Teodor Mircea ALEXIU

Processes of change

A qualitative approach

PRO UNIVERSITARIA®
BUCUREŞTI
2013

Coordonator al colecției
ȘTIINTE PSIHO-SOCIALE: Mihaela Tomiță

Descrierea CIP a Bibliotecii Naționale a României
ALEXIU, TEODOR MIRCEA
Processes of change : a qualitative approach / Teodor Mircea Alexiu. - București : Pro Universitaria, 2013
Bibliogr.
ISBN 978-606-647-639-3

316

Some introductory words

In studying processes of change in the life of persons with intellectual disabilities our research team had to face many challenges. First we had to clarify the concept of quality of life in a period with too many models and too few clear principles to follow. In fact, the quality of life is a rather subjective concept, based on personal satisfaction and therefore very difficult to assess. This difficulty is even harder to overcome when your subjects are persons with intellectual disabilities. That's why we had to base much of our assessment on the accounts from parents and staff members and to focus on our own observations and insights.

For this we are in depth to several organizations, families and individuals who shared their experiences and efforts and made us understand that even with a lack of material resources, lack of space, unavailability of information, inadequate guidance from professionals and even with limited intellectual abilities, many things are possible.

Another striking point was the strong belief in material conditions as a basic factor for needs fulfillment. In fact many of the managers of the projects we visited presented with pride their new heating systems, the modern kitchen devices or the well-equipped bathrooms from their institutions. This is probably understandable in relation to the general living conditions in our country and especially in organizations and families facing disability. But what we discovered in our research is that the images of and attitudes towards persons with disabilities are far more important for the understanding of the quality of services than any material aspects. In every instance of 'success', in terms of improved quality of life for persons with intellectual disabilities, we saw examples of caring, of dedication, of creative solutions, of innovative strategies, of wanting the 'best' for the 'child', willingness to face and overcome stigmatizing situations, ability to postpone/put aside personal interests to the benefit of more critical or basic needs of another.

Another difficulty was the necessity to choose between many strategies or models of service delivery. The selection is based on comparisons and to compare is very difficult in such a complex social world. Everybody is looking for "the right model" but the complexity of particular situations led to a multitude of "right models". So we had to choose between the most complex projects trying to learn from their strengths and weaknesses in order to identify factors leading to positive change that could be transmitted to the people working in the field. We did not intend to make a hierarchy among different projects who applied for this study. Instead we tried to make a selection reflecting a variety of projects and services in Romania.

And finally we had to clarify who the **audience** for this paper should be. We hope that it will go beyond **academia**, on to the **professionals** who are working directly with intellectually disabled persons. But we also hope that it will be available to the **parents** and **families** of disabled people. We hope that this product will contribute to the empowerment of parents and service providers to seek and develop better and more appropriate services. We also hope that those in charge of the administration of **professional and other organizations in the community** that reach out to parents and persons with intellectual disability will also access this paper. We hope that they will be able to use this information and insight to bring about even more effective programs and sensitize persons to existing conditions in the Romanian context. And we hope that the book will be accessed by **governmental organizations** that are indirectly and directly involved with policy making regarding disabilities as well as funding such initiatives.

Chapter 1

ORGANIZATION OF THE STUDY

The research we are going to present started with an invitation from SHIA (Swedish Organisations of Disabled Persons, International Aid Association) in 2004 to participate in an international study in order to identify the most successful ways to achieve sustainable improvements in the conditions of children and adults with intellectual disabilities from four countries: South Africa, Kenya, India and Romania.

The aim of the study wasto explore, understand and describe successful change processes and learn from them. The following research questions have been addressed:

- Which projects resulting in sustainable improvements of life conditions for adults and children with intellectual disabilities can be found in the four countries?
- Which are the most strategic change agents, internationally, nationally and locally?
- Which methods are most effective in order to initiate and maintain processes of change?

