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YHD-Association for Theory and Culture of Disability, an organization run by and for people with disabilities and subscribing to the Independent Living philosophy, started a pilot project in Ljubljana with personal assistance for de-institutionalization and equal opportunities of assistance users.

Pioneering Personal Assistance in Slovenia: An Evaluation of the YHD Pilot Project on Personal Assistance in Slovenia

by J.W. Duyvendak and W.B.A.M. Melief, 2001

Introduction

The evaluation is based on data and information on three levels: 1) the practice level of actual service provision to individual users 2) the organisation level 3) the level of the Slovenian society. The data and information upon which this evaluation is based, were provided by the organisation itself in a format that was agreed on in talks between the organisation, Sinco, the NIZW and the Verwey-Jonker Institute.

For the evaluation on the practice level, the organisation made detailed information available about the individual users of the services of the YHD and the services for these users.

This evaluation-report is build up in the following way.

We first give a short description of the organisation, its services and the problems experienced at the beginning of the Matra project on different levels. This is followed by a description of the outcome during and after the project.

Description of the YHD

The YHD is a not a pure service organisation but a organisation of and for handicapped people with several purposes, that is on the one side an ideological and interest organisation that promotes a certain vision on life with a handicap and the position of people with a handicap in society and on the other side a service organisation that tries to realise a life for people with a handicap that is in harmony with their ideals.

For this evaluation is relevant, that the YHD is of the opinion that people with a handicap should be able to live independently just as every other citizen in a civilised society. They acknowledge that in order to be able to do that, people with a handicap need assistance and support, that for each of them has to be a special arrangement, because no handicap and no person is similar. But apart from this personal assistance, people with a handicap should be able to live in a normal house in a normal neighbourhood and be as free as everyone else to live their lives in their own way.

In order to realise this "independent living" they also run a service providing organisation. It is in particular this service providing part of their activities that was supported with a Matra grant and that is evaluated here.

Problems of the users

The starting problems of the users of the services of the YHD (who are often also members of the YHD movement), are in general that they are forced to live in a situation in which they are more than necessary dependent on other people and in which they have less freedom than they prefer.

In the Slovenian society people with a handicap mostly have the choice between living with relatives (in particular parents or at a later age the family of a brother or sister) or in a institution for the care of people with a handicap, mostly special parts of homes for aged people. In both situations apart from being very dependent on others (relatives or care personnel) people with a handicap also experience a relative large restriction of their freedom. In the house of their parents or relatives they have to live up to the house-rules and customs of those relatives. In institutions they have to live according to the rules of the institution which ,because the way these institutions are organised, can be very limiting.

If they want to live independently they are confronted with a number of major problems. They have to find adequate housing, that is adapted to their handicap or can be adapted to their handicap. They furthermore need a personal assistance arrangement, on which they can depend (is available when needed, also when a personal assistant is ill or is on vacation). To conclude they also need transport (to get to their work, to school or university) and sometimes also adaptations and assistance in the work/study situation. Only a specialised organisation is able to organise this all. But till the YHD (and a few other initiatives in Slovenia) started their activities there was no possibility to arrange this “independent living”. A second problem was, that although for many people with a handicap, a personal arrangement enabling the person to live independently, would be not more expensive than living with the family or in a institution, the funds to finance the independent living were not available. For that purpose a transfer of money from traditional care arrangements to the new arrangement would be necessary and such a transfer was not easily made.

What is specific in the services offered by the YHD?

The YHD basically offers a “network for independent living”, that does the following things:

- 1 Arrange personal assistance at home, working place, school and university for a person with a handicap by employment of paid personal assistants.
- 2 Make arrangements for necessary transport to work/school, to visit friends and relatives and to recreational and other activities for handicapped persons participating in YHD.
- 3 If asked, advise handicapped persons participating in YHD about the procedures they have to follow to obtain adequate housing.
- 4 If asked, provide participants in the YHD with information about their rights and actual possibilities in obtaining adaptations (at home, work place and school) and aids and equipment they need (for example wheelchairs).

Not all of this is necessary for each handicapped person. All the arrangements are made according to the needs the person with the handicap. The person with the handicap decides what assistance he/she needs and at what times.

