

Gerold Schwarz, Peter Stastny, Miriam Kravitz
Consumer-Run Businesses in the USA: A new approach to vocational rehabilitation for people with psychiatric disabilities

About the authors:

Gerold Schwarz, psychologist, obtained his degree at the Freie Universitaet Berlin. He is working since four years in the field of vocational rehabilitation for people with psychiatric disabilities. He cooperated in various research projects on this subjects. The last two years he was working as executive director of a european network for social firms (EUROPSY). The idea to write this article came up during a 2 month study visit in the USA.

Miriam Kravitz, Esq., is the executive director of INCube Inc., a consumer controlled technical assistance agency. She has an undergraduate degree in business management economics and film, and a doctorate of jurisprudence. She is a consumer of mental health services since 1973.

Peter Stastny, M.D., is Associate Professor of Psychiatry at Albert Einstein College of Medicine, Bronx, New York, and Vice-Chairman, Board of Directors, INCube, Inc. Dr. Stastnyt obtained his medical degree at the University of Vienna and has been developing innovative, consumer-run projects for the past ten years.

Introduction

Historically the vocational rehabilitation system has not been able to help people with psychiatric disabilities fully develop their potential and sustain meaningful careers¹. Focus has been on low-level, low-income placement that in many ways does not consider special needs or reasonable accomodations necessary for persons with emotional illness that may contribute to a high recitivism rate.

Nevertheless some aspects of vocational rehabilitation for people with mental health problems have made a lot of progress in the last decades. There has been continuous effort to find more effective ways to support people in the transition from the hospital to community living and to help them to find their way back to society.

An increasingly important part in this progress has always been the re-integration into work. Many people who are hospitalized either never worked in a competetive environment, or lost their jobs. Once released from the hospital most of them are confronted with unemployment. Various experiences show that a long period of unemployment after getting out of a psychiatric hospital diminishes the chances to social reintegration and raises the chances of being hospitalized again.

It appears that on the one side it is very difficult for people to adjust to the demands of the world of work. Even if jobs become available it is often difficult for people to adjust to them without support and reasonable accommodation. They must handle the stress of work, the management of their illness plus the stigma. On the other hand they are confronted with prejudices that make it difficult for them to find a job.

As one possibility to break out of this vicious circle, social firms (in Europe) or affirmative businesses (in the United States) have been created to provide jobs with built-in support and accommodation for ex-patients. So far the leading forces in creating these firms have been professionals working in rehabilitation services. Their aim is to supplement and expand the services that they provide for their clients. To date in Europe, Canada and the United States there are about 500 - 700 of such businesses which offer thousands of permanent work places. It is now obvious that this model has become a success and appears to be a powerful instrument in the process of vocational rehabilitation.

What is the secret of this success? The social firm model helps people to regain self-confidence by providing permanent jobs with meaningful work and a regular salary. The person is not a patient any more but an employee, he is part of productive society. All experiences have shown that the step from the role as a patient to someone who takes part in the fabric of society is an essential ingredient to social reintegration. The social firms have proven that getting more autonomy, self control and therefore more self-confidence must be one main aim of all efforts towards a reintegration of people with psychiatric disabilities.

In this article we focus on experiences that have been made in consumer-run businesses during the last years in the United States. It is our opinion that these projects go further in carrying out the above mentioned goals of personal and professional development.

A consumer*-run business is a business in which consumers initiate, set up, and manage the enterprise having the power and responsibility of ownership and management decisions. Involved providers maintain an advisory role.

* (the term *consumer* is used in the United States to indicate choice in the market place of mental health services by individuals suffering or diagnosed with psychiatric disability, other terms commonly used are survivors, recipients, or ex-patients ...)

Background

In the field of vocational rehabilitation, consumer-run enterprises are a relatively new addition to the alternatives available. Its basic notion of marketing a product or a service, which would produce sufficient revenue to improve the economic status of the organization, and thereby provide gainful employment to its members, is however related to successful, existing Vocational Rehabilitation models. For instance, Fairweather Lodges, which are small groups of former

psychiatric inpatients organized around skills training, independent living and a business idea, have successfully promoted economic self-sufficiency and community integration for persons with psychiatric disabilities and have been replicated across the U.S.².

