. It includes absolutely everything – child's hygiene, clothes, communication in the community, understanding about close and unfamiliar people, and development as a whole. I hope that this Day Care Centre will provide a good model for how other Centres can work, and I hope that they will be able to give support to the children who will be placed in the future small group homes in Kazanlak.

# Phase Seven:

## Sustainability and Additional Services

Ultimately, true socialisation and integration also means that the surrounding community demonstrates a sense of responsibility and ownership toward the fate of social services and the people utilizing them. We envision, one day, a Kystendil in which people of all backgrounds will be active stakeholders in the social services offered to our residential clients. The municipality will have the full capacity to manage the services successfully, peers and schoolmates of the clients will take interest through friendships and cooperative activities, and our clients will take part in every aspect of community life alongside other community members.

For obvious reasons any SGH service developed needs to be sustainable. In previous chapters we outlined how much the Cedar Foundation currently contributes financially to the running of the service, but we also concede that for any service provider – NGO or municipality – this is impossible to sustain over a long period of time.

Additionally, the development of the residential service should be merely the first step in a long process of social inclusion and socialization of clients exiting large institutions. While the quality of the residential service is very important and managers should continually work to improve the quality of care provided in the SGH, measures should also be taken in the community to further develop supporting services and opportunities for social inclusion.

We believe in focusing our energy on helping the former residents of the Home in Gorna Koznitsa achieve social inclusion to the utmost of their potential, and strategically The Cedar Foundation is committed to implementing more projects which will directly affect the residents from Gorna Koznitsa. This chapter outlines some of our thoughts regarding what the future should hold in any community where residents exiting institutions are soon to be welcomed.

### 1. Sustainability of the Residential Service SGH

*“The sustainability or the stability of the social service depends to a big extent on its ability to preserve its main components – structure, aims, strategy, policies, ways of working, and financial sustainability during significant external or internal changes. In Bulgaria it’s difficult to meet the requirement about sustainability of project results following the withdrawal of an NGO, the organization or the sponsor who secured the funding. Sustainability means to maintain the results of the project – a quality social service after the period when the project is funded by an NGO.”*

*Margarita Parmakova, Manager of SGHs “Siyanie”*

#### 1.1 How to achieve sustainability?

There should be a **clear strategic plan** which defines the vision and the mission and the activities for their implementation. The strategic plan focuses upon the path the service would like to follow and how this would be achieved. This document – an important and obligatory requirement for the management of the organization, should be logical, clear, and consistent, without going into details and should form the basis for the work of the service.

The definition of the **aims and the objectives** of the service allow the strategic plan to be implemented. They should reflect the users’ needs and to be adaptable – the change in these needs should lead to a change in the service aims. Through this process we can give an exact characteristic of the situation we are in at the moment and to define the place or situation we would like to be.

**Clearly defined priorities** should be set, which do not get bogged down in details, do not stress upon inessential distractions and do not waste human and financial resources. The planning of aims and priorities should take into account the individual needs, abilities and talents of the users, and at the end of the day should not be too ambitious or unattainable. If the aims are too ambitious then at a certain stage of the service development they could turn into a demotivating factor both for the staff and the users.

An important condition for accomplishing good sustainable results is the process of **risk planning and assessment**.

*“There are always risks, especially given that the service works with a specific and fine material called the human being, which often is difficult to control and manage. That’s why, it’s necessary to identify, analyse, monitor and have a contingency plan to prevent risk situations and control them in case they happen. Sometimes the risk situations arise out of conflict in the teams and then it’s necessary to implement an appropriate approach for conflict management – open discussion, understanding and establishing an atmosphere of trust among team members.”*

*Margarita Parmakova*

**Good team work** is key. Even if they are not included in defining the general main goal of the social service strategy, the team members should participate in planning the service aims and periodically assess the accomplishments which would make the team much more effective. If the team members have the feeling that they not just meet some organizational aims but also develop professionally and personally, then this will motivate them and be a stimulus for achievement of even bigger results. All suggestions which come from the staff should be discussed and reviewed equally. This strengthens the trust among team members and is an indicator for openness and transparency of the service management.

**Motivation** is a driving force in the life of every person. There are mechanisms which can guide, support and stimulate people to be internally motivated. When the staff is convinced, sufficiently prepared, stimulated, feels prepared and at the same time sufficiently autonomous and has opportunity to be creative in dealing with a certain problem, then this serves as additional motivation.

There should be clear and accurate **quality and quantity indicators** for monitoring and evaluation of the service development. This is one of the best ways to measure development as the risks for mistakes are minimized and there is a clear and accurate picture of accomplishments, which respectively is a prerequisite for good planning. The introduction of systems for measurement of effectiveness, efficiency and the quality of the social service is an important prerequisite for its sustainability.

**Sufficient and well trained human resources** form the backbone of good social services. A quality service is set up with optimum number of staff who is well trained and supervised. The process of service development and later on development of a sustainable model of this service is impossible without on-going support training aimed at increasing the effectiveness of the staff’s work, to make them feel confident, to build upon their professional knowledge and skills with the aim to prevent professional burn-out.

Creation of a quality service without the necessary **financial resources** for the implementation of a variety of activities and securing sustainability and development of the service is impossible. The financial resources should correspond to the scale of the envisaged aims and objectives. Despite that the state funding gives to a certain extent security of the service, it’s not enough to guarantee sustainability and high effectiveness of the work.

A short-term and long-term plan – a **management strategy** – which is both clear and innovative and is based on the mechanisms for transparency in the management and active participation of the staff, will ensure the sustainability of quality in any service. The management process is complicated and often contradictory. It requires good knowledge of the strengths and weaknesses of the staff, delegation skills and effective mechanisms for control upon the entire service functioning and feedback about the way the whole system functions. The management body should be able to unite, motivate and manage its team but also itself and the whole working process.

Any quality service is a means for social inclusion, but this cannot happen without **partners in the community**. When the general public is informed, the organization is persistent in initiating joint initiatives, and everyone works together to build tolerance and a joint respect, then the needs of the service users will be consistently met.

## 1.2 Fundraising

For any social service, fundraising is a key element to ensuring financial growth and offering quality care to clients. We are all aware that government funding for SGHs is not anywhere near adequate, and service providers should continually lobby for increased allowances per client. **Fundraising should never have to substitute for adequate government funding, especially when the caretaker-client ratio is at stake.** This is, unfortunately, the current state that SGH services are in, and unless the Bulgarian government takes measures to increase funding for social services, this will remain a great challenge to service providers. That being said, even if it is not an NGO who is the service provider, the structure of the service itself should always allow opportunity and stimulus for the engagement in fundraising activities in the community.

Fundraising can take many different forms, and does not always have to result in financial gain in order to be useful. For example, clothing drives are very practical especially when the target group, due to various reasons, frequently has to change clothing or will grow out of their clothing quickly. Clothing drives can also be very fruitful, as in Bulgarian communities there are often many people who cannot help financially but would like to contribute something. Their second-hand clothing means relief to an already-stretched service budget (though it is also important to uphold the dignity of our clients as much as possible – stained, ripped or ruined clothing should never enter the wardrobes of the clients of an SGH).

These are just a few ways in which extra funds can be obtained for critical service expenses. Other types of fundraising activities or events could include:

- Charity concerts, fairs, dinners
- Raffles or auctions
- Coin collection at local merchants
- Child or carer sponsorship programs
- Corporate material donations
- Local clean-up fundraisers
- Cooking or baking contests / sales
- Photo, film or artwork contests
- Holiday gift drives
- Art and craft exhibitions or sales
- “Wish list” drives
- Municipal small project programs
- Sports challenges or tournaments
- Book fairs or clubs
- Consignment sales for charity
- Small grants from funding organizations

Based on our experience in fundraising in our SGH service “Siyanie” in Kyustendil, we recommend the following:

- Always make sure that you report all funds raised – the public always likes to know what the final tally is – and how the money will be used. Transparency is the key to building trust on a local level, giving people the will and desire to contribute again when given the chance.