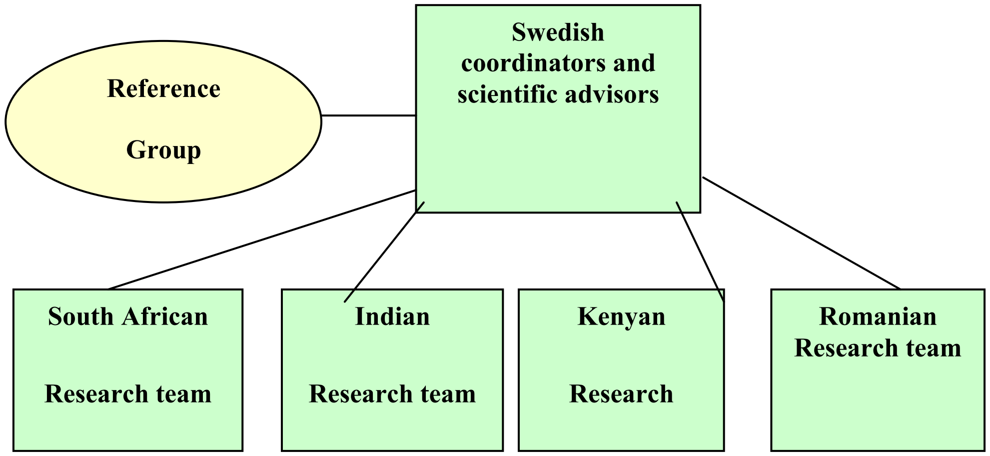
What other factors, deliberate project interventions as well as contextual factors, are important to achieve a positive change? The study has been guided by a Reference Group in Sweden[1]. Research teams consisting of 4-6 persons have been established in each country according to the following guidelines:

- The teams should include one person, who has academically achieved a doctor's degree (or similar research background) to ensure the scientific level of the study

---

[1] Barbro Carlsson, Chairperson and previously Secretary General of SHIA, Viktor Wahlströmex-president of Inclusion International, Fred Heddell, treasurer of Inclusion International, TiinaNummi-Södergren of SHIA, Professor Anders Gustavsson, Stockholm University who has served as a scientific adviser and Annika and Lennart Nilsson responsible for coordination, administration and reporting of the study

- The team should include two representatives from the disability movement to ensure a user perspective of the study. At least one of them should be a parent from the Inclusion International partner organization[2].
- The team should have a team coordinator who is responsible for the actual planning and implementation of the study and for the timely reporting to the coordinators in Sweden.



In Romania the following persons have been on the research team:

- **Conf. Ph. D. *Teodor Mircea ALEXIU*, West University, TIMISOARA, Faculty of Sociology and Psychology, Social Work Department, as team coordinator;**
- ***Laila ONU*, vice-president of Inclusion Romania, parent of a mentally disabled child;**
- ***Sergiu Radu RUBA*, president of National Council of Disability, vice-president of the Romanian Association for the Blind Persons, himself a blind person;**
- ***Aurora TOEA* the director of the Center of Resources and Information for Social Professions.**

---

[2] Parivaar in India, Inclusion from Romania in Romania, DICAG and DSSA in South Africa and KAIH in Kenya

Definition of Intellectual Disability

In this Study we have used the following definition of intellectual disability[3]: **Intellectual disability is a condition where people have significant difficulties in learning and understanding due to an incomplete development of intelligence. Their skills in areas such as cognition, language, motor and social abilities can be permanently impaired. Between 1 % and 3 % of a population have an intellectual disability.A person with intellectual disability has life-long developmental needs. Intellectual disability is a condition of slow intellectual development, where medication has no effect. Intellectual disability can be caused by genetic factors, or by environmental factors, such as infections, or by a lack of oxygen supply of the brain during pregnancy or at birth. Intellectual disability is normally not caused by social or psychological causes. Difficulties in learning and understanding lead to problems in school and working life and to difficulties in being included in the regular life of society. There is a large variety of appearances and degrees of intellectual disability requiring different forms of therapies or support. Intellectual disability is permanent. Intellectual disability is different from mental illness. Mental illness is an illness and can be cured, whereas intellectual disability is a life-long condition. People with mental illness need mental health care, medical and psycho- therapies. In general they have no intellectual impairment and can live independently when their mental health problem is controlled. People with intellectual disability are not ill, unless they have a common illness. They need easy-to-understand information, education or training to live included in society.**