A second model are affirmative businesses, a variant of supported employment that qualify as "integrated worksites" under New York State and federal regulations. An affirmative business usually involves small private subcontractors, retail or manufacturing businesses such restaurants, bakeries or other businesses that provide products or services as for the public. They may employ individuals with and without disabilities, thereby providing integration opportunities with co-workers without disabilities, as well as intensive training and supervision at the work site. This model has received more attention recently and seems to be spreading in rehabilitation facilities and elsewhere³. Their employment options seem more varied than in traditional supported employment.

A third model which provides a blueprint for consumer-run enterprises is the European cooperative employment model, also known as social firms (England, Ireland, Holland, Portugal, Greece and other countries), self-help firms (Germany) and the Cooperatives (Italy). In this model, rehabilitation professionals and skilled, non-disabled workers develop small businesses to employ persons with psychiatric disabilities. They receive technical assistance from national and transnational organisations, partially funded by the European Union. Their viability in the open market and their positive impact on its employees with disabilities has been demonstrated by a series of studies⁴.

What is a Consumer-Run Business ?

We talk about consumer-run businesses (CRB's) if the important decisions in the business are made by consumers, that means, if most of the management staff are consumers, and/or if at least 51% of the board members are consumers.

Consumer-run means that decisions on the initial planning of the business, on the hiring of staff and co-workers, the definition of business plans and policies and the responsibility for the daily operation is in the hand of consumers. In the United States there is a range of consumer participation in (affirmative) businesses. On the one end there are "traditional" businesses with very little or no consumer control and on the other side there are businesses that are nearly completely consumer-run. In between you will find jointly run businesses where consumers have more or less power.

It appears that many consumer-run businesses have some level of non-consumer input, be that in working partnership or through technical assistance. But only if the consumers have the control over the important business decisions can you call that a consumer-run business.

Why do people start consumer-run businesses ?

Consumers start businesses to create environments where they can develop their creativity, personal potential, and have the ability to define their own goals according to their dreams, interest and skills. Also the consumer-run businesses can provide more autonomy and freedom in work and therefore lifestyle. When a person is able to take greater control over his life it facilitates a growth process, and consequently healing can occur.

Another important reason consumers start their own business is that they want to create jobs for themselves which are not only paid jobs but which provide meaningful work, and a valuable social and economic status.

Within the consumer-run businesses consumers have a possibility to get access to levels of economic and social independence that are not obtainable in traditional rehabilitation programs. In consumer-run businesses ex-patients are more likely to pursue professional careers rather than just obtain jobs.

Within consumer-run businesses there is a very strong sense of responsibility for each other, support and understanding. Co-workers develop a strong sense of cohesion. Interacting with other consumers and non-consumers on an equal level, working together as a group, learning to take responsibility for ones own professional life, is a whole process that is rehabilitative in itself.

Of course it is the aim of all rehabilitation programs to provide meaningful work and to lead ex-patients toward an independent social and economic life. But a lot of these programs have the tendency to hesitate for a too long time to hand over the responsibility from the mental health professional to the ex-patient. The consequence of this attitude is that very often ex-patients, who are able to take over the responsibility of their own lives, remain disempowered and become discouraged and at the same time get used to having a job and earning some money, even if they are not living up to their full potential.

The process of starting a own business, is of course full of risks, and in most of the cases consumers need a lot of help at the beginning. Many consumer-run businesses have been created with the help of rehabilitation staff, but the aim of becoming independent after a while makes the whole difference. And the experiences in the United States demonstrate that it is worth to take all these risks.

Some Examples of Consumer Run Businesses

Ace & Ace is a consumer-run cleaning and maintenance business. It was started in a state psychiatric center by a group of in-patients some of whom had experience in janitorial services. Initially the group received technical assistance and support in developing their business idea from experienced consumers and rehabilitation counsellors. Through negotiations with a State rehabilitation agency and INCube Inc. (see below) Ace & Ace was able to obtain a cleaning contract for a six story building. The business provides five fulltime positions and ten temporary jobs.