*“I think that the main reason why people contribute to the Cedar Foundation is that we believe in what we do and they see a real desire to change things for the better in the lives of children and young people with disabilities. People see that we are honest, that we use their funds as we said we would, that we do quality work and mostly that we do it with a lot of passion and will. This infects people and encourages them to help us with what they can. If they are from the business sector and don't have a lot of time, they provide financial means. The environment is also changing and people in Bulgaria are opening up to such activities and are more likely to support different causes and to help people in underprivileged situations.”*

*Toni Stoykova, Marketing and Communications Coordinator, The Cedar Foundation*

- The more the personnel from the service is involved in planning the fundraiser, the more ownership they will feel over the results, and the more enthusiastic they will be during the implementation. Challenge them to come up with fundraising ideas. Make sure they are involved at every step of the way, and congratulate them at every opportunity.
- The clients should also be involved as much as possible, but be wary of exploiting their efforts in any way.
- Local media should always be invited to fundraising events or activities.
- Make sure you develop procedures in the service for thanking donors or sponsors on a regular basis.
- It is helpful to have someone on staff who has experience in (or the professional aspiration to learn) grant-writing. Small grants can be obtained from many different sources, and can fill in gaps in the service budget left by lack of government funding.

## **Interview with Toni Stoykova, Marketing and Communications Coordinator, The Cedar Foundation**

### **How long have you been with Cedar?**

*I've been working for The Cedar Foundation for more than four years. I joined at the beginning of 2008 when the idea about the home had already matured but the process was at the very beginning. It was in February 2008 when I first visited the home with Mark and [Cedar Board Member] Liane.*

### **So you were directly involved in the closure?**

*I attended all the meetings with Mark in order to translate but this gave me the opportunity to learn much quicker about the ideas he had for Bulgaria. So for me this was also a training process. My main task was to co-ordinate the process which included meetings with the two municipalities for the right closure of the home and development of new community-based services. My task was also to facilitate the trainings of foreign experts for the Gorna Koznitsa staff. Part of my responsibilities also included support of the charity ball organization and fundraising.*

*The beginning was difficult. The smaller local authorities didn't recognize best practices according to western standards and what had already been working abroad; the central state agencies and the bigger municipalities managed to react more adequately. We had to come up with creative, working solutions in the context of what we had. However, later things changed with a lot of advocacy and persistency on our side so as a whole my impressions are that there's a hope for change. People realize what needs to be done, and what I mainly learned is that we should aim for the best but we should be also realists and take into account the Bulgarian situation. We started closing the home when the world economic crisis had come. Bulgaria was also affected, and this was reflected to a great extent in the national budget, mostly in the social sphere.*

### **"Cedar" is an organization which has very successful fundraising in Bulgaria and your work is directly associated with that. How do you do it? How did you manage?**

*Credit for this should not go entirely to me, especially at the beginning when I joined and there was already a well-established network of partners and sponsors. However in general we try to be creative in what we do and to raise funds in ways where every party wins, for example the business gets PR and a positive public image, or through the charity events we provide entertainment for everyone. We strive to provide something in exchange for the funds we get as donations. Our aim is not only to receive but rather to provide a good service for the donor, which is useful to him, and the funds are used for our projects.*

### **Is there something from your experience in fundraising that you would like to share with other organizations as a message or a recommendation?**

*For the fundraising, I would advise all organizations to adopt a more business-oriented approach, rather than a purely charitable one. Many people whom we solicit for financial support are in the business sector, and they would like to see that they are making a deal, rather than a donation. Thus it's always valuable to have something positive for the business itself. We are also very clear on where their money is going. What a business wants to see is very clearly prepared budget, how and where the money will be spent. People should be predisposed to "buy" the project.*

### **Is there something else you would like to share from your experience and time with The Cedar Foundation?**

*Because at the beginning, I participated much more in the coordination of the project and the negotiations with local and central authorities: What I could share is that at the beginning I was very disappointed by some of the meetings. It was very interesting for me to find out how the whole state system works and how the individual cases are treated - I saw that there wasn't a lot of individual treatment. With time things are changing and there's more of a desire for effectiveness in state agencies and structures. We meet more and more determined people and I'm very happy with that. I notice a big difference between how people worked then and how they work now that the idea of deinstitutionalization has matured. People get more used to that idea and already are really working for its successful implementation.*

## 1.3 Volunteers

Volunteers are also a key element in the successful development of good services. They bring a dynamic atmosphere to the workplace and can contribute a considerable amount of expertise, energy, and skill to the services. As anyone who has volunteered their time or skills knows, what develops is a mutually-beneficial relationship – the volunteer also gains a sense of well-being when he or she gets involved in helping out the client base. Volunteers also come in many shapes and sizes, and can be recruited from many different areas.

At the Cedar Foundation, we host several different types of volunteers:

- **Volunteers, expert in special needs:** Several groups and individuals with specialized experience visit the services in Kyustendil on a regular basis and give free consultation and/or training based on our needs.
- **Youth volunteers:** We usually host at least one large group of youth volunteers per year. These volunteers are not highly skilled but usually help in the implementation of fun and creative activities in our services – summer day camps, building or constructing playground equipment, spending time with the clients.
- **Other skilled volunteers:** Artists, filmmakers, fundraisers, writers, lawyers, doctors, carpenters - anyone with a specific skill and the desire to help can be included in making the service better for its clients.
- **Fundraising volunteers:** These volunteers assist the Cedar Foundation in our fundraising efforts, which benefit the services in Kyustendil.
- **Local Friend/Mentor volunteers:** We are currently developing a program and looking for local volunteers to spend time with the clients on a regular basis.
- **Interns:** Bulgarian students of social work and/or special education are usually required to complete a number of hours in an accredited social service. At the time of the writing of this material, we have one intern working in our services, Bilyana Stanoeva. Bilyana has been a great asset to the services in Kyustendil, and we hope that she has learned a significant amount in her time with us as well.

Volunteers are essential to providing a quality, dynamic service. They are also a great way to get the community involved in the lives of the clients. In many communities where the public has not been exposed to people with disabilities or people who have lived in institutions, it is very important that every effort is made to build positive public relations and a positive public attitude toward the clients. Volunteer programs can be a great tool not only in giving clients exposure to community life, but also in helping community members adjust to the newest demographic in their town or village.

It is also very important that work with volunteers is strictly regulated; measures should always be taken to protect the interests, rights, and safety of the clients at all times. At the time of the writing of this document, the Bulgarian Act for Volunteers is being revised to protect the rights of children – this should, of course, guide all work done in a service with volunteer assistance.

For the safety of both the volunteer and the client, and for the sake of creating a smoothly-operating volunteer program, we also recommend:

- Organizations and services should have manuals and policies for work with children and/or vulnerable adults. Ours is entitled, “The Cedar Foundation Policy for the Protection of Children and Vulnerable Adults,” and includes all procedures which we undertake Foundation-wide to protect our clients and any other vulnerable groups associated with the Foundation, as well as staff and volunteers – from volunteer screening policies to procedures for transporting clients or children in a staff member’s car. This is very helpful when any questions arise regarding volunteers.
- Background checks should always be provided by volunteers. We require them for any volunteer who will come in direct contact with our clients. This is common practice internationally, especially when adults are to come into contact with children. While this is no guarantee that the volunteers you work with are harmless, it is a great tool for “weeding out” any undesirable persons.
- Volunteer contracts or descriptions should always be drawn up to outline the parameters of any volunteer’s work. Annexed to the contract should be a volunteer plan, which outlines the goals and activities of the given volunteer’s work with the services. Service personnel should discuss this plan thoroughly with the volunteer before drawing up the contract.
- When working with international volunteers, especially expert volunteers, we have found that it is important to help Bulgarian staff make a strong connection between their profession and that of the volunteer. Sometimes staff is hesitant to incorporate methods introduced by foreign volunteers into their daily work – often they have a difficult time comparing their work with the work of the volunteer. Strong and progressive leadership is required to help staff grow professionally, and to take suggestions or advice from foreign experts.

- Also when working with international volunteers it is important to provide those volunteers with continual support. For most international volunteers the Bulgarian mind set is a bit of a mystery, at least at first – they need some encouragement to help them understand where Bulgarians are coming from, and to help them “meet their Bulgarian counterparts where they are”.
- Youth or inexperienced volunteers should never be left alone or to fend for themselves with clients. Activities should always be well-supervised. With expert volunteers, while the risks associated with leaving them alone with clients are smaller, they should be used to *train* Bulgarian staff in methods, not take over for them or do their job.