It is very characteristic for the YHD services, that for each user an individualised service arrangement is created.

Very characteristic for the YHD is also that the organisation is run by people who also need and use the services; a true organisation of handicapped for handicapped.

Potential client population for the services

The ideal of the YHD is, that all people with a handicap in the end will live in independent living arrangements. Because of that they consider all people with a handicap in Slovenia as potential users of their services or similar services of sister organisations. It is to be expected however, that there will always be people with a handicap who prefer to live in an traditional institution or with

relatives. This is the experience in other countries with more or less similar services. But it is also clear from the experiences in other countries that a large proportion (more than 50%) of the handicapped, given the choice, prefer to live in some sort of independent living arrangement, which means that the number of potential users of the YHD type services in Slovenia is many times larger than the number actually served at the moment.

Problems experienced by the organisation at the start of the Matra project funding

AT THE LEVEL OF SERVICE DELIVERY

The organisation managed to attract a larger number of potential users (26) of the services than the planned capacity (15).

It was however a problem to organise the individual assistance arrangements for each potential users, largely because of difficulties in obtaining funds to pay the personal assistants for their services and cover the costs of organising the personal assistance arrangements¹.

The details of these problems can be found in the extensive reports by the organisation which have been added as annexes to this evaluation.

The core of this problem as we understood it, was basically a reallocation problem. By that we mean the following. In Slovenia as in every other civilised country, taking care of handicapped people means that a certain amount of public money has to be spent on specific costs for the individual handicapped person. From this money extra housing costs, care provision either at home or in institutions, transportation etc. is paid. This money is in the traditional situation mostly invested in the care given by the existing traditional service organisation (for instance residential institutions). If this same money available for an individual person with a handicap could be reallocated to finance his/her personal assistance arrangement, much of the funding problems would be solved. This is for example clear from the experiences in other countries. But to bring this thought into practice, is always a lot more difficult because it involves changing rules and regulations and the personal entitlement of a handicapped person to certain payments from public sources. The same reasoning applies to the cost of organising the services for an individual user of the services (case management costs).

See for the actual blockades the attached annexes.

AT THE ORGANISATION LEVEL

- 1 Inadequate funding of the service provision and the case management, largely due to the problems described for the service level before.
- 2 Inadequate funding of the organisation costs. The organisation is largely run by volunteers, but as running a service organisation is professional managerial work, sooner or later this will have to be paid. The inadequate funding also related to material costs, housing, a vehicle to transport handicapped people and equipment/materials.
- 3 Unclear status of the organisation in the service network Slovenia. The organisation was at the beginning of the Matra funding not considered as a regular service providing organisation, but more as a new initiative of basically volunteers.

¹ The person doing this organisation of service arrangements for individual users, is mostly called a “case manger” in Western European service jargon.

AT THE LEVEL OF SOCIETY

The organisation related their problems on the organisation level to the following factors in the Slovenian society.

- 1 The novelty for Slovenia of the model of “independent living” as an attractive alternative for living in a institution or living with relatives.
- 2 The position of NGO’s in the field of social and health care provision. NGO’s have been accepted as organisations that exist in a modern mixed economy. There is a beginning of a certain degree of acknowledgement that NGO’s can fill certain gaps and shortcomings in existing service provision and sometimes offer clients an alternative for the standard care by large traditional service organisations, that fits better to the client’s needs. Nevertheless the Slovenian society still has a long way to go before a full appreciation of the advantages of the NGO’s is realised.
- 3 The status of NGO’s run by users of the services. The normal construction in service provision is, that the service organisation is run by professionals.
- 4 The misconception that a NGO is an organisation that basically can be run with the employment of only volunteers. The work of volunteers is an important aspect of NGO’s and can allow them to do more for the same amount of money and with less bureaucracy and overhead. But providing quality services in sufficient quantity is impossible without the employment of professional and adequately paid staff.
- 5 The fact that funding for NGO’s mostly comes from budgets that until now were allocated to traditional services, which very understandably causes strong adverse reactions from these traditional services, that use all their considerable influence to block this reallocation of funds.

Summary of relevant elements of the start situation

If we summarise the positive and negative elements of the start situation at the beginning of the Matra project, we need to mention the following elements.