Albert & Associates, a graphic design and desktop publishing facility producing brochures, flyers, announcements, posters, etc., primarily for mental health agencies and services. The owner, who has 30 years experience in the field, started the business on her own initiative. As a sole proprietorship it provides home-based work for three individuals.

Words-R-US, a consumer-operated word processing business that has recently recieved an award for excellence from the Mental Health Association in New York State. The business provides training oportunites and jobs with reasonable accomodation for 20 consumers.

Other consumer-run initiatives

Besides the consumer run businesses there are other consumer-run projects in the fields of communication, legal advocacy, drug treatment, multimedia, education, and housing. Some are funded through state or federal money other seek to get private grants. Some of them are part of the mental health services.

In New York City, there is for example a housing project (INCA Housing), which is completely run by consumers and provides apartments for ex-patients, helps people to find an apartment and supports people who live in their apartments. INCA Housing employs 8 consumers on a full-time basis and provides services to 50 individuals and families on the Bronx. Similar projects exist in Upstate N.Y. in New Jersey and in other States.

Another example is the peer specialist project in New York, a group of ex-patients, employed by the Bronx Psychiatric Center. This group works in partnership with the Intensive Case Management Program of the hospital. The peer specialists support patients on their way out of the hospital. The own experiences of the team members by getting out of the hospital are an enormous help in advising the professionals and in supporting their clients.

Providing Technical Assistance for Consumer-Run Businesses/ Cooperation of Consumer-Run Businesses on the national level

With the growing number of consumer-run projects in the United States the need for specialised support and for the exchange of ideas and experiences among projects becomes more evident. The first project with the aim to support people to start their own business and to link up consumer-run projects was founded 1988 by two consumers. INCube Inc., with its office in Manhattan, New York is a consumer controlled advocacy service agency, offering technical and peer assistance to individuals and groups seeking to operate their own business. All of its employees and a majority of board members are persons recovering from psychiatric disabilities. In addition the federal Government currently funds two technical assistance centers which assist consumers in starting projects, but do not have business orientation.

INCube provides technical support by making accessible professional services such as legal, accounting and management expertise to consumer-run businesses and service projects. INCube acts as conduit for insurance, grants or other services until the fledgling business or service agency can achieve autonomy. INCube has established an office with an atmosphere which encourages creative collaboration and peer support among the staff and clientele. Incube also serves as a link to private resources, government agencies and academic institutions, and educates the mental health community through presentations on self-help and self-confidence in personal decision making.

In the near future INCube will offer an array of services, including business consultation, resources development and referrals, and training for people working in consumer-run businesses. At this time, Incube is building up a electronic computer network to support the cooperation and the exchange of ideas and concepts among consumer run businesses. By using modern communication technology it will be possible for consumers who want to start their business and for the existing consumer run projects to get helpfull and necessary information and to exchange experiences and cooperate with each other.

How is the current situation of Consumer-run businesses in the USA ?

To get a general idea on the overall situation of consumer-run businesses in the USA we reviewed the two only surveys on this topic that we are aware of. A national one, and one in the State of New York. The national survey did not concentrate on consumer-run businesses but consumer participation in affirmative businesses was one of the subjects. The survey on the New York state level was focussed on consumer-run businesses. Therefore we were able to get a general idea on the level of consumer participation on the national level; while obtaining more detailed information on the NY State situation.

Consumer participation on the national level

One study, published by Barbara Granger in 1993 gives an overview on the Agency-sponsored entrepreneurial businesses employing people with psychiatric disabilities (ASEBS) ⁵. Its aim was to provide a look at the nature and development of these enterprises.

Although the main aim of this survey was not consumer participation it gives an idea of the overall situation of consumer involvement in the affirmative businesses in the United States.

298 affirmative businesses in the United States were identified and surveyed. Most of the businesses are small, the average size is about 25 employees. The businesses are working in many fields, such as janitorial, restaurant, food services, landscape, copying, automotive maintenance and other.

One area of the survey focused on consumer participation. Although very few of the businesses were started by consumers, most of the businesses reported that the consumers participated in the decision-making process in some way. Many businesses indicated that participation of consumers in the decision-making was currently under discussion. The most common process was that consumers informally reviewed routines daily and had more formal meetings every week or month. Only a few businesses had more formal decision making structures with involvement of the consumers, as for example consumers as members of the board or management staff.