## 2. Spectrum of supporting services and partnerships

It is increasingly obvious to us that residential services should form only the backbone of a spectrum of services offered in any community for people with disabilities. Three other types of services currently exist in Kyustendil – a Day Centre for Children with Intellectual and Multiple Disabilities, a Centre for Social Rehabilitation and Integration, and a Resource Centre for Special Education – which offer specialized expertise in working with people with intellectual difficulties. However because their capacity is still too small to handle the increased numbers of clients since the closure of the Home in Gorna Koznitsa, they have been able to pick and choose which clients they will accept into their centres, and who they will not. Thus our clients do not benefit fully from these services. Additionally, the focus of their work has for the most part been on a different target group, children with disabilities who live in a family setting. Clearly, children and young adults who grew up in institutions come with a very different, and often more severe, set of needs. In many cases, even if they are open to welcoming the new set of clients, existing services are unprepared to meet the needs of this type of population.

Thus over time it is also vital that this “spectrum” of services in the community is widened, to include specialists and activities which can meet the wide variety of individual needs of all types of people with disabilities in the region. The Cedar Foundation is currently working on building the Foundations for such services. Additional services could include:

- **Occupational services:** As described in Chapter 6, This type of service should be aimed at assisting people with disabilities in obtaining gainful employment based on their individual needs, skills and abilities. This could include anything from the establishment of a centre, workshop or business specifically designed to hire people with disability, to career counselling, training and job mentoring programs for people ready to enter the external work force, with local businesses.
- **Civic participation services:** In many cases people with disability are excluded from civic and recreational participation due to lack of access, social exclusion, or discrimination. An organization which lobbies and works for the rights of people with disabilities and develops opportunities to encourage and enable civic participation is an important part of any community which welcomes all to participate in community life.
- **Housing services:** Housing services help people with disability find appropriate housing, and may offer assistance with daily living activities.
- **Therapeutic services for adults:** Children are not the only target group which can benefit from different types of therapy. However few services are aimed at providing adults with therapeutic programs, and such services need to be developed.
- **Wider variety of therapeutic services for children and adults:** There are many different sources and types of therapy which, although highly effective, are as of yet untapped in Bulgarian communities. We would like to see a much wider variety of therapeutic activities – art, music, dance, therapeutic riding, for example, become available to both children and adults in Kyustendil.
- **Wider variety of educational services for children:** While in Bulgaria resource services for children with learning disabilities have drastically improved, there still remains a big deficit in capacity, and most existing programs are not yet equipped to serve the educational needs of children exiting institutions and entering the community. We believe that a whole spectrum of educational support services needs to be developed in Bulgaria, which would include special schools and mainstream education.
- **Early Intervention programs:** Early intervention has been proven to be very important in the treatment of people with intellectual disability.
- **Foster care programs for children with and without disability:** Foster care is the next step in the spectrum of residential care programs for children with or without disability. When implemented correctly, foster care is an excellent, more effective alternative to SGHs, and we hope that someday SGHs will be replaced by foster care in Bulgarian communities. For children with disabilities, foster care parents must be specially trained.

- **Adoption programs:** In the past several years, Bulgaria has made significant progress in reforming its adoption procedures. However there is much left to be done to improve the processes for assisting Bulgarians and foreigners who wish to adopt children from Bulgaria.
- **Prevention and parental support programs:** Programs, in which trained social workers work with risk groups such as new parents, teenage parents, and parents of children with disabilities, should be implemented in every community in order to prevent the abandonment of children in institutions or community-based residential services.

## *Interview with Mark O’Sullivan, Founder and Executive Director of The Cedar Foundation*

*When you look back at all that Cedar has done since the closure of the institution, how do you feel about it – what do you see?*

*In some instances I’m very encouraged because I think that it’s very good that the government has changed a lot of its policies... now there is a plan to close all institutions; when we started closing the Home there was no such plan in place. They were still talking about restructuring and basically renovating institutions. So I feel our doing what we did has really helped as well to get the government to start looking at the problem from a wider perspective in the right way, in other words to close down all institutions. It’s always going to be a very difficult process because it’s a huge, complex issue.*

*So the discouragements have been things such as still not having proper alternative care for children or young adults with extremely challenging behaviour in Bulgaria. This is something that needs to be addressed immediately. The other obvious discouragements are: as a profession in general, for people working in the alternative care services, the wages are just not enough. It’s hard to attract good people, no one wants to work for that kind of money – which is a real problem. They need to start finding ways and means of raising the standards of all the professions involved in deinstitutionalisation, of raising the profile so it can become a more attractive job. That needs to be of the highest priority.*

*I still have worries because still I think there are one or two institutions that might slip through the net.*

*If you had the chance to repeat the process now, would you do anything differently?*

*One of the things I think we failed in (although we had no other choice really) is that I would not have four small group homes together. But we were forced to because of the budget which was made available. It makes it much harder to integrate disabled people in the community when they’re kept together in larger groups. Better to spread them out around the community. If you have a house where there are only three or four kids then people don’t see them as such a big threat. And the public, instead of being a force working against them, becomes a force working for them. We fought as hard as we could, because what we got it from – they wanted to build one house for twenty-four kids which is another institution. So we managed at least to get it to four separate houses and it has only a capacity of 16, but even still that should never happen again because in a few years that’ll be completely outdated.*

*We were put in an impossible situation because there was no plan from the government regarding how you cater for the period of the closure. We were put under incredible pressure just to take people out of the institution and shove them somewhere else, which is obviously the wrong way of doing it. They also tried to do it in one straight line: to close the institution on a Thursday, and open the new services on the Friday. You can’t do that. We put together a plan of how you would look at placing the residents, from the perspective of caring for their rights. But it became impossible to implement because we just didn’t have enough staff to be so spread out – to be in different places at once.*

*The other issues that need serious consideration are the development of the other relevant institutions in the community. In particular, things like hospitals – their ability to cater for disabled people, so we don’t have situations like we had with one of our residents – a girl who was strapped to a bed because the psychiatric ward couldn’t cope with her autism. The government needs to look at resourcing hospitals and other institutions so that they also can cater for our residents.*

*There needs to be much better, closer coordination between all the services that would be used by the users: schools, day-care centres, the hospitals, so that everybody’s aware of a particular resident, what their care plan is, making it more efficient to be able to deal with them.*

### **How do you think this can be achieved?**

The short answer is I don't know. You have to look at developed systems around the world, see where it works better, try and look at what makes it work and then adapt it so that it can work in Bulgaria. Ultimately I think there needs to be a massive report done, a very detailed one with very workable solutions to the key problematic areas. Also the national strategy and Action Plan need to have built-in review systems to allow the plan to adapt... What seems to be a modern approach today will most likely be completely outdated in 2020.

### **When you look at Cedar services, which do you think are the key areas of improvement from now on – where is improvement most needed?**

It's hard to identify one area as they're all connected, but for example the immediate care that the residents are receiving needs to be improved. The clients need more one-to-one attention. Development will only take place if a human being has a trusting relationship with someone else. To make that possible you need people available to do it. So you need more people working with the residents so that they can begin to trust them and they can begin to develop. Also if somebody's assessed properly and deemed that they're at a certain level then the resources should be made available to provide a higher level of care. At the moment it just doesn't exist.

So they need to produce services that can work in a quality way with people with challenging behaviour. We're caught in a sort of vicious circle where a lot of what we're doing is just what we call 'plugging holes and putting out fires', rather than actually seriously implementing individual care plans and different things like that. Somebody has to spend quality time with Maria, with Rumen all of them – they just need far more attention than they're getting. It's as simple as that and we can't do it as our hands are tied as the budget isn't enough. They need to find a way of making a bigger budget for those that have a higher need – and that's urgent.

### **What's next – which direction do you see Cedar taking from now on, how do you see its development both as an organization and as a service provider?**

The ultimate project is integration, so continuing to, for those who are employable, to find employment for them; for those that are unemployable, provide them with therapy to improve the quality of their life; to work more in the community to raise awareness for the struggles of disabled people and to make sure that society's not letting people slip through the cracks of the system - buildings, roads, they're being made accessible for disabled people.