STRONG ELEMENTS WERE

- 1 A very enthusiastic and devoted group of unpaid professionals and volunteers delivering quality services on a very small scale.
- 2 Innovative services, that up to then were not offered by traditional service organisations and only in very limited quantity by sister organisations.
- 3 Services offered by the same people that use the services
- 4 Service delivered with the advantages of NGO’s
 - Flexible
 - Closely tuned to the needs of the users
 - Maximum involvement of the users
 - Very cost effective because of the low overhead and the employment of volunteers.

PROBLEMATIC ELEMENTS

- 1 Lack of funding and because of that
 - To low capacity
 - Insufficient staff
 - Little opportunity to improve expertise of staff.
- 2 Lack of status and recognition and because of that:
 - Little co-operation with existing services
 - Little opportunity to improve

Outcome

For the users on the practice level.

The YHD succeeded in serving 27 persons with a handicap with a personal “independent living” arrangement in 1999.

Five more persons had applied for participation in the project

THE USERS AND THE ARRANGEMENTS

Some characteristics of the users

Most users (22) were less than 40 years old. Five of them were older than 40

16 users were women and 11 were men.

Most users (18) were either students or persons working in a regular job (including the three staff members of the YHD).

Six users were still living with their parents. Five users were living with a partner (married or unmarried) and three of them also had children. Two female users were living together with friend. One lived in a religious community. The other 13 users were living alone or living in an institution or accommodation of an organisation of handicapped people.

The kinds of handicap and the corresponding needs for assistance

The large majority (16) of the users were people who were dependent on a wheel chair while six more persons had also problems with muscle control and balance without needing a wheel chair.

Four users had vision problems (blind or partially sighted), one in combination with muscle control problems. Two persons were handicapped by a combination of muscle control problems with complicating psychosocial factors.

Most of the users (16) needed some or much assistance in doing household work, cleaning, etc. An even larger number (18) needed some to much assistance with personal care. Nine of the users were so seriously handicapped that they needed 24 hour attendance.

The blind users (4) specifically needed assistance in dealing with written documents (reading, recording written text on tape, etc.

The need for transportation to work, school or university, was explicitly mentioned two times, but is very likely much more needed.

Three users needed company or someone to accompany them, when going out also to take away the burden of the people normally taking care of them (relatives for example).

For four users it was explicitly mentioned, that they needed assistance on the work place.

One person needed besides assistance with personal care, also some guidance and mediation in dealing with other people.

Original assistance before they entered the program of the YHD

Before they entered the program of the YHD, most users had already some sort of assistance, which nearly always was insufficient or in other ways bothersome.

Most of them (15) were more than they liked dependent on friends, partners, colleagues, parents and other relatives. Some of them (3) paid from their own income inadequate personal assistance.

Several users (7) were dependent on insufficient or very rigidly organised care of an institution or an organisation of people with a particular handicap. Complaints were, that the assistance was only available in the institution and for example not at the workplace or when going out. One person received insufficient help from a home help organisation.

At least two users, serving on the staff of the YHD, had, long before the YHD came into being, for themselves organised an arrangement that was very similar to the arrangements they later offered as the service of the YHD.

Assistance in the independent living arrangement

The assistance arranged by the YHD always consisted of personal assistants for certain specified moments and periods, that varied corresponding to the needs of the users. The services of some of the assistants were shared by more than one user. But each user also if that was that case, got a different arrangement.

The assistance arranged by the YHD was not always the only assistance people received. Sometimes the help already received before becoming user of the YHD was continued, especially when someone lived in an institution where this assistance was part of the service of the institution.

Changes in housing conditions

The original housing conditions were very varied. Five people lived in institutions, mostly homes for the elderly with a special department for handicapped younger people. Six people were living with their parents or on a different floor in the same house as their parents.

Eight users lived in an apartment, a normal house or a rented room. Two users lived in student housing. For five persons the original housing conditions remained unspecified, three of whom were blind. One user lived in a religious community (nun's convent) and one in accommodation of an organisation of handicapped people.

These living conditions did not change dramatically during the project, but one has to realise that supplementary assistance created much more freedom for the users, even for those who stayed in their original housing conditions. Adequate and flexible assistance made them also less dependent.