In summary, all respondents spoke of consumer participation and the consumers had some influence on the decision-making process, but few of the businesses had structured consumer control.

Consumer-run businesses in the State of New York

Another survey was made recently by Linda DeHart regarding the current situation of consumer-run businesses in the State of New York⁶. The survey was focused on businesses with structured consumer participation. It gives an interesting picture of the current situation of CRB's in the State of New York. We thank Linda de Hart for providing us all the data and information that she has collected and analysed.

Thirty-eight groups representing 48 businesses responded to the survey. The businesses had been in operation for an average of 7 years. The oldest business was a mailing service opened over 26 years ago. Ten businesses out of the 48 (21%) were started by consumers or consumer-run agencies. 13 businesses were started in the last two years, they showed much higher rates of consumer control and were more likely to have been started by consumers. These results indicate that there is a trend toward consumer-initiated business development and increased consumer involvement in agency-initiated businesses.

The businesses are working mostly in maintenance, clerical or food services, the other businesses are manufacturers, retail stores or other services, including a TV production company, a bottle and can redemption center, a

graphic designer, a home renovation contractor and a professional placement service, among others.

The businesses employed an average of 21 people. Ten percent of the businesses employed fewer than 5 people. Nearly all of these smaller businesses were started by consumers. In total there are 1412 work places provided by the 48 businesses.

- Consumer Control

Nineteen percent of the businesses described themselves as consumer-run, 54 percent indicated that they were jointly-run, and 27 percent said they were staff-run. An average of 55 percent of the administrative and managerial positions in the businesses were filled with non-consumers. In contrast, just 5 percent of the "labor" positions were filled with non-consumers. On average, consumers held 55 percent of the seats on the boards, and in 13 businesses consumers held an average of 91 percent of the seats. Additionally, in those businesses, 77 percent of administrative and managerial positions were filled by consumers.

- Start-Up Money

Sixty-eight percent of the businesses received all or part of their start-up money from mental health funding. Eighteen percent received start-up funding from vocational agencies and 9 percent received money from private grants. Only 4 percent of the businesses were started with business development funding. Only 23 of the businesses provided information about the amount of start-up money that was used. Of those, 43 percent were started with over \$50,000, 26 percent were started with \$20,000 to \$50,000 and 30 percent were started with less than \$20,000.

- Types of Employment

Fifty-nine percent of the businesses reported that they offered mostly part-time work, 40 percent offered long-term or permanent work and 31 percent offered both short-term and long-term positions. Businesses that were consumer-run were much more likely to offer long-term and permanent employment. Forty-two percent of the businesses described their work as skilled labor. Businesses that were consumer-run were more likely to describe their work as skilled labor.

- Budget, Income & Sales

The average operating budget was \$225,619. However, that number was skewed by two businesses with budgets of over \$950,000. The median operating budget was \$113,500.

The businesses received an average of 54 percent of their total incomes from sales and contracts. An average of 45 percent of their incomes they received

from public mental health and vocational agencies.

The largest customers of 43 percent of the businesses are public and private mental health agencies. Seventy percent of the businesses reported that they did at least some business with these agencies. The largest customer for another 43 percent of the businesses is the general public. Nearly all of the businesses (93 percent) made at least some sales to the general public.

Final remarks

In the United States consumer participation is finally on the way to become more implemented in vocational rehabilitation. After years of continuous efforts from the side of the consumers, there is a trend towards more consumer involvement and control in "traditional" rehabilitation services. On the other side many consumer-run projects have been started by consumers themselves in the last years in the United States. They have proven to be a effective tool for a re-integration of people with psychiatric disabilities into society.

Social firms in Europe and consumer-run businesses in the United States have a lot of common roots. In Europe to date there is a growing discussion about the implementation of consumer control into the social firms, and european projects are now on their way towards more consumer participation. All the experiences that have been made in this field in the USA could become a valuable ressource for European social firms.

Legal and financial possibilities to support social firms are very well developed and efficient in some of the European countries. It would be worth to discuss how experiences that have been made in Europe in these fields could be made available to the projects in the United States. European social firms could promote this process and help consumer-run projects getting more effective support.

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