It's not just the child who's disabled, it's the whole community that's disabled, and we need to make the community less disabled and more able to cope with the people that live in the community - not just a certain section of the people. So that means working more and more with for instance the municipalities like Kyustendil, helping them with their regional plans, their district strategies and making sure that it's up to standard. But definitely we need to focus on integration – integration of the children into schools, development of the schools so that they can help with integration, that the kids should be out of their houses as much as possible during the day so that they get to explore more of the world rather than constantly being kept inside because the community can't deal with them.

We need to be in constant contact with the wider world so that we can provide a channel where help can flow from one country to the other, where expertise, new ideas, new innovation can be passed on. A lot of thought and organisation has to be put into it.

I also definitely believe that we exist to help others and to help others develop. It's as simple as that so I'm very open and happy to help others who are in this process. I think we can offer quite a valuable insight because Cedar involves a lot of foreigners in Bulgaria, so I think we can come at it from both sides, bringing knowledge from the outside in, but also being aware of what's happening on the inside. We've been here long enough and know how frustrating and annoying it is sometimes, how much outsiders can get it wrong. Just because something works in one country doesn't mean it's going to work in another country. You have to be aware of cultures in particular. We would be open to working in as many countries as possible – where it's appropriate and manageable for us.

### **Is there any message you would like to send to other NGOs which will be involved with deinstitutionalisation and will now begin the process, or just to the whole society?**

I remember the best piece of advice I ever got was from somebody who said, "we will succeed because we're right". It sounds very simple but actually gave me incredible encouragement, that you can't stop the flow of what is right. All you need are people with the energy to take it on and keep it going. I would encourage people to not give in too easily or to settle for things which aren't of high quality, because you just end up slowing the whole development down

*and not giving the new alternative services a chance of working. Certainly the simplest thing is you will succeed because you are right.*

*This is one case where you're helping people who have no ability to help themselves so it demands the utmost integrity. Municipalities have got to show absolute integrity with the way they're channelling money, the way they're managing money. Government does, NGO's do – all of us have to try our best to do the right thing in a world where everything isn't black and white. I'm not saying it's always easy, it's not. It's the extreme opposite. We have to try our best to be honest as much as possible.*

# Conclusion

Institutional living violates fundamental human rights. It deprives the individual of his basic freedoms and – when it comes to children – leaves permanent scars in their psychological, emotional, intellectual and physical development. There are many policy and legislative EU and international documents which assert the right to community living and prohibit institutionalisation. All of this, together with the international attention attracted by the BBC film about the residential institution in Mogilino, has triggered a drive for the Bulgarian government to initiate mass deinstitutionalisation reform, starting with institutions for children and aiming at gradually closing all similar settings.

Even before the official start of this reform The Cedar Foundation began its “own” deinstitutionalisation process by closing down, in cooperation with national and local leaders, the Home for children with intellectual disabilities in Gorna Koznitsa. The closure of the Home and the parallel construction and establishment of the SGHs “Siyanie” in Kyustendil, where 24 of the formerly-institutionalised children and young adults now live, has been a journey of learning by doing, by consulting with other countries’ good practices, rapidly gaining expertise and implementing it in day to day work. More than anything it reflects a desire to create a higher quality of life for the children and young adults residing in “Siyanie” and to see their full social inclusion put into action and daily practice. In this journey Cedar has managed to attract the support of many short and/or long term advocates and partners and to win them over for its cause, i.e. the cause of all the children and young adults with disabilities in Bulgaria.

The Foundation has faced a variety of challenges on the way to making its beliefs a reality. The reasons for them have been different: the novelty and freshness of the experience in the context of Bulgaria; the lack of a completed successful local model to follow; the initial lack of expertise; the lack of understanding of some of the key institutions and the prejudices in the local community; the lack of a full set of supporting services which is a serious obstacle to inclusion; the lack of methodology for essential services - and expertise for their development - without which deinstitutionalisation of some of the residents becomes impossible; the lack of qualified staff...the list continues. More importantly, however, Cedar has recognized the challenges and deficiencies as such and has been constantly looking for ways to overcome them.

This has led to such significant achievements as children being integrated into mainstream schools and young adults being the first ones with severe intellectual disabilities to be employed on the open labour market in the country.

The story of Cedar does not presume to be *the* answer to deinstitutionalisation. But it is, without a doubt, one of the possible answers. Moreover this story is an honest account of what the Foundation has gone through, which can be used as a basis for comparison for other organisations which have been or will be dealing with that same process. It also points out some of the weaknesses of the practical realities of the on-going reform, purely with the intention to inspire actions for their timely improvement.

The insights of The Cedar Foundation, shared in this document, have been borne by the clashes between the urgent wish and need for changing lives of those who haven’t really lived a life, and the above mentioned circumstances. Though they have been summarised in seven phases, it is crucial to make it clear that these steps do not guide the overall journey, but only mark its beginning.

# Glossary

## **Alternative services**

Community-based services offered as an alternative to the institutional model. This broadly-defined category includes services which support vulnerable groups in social inclusion, helping clients utilize mainstream services such as health care, education, or employment, or offer residency or housing options in a family-type or foster family setting.

## **Challenging behaviour**

Culturally abnormal behavior(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.<sup>23</sup>

## **Community-based services**

Services provided at the community level, located within (not isolated from) a particular community, and/or organised in partnership with or by the members of the community. Emphasis is placed on the involvement of users in the whole process, including the prioritisation of needs, the service planning and the evaluation of services received.

## **Deinstitutionalisation**

The change in the provision of social or medical services, which involves:

- *On the individual level*, discharging the client from institutional care, into a family setting or into community-based alternative services which imitate the family setting; working to integrate the individual into his surroundings as an equal member of the community;
- *On the administrative or policy level*, systematically replacing large institutions with community-based services.

## **Family setting**

*As defined in this document:* The environment in which a child or adult lives with and is cared for by member(s) of his immediate or extended family and/or relatives through blood, adoptive or marriage lines, such as uncles, aunts, parents, grandparents, husbands, wives, children, brothers and/or sisters. *The United Nations identifies the family as being "the fundamental group of society and the natural environment for the growth, well-being and protection of children"*<sup>24</sup>. An alternative residential service with a "family-type" setting, such as a Small Group Home, may try to imitate this family atmosphere by creating a supportive environment in which the child or adult's needs are met on an individual basis in a small group setting. A situation in which a child is placed with a foster family bridges the gap between the "family" setting and the "family-type" setting, as they live in a natural family setting but with people who are not directly related to them by blood.

## **Family-type setting**

Any social service provided in a residential setting which is intended to replicate the family setting as much as possible, including Small Group Homes, Children's villages or other similar services.

## **Institution**

*As defined in this document:* Any facility which houses children or adults, with or without disability, and provides care based on the institutional model.

*As defined by Professor Kevin Browne (2005), "a large institution is characterised by having 25 or more children living together in one building. A small institution or children's home refers to a building housing 11 to 24 children. Alternatively 'family-like' homes accommodate 10 children or less, usually separated with 2 to 3 in each bedroom."*<sup>25</sup>

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<sup>23</sup> Challenging Behaviour: Analysis and intervention in people with learning disabilities, Eric Emerson, Cambridge University Press, 1995

<sup>24</sup> Resolution adopted by the General Assembly [on the report of the Third Committee (A/64/434)], Guidelines for the Alternative Care of Children (A/RES/64/142), UN General Assembly

<sup>25</sup> De-institutionalisation and transforming children's services: A guide to good practice, Georgette Mulheir, Professor Kevin D. Browne, et. al., University of Birmingham Inst. of Local Government Studs, 2007

**Institutional model**

A model of caregiving which often results in an attempt to meet the *collective* needs of a group of people rather than allowing for the individual's needs and wishes. This model often neglects the individual for the sake of the collective or in favour of the institution's regime, resources and standing in society.

**Integrated employment**

The employment of persons with disabilities through the open labour market, ensuring adequate remuneration, which creates an environment in which they are deemed equals and are fully integrated with their colleagues.