Four users preferred to stay in an institution, because they feared not to be able to live totally independently. Six of the users still lived in their parent's home. Of five people (including the three blind ones) living conditions remained unclear. The number of persons living in an apartment or a house had increased and some of this housing was also especially adapted for handicapped people.

Only one user still lived in student housing. The nun stayed in the convent and the person living in the accommodation of the organisation for handicapped people still lived there.

Alternative situation without the YHD services

From the information about the users we could estimate that 13 of them would be much more dependent on the assistance by friends, colleagues, partners, parents or other relatives.

Five of them would probably have been forced to give up their independence and live in an institution.

For two of these five another option would have been an overburdened partner or parent. Two of the users would not have been able to keep their jobs. Two users would probably have arranged something for themselves very similar to the services of the YHD, because that is what they had arranged before. For the five others the alternative was not clear, but some of them certainly would have become dependent on institutional care.

Slow changes

The findings also show that the changes from a situation of dependency, also in the matter of housing, towards a situation of independency, is a slow and gradual one. At the beginning of the project year, most users were very reluctant to give up the "safe" position in the institutions or in their parents home, even though they did not like (hated) the dependence. Some of them summoned

enough courage to take the step to independence . Others are still in a position of relative dependence but are considering to take the step to full independent living in the next future.

Involvement in work for the YHD

Three of the users worked as employee's for the YHD. Of three users it was explicitly mentioned that they served as volunteers for the organisations. It remained unclear in what way or not the other 21 users were actively involved in the organisation

THE IMPORTANCE OF THE INDEPENDENT LIVING ARRANGEMENT FOR THE HANDICAPPED PERSON

What did the services mean for the users? A selection of satisfaction statements.

"Feel much more independent"

"I can arrange the personal assistance exactly the way I want it"

"Do not depend any more on the "Good Will" of some organisation, friends or relatives"

"Don't have to ask anybody any more"

"I am not dependent any more on my partner; don't feel guilty any more that he has to do all the work when he comes home after a busy day in the office"

"I can spend time with parents for other things"

"I am now able to fulfil my work duties; I can keep a job"

"It relieves the burden for my parents"

CONCLUSION ABOUT THE RESULTS ON THE PRACTICE LEVEL.

All the independent living arrangements realised for the 27 handicapped persons offered at least some improvement and in many cases a considerable improvement. The results also show that the services of the YHD, because of the "user centred" and flexible way in which they are arranged, can accommodate users that want some but not full independence.

The number of people served was much more than the intended number of around 15 for the first year. There seems to be a growing demand, because at the beginning of 2000 another group of five had applied to become user.

Outcome on the organisational level

POSITIVE OUTCOME

There were by the end 1999 several positive findings.

- 1 Because of the Matra funding the organisation could employ a paid staff of three people which allowed the YHD to organise the assistance arrangements and further support of the independent living in a professional way.
- 2 The capacity was not only created but also used, because more people were served than was planned.
- 3 The YHD has proven that handicapped people if provided with the necessary means, are very well capable of running a service organisation for handicapped.
- 4 Given adequate funding of the salaries of the staff members, the organisation has a growth potential. The YHD staff estimates that the current organisation could probably serve a total of 50 users. For more growth, the organisation should be drastically changed and probably lose some of its easy accessibility and flexibility.
- 5 The organisation experiences more acceptance from other organisations, although there is still a long way to go, especially in the co-operation with more traditional service providing organisations.

- 6 The organisation seems to have been quite successful in creating attention for their cause in Slovenia because they have had a considerable amount of media coverage and are now sometimes asked as negotiating partners.

NEGATIVE OUTCOME

There are also many issues of concern. They are spelled out in full detail in the attached annexes by the staff of YHD. But some issues need to be mentioned here.