In **Romania,**the state constitution refers to the protection of handicapped people, and the word “handicap” is used in official law and policy, though experts agree that such terminology is outdated and stigmatizing. There is no specific definition of intellectual disabilities used in legislation, nor are there discrete statistical data on the number and situation of people with intellectual disabilities. The most frequently used term is “mental handicap”, and in some cases, “mental deficiencies”. The first definition of persons with

---

[3] Inclusion International information leaflet

handicaps appeared in Law 53/1992 on the Special Protection of People with Handicap, which has been modified many times. The definition remains outdated, however, as it is based on terminology elaborated by the WHO in 1990. Experts in the field have called for the definition of people with handicaps to be reworked in the Romanian legislation, to bring it in line with definitions accepted at the international level.

Chapter 2

RESEARCH STRATEGY

A basic assumption is that both living conditions of disabled people per se and changes in such living conditions, to a large extent; depend on contextual characteristics such as the national economic conditions, rights and obligations linked to the citizenship, cultural representations and customs etc. As a consequence processes of change affecting the living conditions of people with disabilities are likely to differ between countries and action that prove to be effective promoting change in one country are not necessarily the most effective in another country. This has important consequences for our study.

First, our understanding of the processes of change and improvement is better facilitated by rich contextual data than by comparisons with other similar interventions aiming at social change. As a consequence, extensive case studies are likely to be more helpful than broad comparisons of many different cases. We have therefore decided to limit the study to three successful projects resulting in improved living conditions of people with intellectual disabilities in each of the four countries.

Secondly, in order to investigate and understand the dynamics of specific processes of change, the process first of all has to be studied in its own unique national and local contexts. This means that the projects will be studied in their own historical, national and cultural contexts and that the comparative phase of the analysis is introduced in the final analytical step to explore interesting similarities and differences in the basic factors of change identified in each individual change process. In short, the study starts with a rather *open exploratory* approach with the aim of increasing our understanding of successful projects in the four countries and identifying basic, important factors promoting change and ends with a more *comparative* approach exploring similarities and differences between the three processes of change analyzed by each national team. Because of the big contextual differences between and within countries, the research methodology has been developed in a participatory process where each national team has played an important role.

Finding a common frame of reference for the choice of the successful projects

The design of the study is rather open and sensitive to the approaches that the national research teams find most productive. However, identifying differences and similarities in change processes within the 4 countries requires a common basis for the selection of the cases.

It was agreed that

> The examples of change processes to be selected for the case studies should be called ***PROJECTS.*** A project is a deliberate effort to achieve positive changes in the situation for persons with intellectual disabilities. A project has a starting point and an end point.

It was also agreed that the following 4 criteria should guide the selection process:

1. A substantial impact on the quality of life of persons with intellectual disabilities. The project must have impacted positively on at least four of the Quality of Life domains in order to be selected (or had an exceptional impact on one of them).The following IASSID consensus quality of life domains was used as a common frame of reference[4] to describe quality of life.

---

[4] The Reference Group has examined different instruments and more general points of departure that could be used for evaluating impact of the successful projects. Different tools have different benefits and disadvantages. As the research teams were about to study relative changes in various cultural, political and economic settings, they needed to use a tool that is flexible, easy to use and which is not relating to too detailed and context bound measurements of life conditions. They needed a qualitative instrument that can capture the improvements on both individual and society levels from a user perspective. In this particular study the Reference Group gave priority to strategies that were likely to picture the dynamics of the changes in an empirically sensitive way. While being aware that quantitative instruments usually are preferred when making comparative studies, the Reference Group agreed that such instruments are not possible to use in this study.After a long discussion, the Reference Group decided to recommend the IASSID Consensus Quality of Life Indicators as more general guidelines in the choice of the successful projects. This means that the indicators will be used first of all as a list of qualities or criteria. The Reference Group did not think that it would be possible to carry out precise measurements of individual persons' quality of life or changes in their quality of life.