**Job coach**

The person who mediates and supports the process of job-seeking for persons with disabilities by assessing the skills of the potential employee, directing him/her to an appropriate type of employment, teaching the employer and co-workers on how to best integrate the disabled worker into the work environment and how to best make use of his/her skills and capacity.

**Medical model for disability**

A model by which disability is considered to be the result of a physical condition, intrinsic to the individual (part of that individual's own body), which may reduce the individual's quality of life, and which thus creates a clear disadvantage to the individual. Under this model the "problem" of disability is located within the individual, i.e. a person is disabled due to his individual impairments and therefore requires medical intervention to gain skills to adapt to society. This model categorizes individuals by medical definitions and focuses on their impairment and how this excludes them from mainstream society.

**Person-centred approach**

A caregiving approach which focuses on each client as an individual and prioritises his individual needs, wishes, abilities and life story, and which arranges services in a way which enables his needs to be most effectively met.

**Group home or Small Group Home (SGH)**

A family-type setting - a house or a flat - where fewer than 10 people, usually with similar needs, live communally with organised support. In this publication the term "Small Group Home" (SGH) refers to the Bulgarian social service (in Bulgarian, termed "Family-type Residential Centre"), where children or adults receive 24-hour care in a family-style environment.

**Social model for disability**

A model by which the issue of „disability“ is seen as a socially-created problem and a matter of fundamental human rights. In this model, disability is not considered to be an attribute of the individual, but rather a complex collection of conditions, many of which are created by the social environment. Thus, it is *the environment* which creates the disability and deprives the individual from equal participation and inclusion. Therefore the solution requires social action and the collective responsibility of society to make the necessary legal, policy, environmental and mentality adjustments in order to ensure integration of persons with disabilities.

**Supported employment**

A social service model designed to enable people with disabilities to obtain and maintain employment on the open labour market. These services provide a range of support such as job-seeking and job coaching, equipment to assist the person in fulfilling his duties, specialized job training and individually tailored support and supervision.

**Supporting services**

Any combination of planned services in the community which support people with disabilities *outside of the residential setting* and aim to ensure equal access and participation in all areas of community life. Such services include Day Centres, Centres for Rehabilitation and Integration, Educational Resource Centres, and employment services.

# Appendices

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## **Appendix 1 European and international legislative and policy instruments supporting deinstitutionalisation**

### **1. The UN Convention on the Rights of the Child**

The Convention obliges the states “to ensure to the maximum extent possible the survival and development of the child” (Article 6, (2)). It also states that “a child temporarily or permanently deprived of his or her family environment, or in whose own best interests cannot be allowed to remain in that environment, shall be entitled to special protection and assistance provided by the state as well as that the states are obliged in accordance with their national laws ensure alternative care for such a child” (Article 20, (1), (2)). According to the Convention states must recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community ( Art, 23 (1). Further on it says that states must “recognize the right of every child to a standard of living adequate for the child’s physical, mental, spiritual, moral and social development” (Art. 27). All of this is in line with the on-going deinstitutionalisation reform.

### **2. The UN Convention on the Rights of Persons with Disabilities (UNCRPD)**

The convention is an overarching framework for disability which covers all areas of life. It entered into force on 3 May 2008 and was ratified by Bulgaria in the beginning of 2012. The following general principles (Art. 3) are integrated in it:

- Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Art. 7 is focused on children with disabilities and states that “States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children” (1). It also declares that in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration (2). The Convention entitles to the children with disabilities the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right (3). The Convention also pays special attention to the right to living independently and being included in the community (Art. 19) by saying that persons with disabilities “have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”(1). It puts forward the access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. Deinstitutionalisation is the process which ensures the exercise of these rights when properly undertaken.

### **3. UN Guidance for children living in alternative care**

The UN Guidance for children living in alternative care is another important document supporting deinstitutionalization. The Guidance clearly proclaims that every child and young person should live in a supportive, protective and caring environment that promotes his/her full potential. It also concludes that “children with inadequate or no parental care are at special risk of being denied such a nurturing environment.”(II. General principles and perspectives; A. The child and the family). The Guidance further imposes the responsibility for protecting the rights of the child and ensuring appropriate alternative care to the state, with or through competent local authorities and duly authorized civil society organizations, where the child’s own family is unable, even with appropriate support, to provide adequate care for the child, or abandons or relinquishes the child. The guidance makes it very clear that it is the role of the state, through its competent authorities, to ensure the supervision of the safety, well-being and development of any child placed in alternative care and the regular review of the appropriateness of the care arrangement provided. Another important issue which is stressed on is the quality of alternative care provision, both in residential and in family-based care, in particular with regard to the professional

skills, selection, training and supervision of carers. Their role and functions should be clearly defined and clarified with respect to those of the child's parents or legal guardians. (VII. Provision of alternative care)

#### **4. Charter of Fundamental Rights of the European Union**

The Charter has a special Article 24 on the rights of the child. It says that "children shall have the right to such protection and care as is necessary for their well-being" (1). It further continues that children may express their views freely and they shall be taken into consideration on matters which concern them in accordance with their age and maturity. The Charter underlines the supreme character of the child's best interests in all actions relating to children, whether taken by public authorities or private institutions (2). Article 26 is focused on integration of persons with disabilities and proclaims that "the Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community". There is no way these rights to be exercised in a segregated institutional setting.

#### **5. Europe 2020 Strategy**

Inclusive growth is one of the three main strands of the Strategy. It means more and better jobs, investment in skills & training, modernising labour markets and welfare systems and ensuring the benefits of growth reach all parts of the EU. This should be achieved through 2 flagship initiatives:

- Agenda for new skills and jobs - helping people acquire new skills, adapt to a changing labour market and make successful career shifts
- European platform against poverty - guaranteeing respect for the fundamental rights of people experiencing poverty and social exclusion, and enabling them to live in dignity and take an active part in society; and mobilising support to help people integrate in the communities where they live, get training and help to find a job.

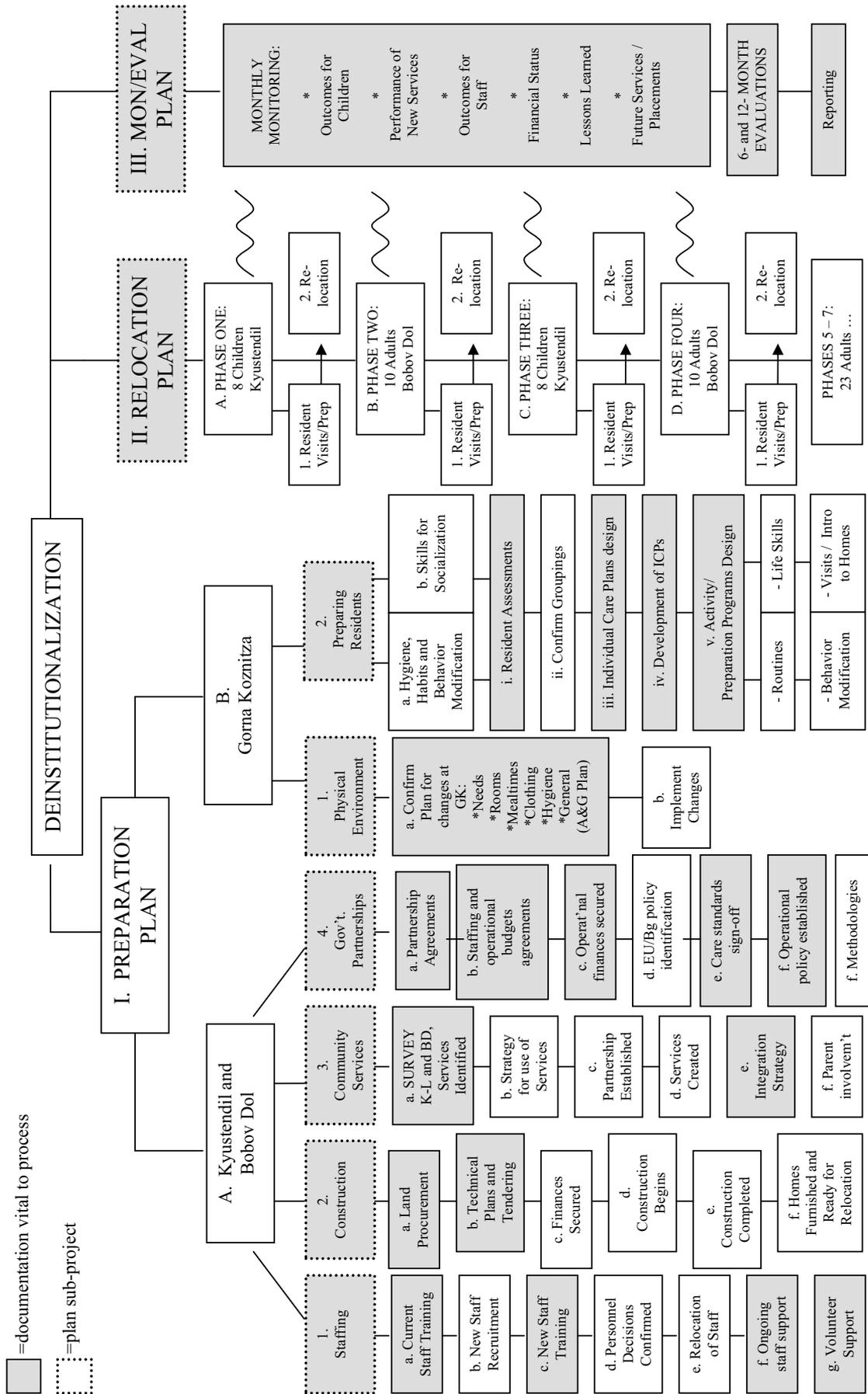
This links to the deinstitutionalization of young adults and their integration in society taking employment as the best means for social inclusion.