- 1 The organisation still has problems in obtaining government acknowledgement. Government accepts its existence and acknowledges that the organisation provides useful services, but there is as yet no full acknowledgement that the organisation offers a specific service necessary for the target group that is not served in sufficient quantity by other service organisations.
- 2 Because of 1 the organisation still has problems in getting access to regular and permanent funding from public sources. There are two different kinds of funding problems.
 - a. First of all the funding of the work of the personal assistants. These assistants are currently financed from, as far as we understood, a government employment program, in which people, who have difficulty in finding regular employment, can be offered temporary employment in special government supported projects. The problem with this employment program is that the jobs offered are temporary so that the continuity necessary for the personal assistance is very difficult to maintain. A second problem is, that the staff of the YHD has very little influence on the selection of the people for the job of personal assistant.
 - b. The second funding problem is the funding of the management and co-ordination tasks of the YHD office. The first task of the office is, what can be called case-management. This can only be done by an adequately paid competent staff such as has been employed with Matra funding. It is not realistic to count on volunteers for this work
- 3 Item 2 is very important because the Matra funding was temporary, so that the organisation urgently needs more funds to be able to create continuity in the services.

Outcome on the level of society

POSITIVE OUTCOME

- 1 The organisation provides a kind of service for a large category of people in need of these services in the Slovenian society, which service was not available for these people in this innovative form.
- 2 The results reached with these services are not only valuable for the people in question, but also for society. When handicapped people are feeling more independent and behave more independently, they are on the long run much more inclined to be active and productive citizens, who make the best of their difficult situation. Very valuable is also that the approach of the YHD gives an example of how also people with handicaps or other restrictions of their possibilities can take their lives in their own hands and be responsible for these lives in place of waiting passively what society arranges for them.
- 3 The organisation demonstrates the ability of a NGO to realise an innovative kind of service in a very cost effective way

- 4 The organisation demonstrates the ability of a NGO to realise flexible services that are very much adapted to the needs of the users.

NEGATIVE OUTCOME

- 1 The position of NGO's as appropriate organisations for the provision of certain innovative and or flexible services supplementing the existing service network, is still too marginal.
- 2 There is still insufficient acknowledgement that NGO's who provide services of good quality, cannot depend only on volunteers, but need a professional adequately paid staff.
- 3 The accessibility of public financing for NGO's providing services is still insufficient, causing a constant threat for the continuity of service provision and program development of the NGO's.

A solution for these problems could be found in a system of personal service budgets for handicapped people. Under such a system, people in need of services receive vouchers (the right to spend a certain amount of money) with which they can obtain (buy) services and are free to select the service arrangement that they like best, provided they stay within the limits of the vouchers and only spend the money on services of a acknowledged quality. The YHD could be one of the organisations offering services for which they could ask a tariff that includes the organisation costs. Because such a system could take a long time to be implemented, it might be necessary to grant NGO's more access to public funding both for maintaining acceptable direct service and for the employment of the necessary the staff organising the services.

This evaluation is a preliminary version that very soon will be followed by an official version (end of May 2000) that may show small changes in the wording but not in the contents.

Declaration:**Evaluation of YHD (Association for theory and culture of handicap)**

We declare that our evaluation of the material provided about the service provision and further functioning of the YHD (Association for theory and culture of handicap) and the information obtained in extensive interviews with the persons running this organisation, produced the results reported in the attached document.

Our general conclusion is, that the YHD provides services, that meet general standards for such services and that these services are beneficial for those people with a handicap who need assistance and support to be able to live independently according to their own preferences. The services are innovative and can be considered as supplementary to existing services. We can recommend continuation of these services, because apart from offering specific services, they also contribute to the emancipation and integration of persons with a handicap in Slovenian.

We furthermore came to the conclusion that the continuation of the services is under constant threat because of the lack of permanent funding of the work of the organisation. Given the fact that service provision in Slovenia is largely financed from public money, it is recommended that the organisation is granted permanent access to public funding. What specific form this access should have is beyond the scope of this evaluation. There are several possibilities such as:

- a) A systems of personal service budgets for handicapped persons with which they can pay for whatever services they want to use.
- b) A block grant of a adequate budget that each year is adapted to inflation and changes in the needs of the users and the workload of the organisation
- c) Subsidy of a certain number of paid personal assistant positions and paid case manager positions. The number of positions should also regularly be adapted to changes in the needs of the users and the workload of the organisation.

Prof. Dr. J.W. Duyvendak General Director

Drs. W.B.A.M. Melief, Senior Researcher and Evaluation Consultant