#### **6. European Disability Strategy 2010 – 2020**

The eight areas of action of the Strategy are Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health, and External Action. The Strategy recognizes the necessity of integrating appropriately people with disabilities, in particular children, into the general education system and providing them with individual support in the best interest of the child. It also says that the Commission will support the goal of inclusive, quality education and training under the Youth on the Move initiative. In the Participation area the Strategy declares the engagement of the EU to support national activities to achieve full participation of people with disabilities in society by "providing quality community-based services". In addition it engages itself with promoting the transition from institutional to community-based care by: using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people. It also voices the intention EU action to support national activities to achieve the transition from institutional to community-based care, including use of Structural Funds and the Rural Development Fund for training human resources adapting social infrastructure, developing personal assistance funding schemes, promoting sound working conditions for professional carers and support for families and informal carers. In the Employment area the Commission is willing to "pay particular attention to young people with disabilities in their transition from education to employment...; to develop services for job placement, support structures and on-the-job training" and "to enable many more people with disabilities to earn their living on the open labour market".

#### **7. The Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006 – 2015**

The Action plan has 15 action lines among which Community living, Education, Social protection and Employment, Vocational Guidance and training. The Action Plan proclaims that people with disabilities should be able to live as independently as possible, including being able to choose where and how to live. It stresses that opportunities for independent living are "first and foremost created by living in the community". CoE recognizes that enhancing community living requires strategic policies which support the move from community care to community-based settings, ranging from independent living arrangements to sheltered, supportive living in small-scale settings. This understanding also turns the wheel of deinstitutionalization.



### Appendix 3: Kyustendil Small Group Homes Floor Plan



## Appendix 4: Sample Transition Plans

Name of Resident:	Date of Relocation:
Location of New Service:	Type of New Service:
GK Staff overseeing Relocation: New Service Staff overseeing Adjustment:	Other GK Residents moving to service:

### Preparatory Visits to New Service:

#### **VISIT #1: Introductory Visit**

**Date:**

- Resident is introduced to primary care staff of new services
- Resident is introduced to other service users in new services
- Resident is provided with a tour of new service facilities; sees living quarters and dining quarters
- GK Staff is introduced to primary care staff of new services

Notes (resident reactions, does the resident understand that they will be living in new services, reaction to staff and other service users, reaction of staff/other service users to resident):

#### **Visit #2: Getting to Know You**

**Date:**

- Individual Care Plan (ICP) is completed for resident and provided to primary care staff of new services
- GK Staff and resident meet with primary care staff of new services (ICP review, transition plan review, resident character discussed)
- Resident allowed 1 hour of individual activity time with at least one primary care staff of new services
- Resident is taken on short tour of the community

Notes:

### Visit #3 and Relocation: Transitioning into New services

#### DAY ONE (Arrival):

- Resident sleeps in new sleeping quarters and eats in new dining quarters
- GK Staff accompanies resident in all activities with primary care staff in new service
- GK Staff and primary care staff in new service assist resident in unpacking and decoration decisions (minimal funds to be provided)

Notes:

#### DAY TWO (Adjustment):

- GK Staff accompanies resident only partially during daily activities
- Resident and primary care staff of new services decorate room and settle resident in
- Group activity with resident and other service users (new care staff and GK staff)

Notes:

#### DAY THREE (Farewell):

- GK Staff meet with primary care staff of new services to discuss transition and make final edits to ICP
- Primary care staff conduct individual activity with resident
- GK Staff says brief farewell to resident and returns to Home in GK

Notes:

### TRANSITION SKILLS and RISK ASSESSMENT

Objective: Skill to be acquired	Method	Projected Outcome (Resident will...)	Responsible party	Objective met (date)

## Transition Risk Assessment

Are there any associated risks in the transition of this young person? If so, please state, together with agreed strategies/sanctions that can be adopted by care staff (old and new).

## Appendix 5: Staffing Charts, Institutional vs. Community care models

### Institutional Model (Gorna Koznitsa Institution)

Employees responsible for administration		Employees working directly with client	
Director	1	Nurse practitioner	1
Accountant	1	Head nurse	1
Steward	1	Staff nurse	3
Cashier	1	Hygienist	13
Driver / Purchaser	1	Rehabilitator	1
Stoker (heating systems)	2	Educator	10
Laundry attendant	2	Assistant Educator	3
Cook	2		
Assistant Cook	1		
Tailor	1		
<b>Total</b>	<b>13</b>		<b>32</b>

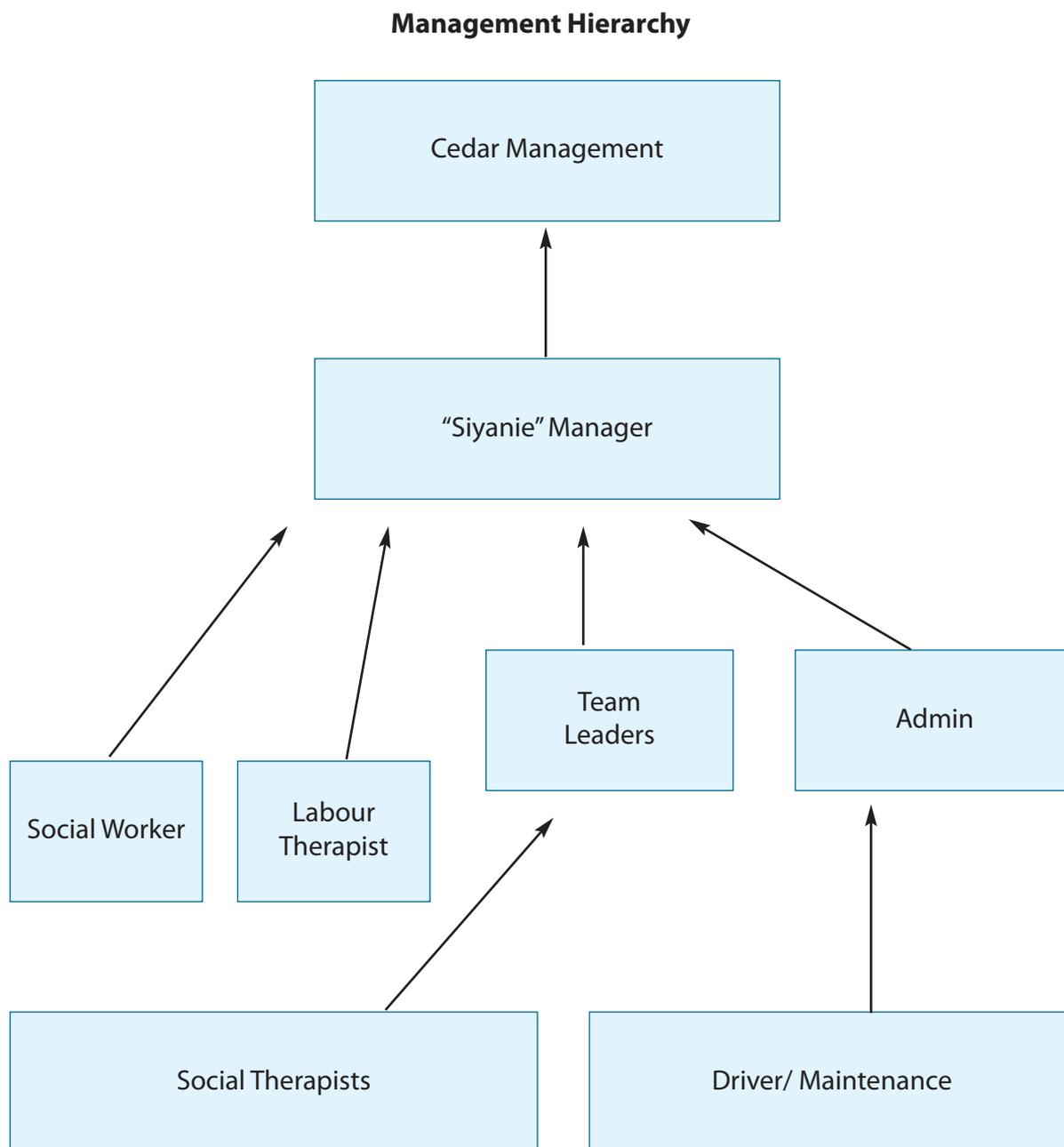
### Community-based Services Model (SGH Siyanie-Kyustendil)

Employees responsible for administration		Employees working directly with client	
Director	1	Key Social Worker	1
Accountant	1	Labor Therapists	2
Driver/Handyman	1	Team leaders	3
		Care workers	25
<b>Total</b>	<b>3</b>		<b>31</b>

### Comparison chart: Institutional model v. SGH model, personnel

	Employees responsible for administration only		Employees working directly with client	
	No.	%	No.	%
Institution (GK)	13	<b>29%</b>	32	<b>71%</b>
SGH Siyanie	3	<b>9%</b>	31	<b>91%</b>

## Appendix 6: SGH "Siyanie" Management structure



## **Appendix 7: Policy and Procedures Document List, Cedar Foundation SGH Siyanie Kyustendil**

As of April 2012, this is the current version of our master list for all documents guiding our work in the SGH “Siyanie”, Kyustendil. We regularly update this list, adding or streamlining policies as necessary. Thus, it is a constantly evolving document, and while it is thorough, there is always room for improvement. Readers can use this as a baseline for the documentation they develop for newly-created SGH services in Bulgaria.

### **The Cedar Foundation SGH “Siyanie” - Kyustendil Policies and Procedures for the Management of the SGH Service**

#### **I. General Documents:**

<b>ID</b>	<b>Document</b>	<b>Location *</b>
1.1	Service development programme	SGHs and CMU
1.2	Schedule of service activities	SGHs and CMU
2.1	Total annual service budget	SGHs and CMU
2.2	Individual SGH budgets	SGHs and CMU
2.3	Payrols	CMU
3.1	Outside sources of financing	CMU
4.1	Fire Safety Service	CMU
4.2	Labor Safety Service	CMU
4.3	Security company	CMU
4.4	Companies responsible for upkeep, maintenance and installations	CMU
5.1	Orders book for internal directives	CMU
6.1	Daily report Notebooks – see Report Books, IV.3.3	--
7.1	Ethical code, signed by employees	SGHs and CMU
7.2	Philosophy and responsibilities	SGHs and CMU
7.3	Principles of Care and Support of SGH Clientele	SGHs and CMU
7.4	Written procedure for solving problems of an ethical nature	SGHs and CMU
8.1	Rulebook for Internal Order (RIO) with signatures	SGHs and CMU
8.2	Meeting minutes from discussions of RIO with children/clients	SGHs and CMU
9.1	Bulgarian methodology for SGHs for children	SGHs and CMU
9.2	Bulgarian methodology for social services for people with disabilities	SGHs and CMU
9.3	Bulgarian Child Protection Act	SGHs and CMU
9.4	Bulgarian Integration of People with Disabilities Act	SGHs and CMU
9.5	Bulgarian Social Assistance Act	SGHs and CMU

## II. Safety and Security

ID	Document	Location *
1.1	Plan of Action for Personnel in the case of fire, flood, or emergencies of a similar nature	SGHs and CMU
1.2	Fire Evacuation Plan – approved by authorities	SGHs and CMU
1.3	Fire evacuation map/diagram	SGHs and CMU
1.4	Procedures for the registration of incidents and notification of the appropriate authorities	SGHs and CMU
1.5	Annual risk assessment	SGHs and CMU
1.6	Plan of Action for Personnel in the case of emergency electrical cutoff and the restarting of gas elements	SGHs 1,2 and CMU
2.1	Protocol for team action in the case of incidents and emergency crisis situations	SGHs and CMU
2.2	Plan of Action in the case of a missing client	SGHs and CMU
2.3	Procedures for the safe-keeping and use of potentially harmful substances and access to the medical storage box	SGHs and CMU
2.4	Report book for emergency/crisis situations (incidents)	SGHs
2.5	Rules for the prevention and restriction of unacceptable behaviors	SGHs and CMU
2.6	Registration book for deceased clients and procedures for notifying the competent authorities	SGHs and CMU
2.7	Plan of Action for Personnel in the case of escalating aggression in a service user's behavior	SGHs and CMU
3.1	Policies for receiving visitors in SGHs	SGHs and CMU
3.2	Procedures for receiving clients' close friends or relatives and the implementation of visit observations	SGHs and CMU
3.3	SGH Visitation Registers	SGHs
3.4	Plan of Action in the case of Aggressive Behavior on the part of a Visitor	SGHs and CMU
4.1	Procedures for filing a complaint or petition	SGHs and CMU
4.2	Rules governing the activities of the Commission for Reviewing Complaints and Petitions	SGHs and CMU
4.3	Files for every complaint or petition and the actions taken by the service provider to eliminate the violation	CMU
4.4	Procedures for working with children to protect them from violence, abuse or discrimination	SGHs and CMU
4.5	Program for the prevention of violence toward children, parents or personnel	SGHs and CMU
4.6	Procedure for responding to suspicion of violence or abuse, or the social violence perpetrated over a client	SGHs and CMU
4.7	Procedure for confidentiality of information / access to information	SGHs and CMU
4.8	Book of complaints and petitions	CMU
5.1	Procedure for securing an appropriate chaperone during visits to public places	SGHs and CMU

### III. Health and Medical Care

ID	Document	Location *
1.1	Record book for the disbursement of medications	SGHs
1.2	Procedures for access to medical closet, storage and disbursement of medications	SGHs and CMU
1.3	Medical care plan for each individual child/client	SGHs / client files
2.1	Medical documentation for each individual child/client	SGHs
2.2	Program and activity cards for rehabilitation for each child/client	SGHs
3.1	Procedures for action in the case of need for emergency medical care and the administering of first aid	SGHs and CMU
3.2	Procedures for schooling and discipline	SGHs and CMU
3.3	Procedures for action in the case of infectious or contagious illnesses	SGHs and CMU
4.1	Menus – weekly and daily	SGHs and CMU
4.2	Procedures for food storage and preparation	SGHs and CMU
4.3	Procedures for the disinfection of hands, surfaces and utensils	SGHs and CMU

### IV. Personnel and Volunteers

ID	Document	Location *
1.1	Written procedure for the recruitment and hiring of personnel with criteria for evaluation of candidates	CMU
1.2	Job descriptions for all positions	SGHs and CMU
1.3	Employment contract template	CMU
2.1	Written programme for induction training	CMU
2.2	Training programme for newly-hired staff	CMU
2.3	Annual plan-schedule for training activities for personnel	CMU
2.4	Written reports on trainings already conducted	CMU
2.5	Procedures for support and supervision of personnel	SGHs and CMU
2.6	Minutes/notes on weekly supervisory sessions conducted	CMU
2.7	Personal plans for professional development	CMU
3.1	Monthly work schedules for personnel	SGHs and CMU
3.2	Minutes books for team discussions, team meetings and meetings with groups of clients	SGHs
3.3	Report books	SGHs
3.4	Attendance Form 76	SGHs / CMU
3.5	Personal staff files	CMU
3.6	Rulebook for Internal Labor Order	SGHs and CMU

ID	Document	Location *
4.1	Policy for the protection of personnel (Labor safety service)	CMU
4.2	Procedures for the preparation of monthly work schedules and utilisation of paid annual leave	CMU
5.1	Procedures for the recruitment and training of volunteers	CMU
5.2	Personal files for each personal assistant and volunteer	CMU
5.3	Contract with volunteers, outlining rights and responsibilities	CMU
5.4	Child and Vulnerable Adult Protection Policy	SGHs and CMU

## V. Therapeutic Plans and Programmes

ID	Document	Location *
1.1	Individual care plans for every service user	SGH / client files
1.2	Case management list	CMU
1.3	Description and rulebook – case managers	SGHs and CMU
2.1	Social skills programmes	SGH / client files
2.2	Plan for the Support of a child entering adulthood	SGH / client files
2.3	Plan of Action for preparing the child for school or kindergarten	SGH / client files
2.4	Programmes for professional orientation and preparation	SGH / client files
3.1	Skills Assessments	SGH / client files
3.2	Assessment of parental capacity	CMU
3.3	Plan of Action (Department of Child Protection)	CMU
3.4	Plan for reestablishment of connections between the client and close friends/relatives	CMU
3.5	Diaries and personal history of the client	SGH / client files

## VI. Administrative and Financial Documentation

ID	Document	Location *
1.1	Written procedures for placement and admittance into SGH	SGHs and CMU
1.2	Procedures for the termination of placement and discharge from SGH	SGHs and CMU
1.3	Packet of necessary documents for the client during admittance *	SGHs
1.4	Client Register	CMU
1.5	Incoming and outgoing document diary	CMU
1.6	Client files, containing a packet of documentation **	SGHs
2.1	Procedures for the implementation of internal control (monitoring) over the functioning of the service	SGHs and CMU
2.2	Protocol of monitoring activities	SGHs and CMU
2.3	Plan for the improvement of quality of the service	SGHs and CMU

ID	Document	Location *
2.4	Annual general report on monitoring and the approved activities for the correction of oversights found	SGHs and CMU
2.5	Reports on activities conducted	CMU
3.1	Internal rules for financial management	SGHs and CMU
3.2	Internal rules for salary and payment calculations	SGHs and CMU
3.3	Inventory book, reports and accounting forms with expiration date, in compliance with the Bulgarian Accounting Act	CMU
3.4	Protocol notebook for the registration of donations and accompanying documentation	CMU
3.5	Household book	CMU

\* SGH – in each individual SGH; CMU – in the Central Management Unit offices

(\*) Packet of documentation required for the admittance of a client to the service:

- Birth certificate
- Certificate for educational level completed
- Medical report from the General Practitioner, confirming actual health status of the child;
- Medical certificate from the General Practitioner confirming that the child has not been in contact with contagious illness/infestation;
- Personal ambulatory/health card of the child, immunization passport, personal health card, test results;
- Documents, confirming the disability of the child, and existing medical analyses;
- Personal cases of the child from previous placements outside of the family (with close friends and relatives, foster families, and/or specialized institutions);
- Referrals / orders for utilizing additional social services;
- Reception protocol, in which is described the condition of the child at the time of admission to the service.

(\*\*) Personal client files, which contain:

- Personal data – three names, ID number;
- Birth certificate;
- Order signed by the Director for the Unit of Social Assistance for the placement of the child in an SGH, Decision made by the Regional court for placement of the child; assessment of the case, plan of action, and social report from the Department of Child Protection;
- Required documentation for the admittance of a client to the service;
- Specialized assessment and Individual Care Plan;
- Referrals/orders for the utilization of other social services;
- Template / reports on the development of the child in the SGH;
- Protocols from team meetings during which the child was discussed;
- Medical, educational and other documentation collected by the case manager in the SGH;
- The Document, "My Life History" of the child;
- Personal diary;
- A photograph of the child;
- Other appropriate documentation, connected to the child.

## **Appendix 8: Cedar Foundation Philosophy and Obligations Policy**

### **Cedar Foundation Small Group Homes Philosophy and Obligations**

#### **We believe:**

- That all people are endowed with unimpeachable human rights, irrespective of their race, color, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.
- That all people have the right to participate actively in their community and, if they cannot live in their biological family setting, to be provided the opportunity to live in a setting which most resembles the family unit.
- That all children and adults have the right to a comprehensive support system which strives to help them reach their fullest potential, to live their lives independently, and to enjoy self-determination to the greatest extent possible.

#### **All social services supporting persons with or without disabilities, including the Family-Type Centers in Kyustendil, are obliged to:**

- protect and advocate for all recognized rights of the service users, and to not allow the violation of those rights within the service or by outside bodies;
- provide a safe and secure environment, free of abuse or neglect, in which the service user receives all necessary support for living;
- respect the service user's right to privacy, confidentiality, dignity, and personal space and belongings, especially in a residential service setting;
- treat all service users as individuals, with individual needs and wishes, and respect the individual's views and opinions;
- make decisions regarding the service and/or the service user only in the best interest of the individual and including the participation of the service user to the greatest extent possible;
- support service users to live as independently as possible and to reach their fullest potential;
- preserve and protect the service user's right to an identity, including his/her nationality and family ties, without discrimination;
- uphold children's right to education;
- provide means through which individuals can participate fully in community life, through occupational opportunity, leisure and cultural activities;
- support and encourage the development of an individual service user's network of social contacts (with colleagues, friends, and regular contact with other community members) as a basic part of community participation;

## Appendix 9: Sample Man-hour calculation table

The following is a *sample* man-hour calculation for two SGHs housing 8 children each. Every service provider should determine the number of caretaker, specialist, supervisory or other staff needed on each shift, and plan accordingly. This is one method through which the total number of necessary staff members can be calculated.

### SAMPLE MINIMUM Staff Schedule for Family Type Center Service

Two Family-type centers, providing 24 Hour Care for 8 children each				
One Family-type Center (8 children)				
<b>Regular Caretakers</b>				
Shift Times	Number of Staff	Hours Not Incl'd Breaks		Total Man Hours To Fund
<b>MON-FRI</b>				
6am - 2pm	2	7	= 7 * 2	14
2pm - 10pm	2	7	= 7 * 2	14
10pm - 6am	1	8	= 8 * 1	8
<b>SAT - SUN</b>				
6am - 2pm	2	7	= 7 * 2	14
2pm - 10pm	2	7	= 7 * 2	14
10pm - 6am	1	8	= 8 * 1	8
Total paid hours per weekday, Regular Caretakers				36
Total paid hours per weekend day				36
Total for 7 days				252
Number of regular staff required if each works 35 hours per week				<b>7.2</b>
ROTATING / ON-CALL / PART-TIME SUBSTITUTE CARETAKER				1
<b>Supervisors</b>				
<b>MON-FRI</b>				
8am - 4pm	1	7	= 7 * 1	<b>7</b>
<b>SAT - SUN</b>				
6am - 2pm	1	7	= 7 * 1	<b>7</b>
2pm - 10pm	1	7	= 7 * 1	<b>7</b>
Total paid hours per weekday, Supervisors				7
Total Paid hours per weekend day, Supervisors				14
Total for 7 days				63
Number of supervisory staff required if each works 35 hours per week				<b>1.8</b>
<b>Two Family-type Centers (16 Children)</b>				
<b>Total Regular Care Staff Required for 16 Children</b>				14.4
<b>Total Supervisory Staff Required for 16 Children</b>				3.6
<b>Total Rotating / Part-Time Substitute Staff for 16 Children</b>				2
<b>Total Care Staff Required for 16 Children</b>				<b>20</b>

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