Development of a co-operative information system for the follow-up of evolution of users’s situation (Children, youngs and adults mentally handicapped).

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To cite this version:


HAL Id: halshs-01003337

https://halshs.archives-ouvertes.fr/halshs-01003337

Submitted on 10 Jun 2014

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DEVELOPMENT OF A CO-OPERATIVE INFORMATION SYSTEM FOR THE FOLLOW-UP OF THE EVOLUTION OF USERS’ SITUATION (CHILDREN, YOUNGS AND ADULTS MENTALLY HANDICAPPED) JULY 2006

1 - “PARADA”, OBSERVATORY OF THE ADAPEI USERS’ PROCESS OF INTEGRATION

Context
In 1994, the SASP/SIP (Service of Social and Professional Accompaniment) of the Adapei of Besançon (association of the friends and parents of mental handicapped people) begins an evaluation program for his users’ process of integration.

The legal context which governs the medico-social sector at that time starts to favour the individual project of the mentally handicapped persons as a base of the associative and services projects. It introduces notions of “management by project” as a base for the accompaniment by specialized institutes. New technologies from now on are considered like possible tools for the realization of the individual project.

Aims of the SASP are to use the NTIC like:
- Tool for an evaluative step of his users’ social integration based on the observation of the user/service interaction as an indicator of the evolution of the insertion of the users. The main idea is that there is a strong and complex link between the actions in direction of the user and the quality of his insertion.
- Database to improve the observation of the evolution of the social action for the users of the service, (analysis of the practice).
- Means of presentation of the results obtained by the service in direction of the association and the financial authorities.

Catalyse
It is in 1997, with the help of a European financing (program “Horizon Adapt-Employment”), that a partnership is founded between the SASP of adapei of Besançon and the Center MTI@SHS of the University of Franche-Comté. It’s based on the method and the tools CATALYSES that it develops.

Its aims are:
- Create a car-evaluation software based on a questionnaire of standard evaluation and its note of accompaniment,
- Install it, try it, train the users and follow-up the work realized
- Work out a first statistical position and accompany its analysis, interpretation and synthesis of the results with the participation of the operators.

Finally, the designed tool allows the improvement of the users’ monitoring, but also their evaluation and the activity of the social workers.

Reserved for all the professionals of accompaniment who wish to facilitate the evaluation of their actions, it supports:
- Collection of information regarding the initial situation and difficulties of the users or their families
- Emergence of the actions to set up in order to comply with their needs
- Emergence of those which were realized
- Description of the user’s final situation.

The analysis of this information by the professionals, periodically allows them to evaluate the projects by comparing the aims and the achievements, and to improve their strategy of action.

Description of the software PARADA
A file of user contains the whole information necessary to the social workers to ensure the reception and the
accomplishment: principal information relating to the person, data on marital status, information on residence, health, professional situation... and of all the actions this user benefited from since his arrival.

For each intervention, the professionals of services SASP/SIP fill an “intervention card” which makes it possible to keep track of the actions.

Each intervention is recorded in the software. For every intervention, the elements of user’s situation can be updated, if necessary. Previous information is archived in the software and can be subsequently consulted. This data recording allows for the follow-up of the user’s process of integration, and provides fundamental information to work with his evaluation.

The software takes into account the legal norms defined in France by the CNIL (Data-processing National Commission and Freedom). The access to the data is made safe by the use of logins and passwords, and by the possibility to define different levels of use and restrictions in the access to information according to their nature.

From a single-user tool, designed so that each professional manages the files of his users, the software evolves from 2000 to a network in which each one can have access to the whole of the files (350 users concerned).

It should be noted that this tool does not abolish times of exchange between social workers, but it optimizes them: from now on, these meetings are not more dedicated to get informed about the actions made, but to think together to the total situation of the user.

Principal difficulties for the implementation of PARADA
- A very long work of development
- Fears of the personnel about the change of its practices, about the possible risks of “control” dependent on the data-collection and their use by the directors, and about the deontological implications.

Prospects at the end of 2000
At the end of this project, it appears necessary to allow for a greater personalization of the system, so that PARADA is used in autonomy by the services (for the changes of items, of way of interventions, request of the financial power...), for a better adaptation and speed of response specifically because of the changes of the context.

2 - BASE DATA AND TOOL FOR COLLECTIVE EVALUATION ON LINE IN A REGIONAL PARTNERSHIP “EXIGENCE”

Description of the tool “EXIGENCE”
It is an individualized talk guide on the Web, made safe, accessible on the partnership intranet site for data collection, consultation, creation of interventions and dashboards of the actions and various criteria.

The aim of this talk guide is to fill the data progressively with the information provided by the user, and to update it according to the evolution of his situation. The talk guide details the situation of the user at his entry in the service and at his exit, and the actions realized. It is composed of 3 parts:
- The first part (reception) includes general information, often obtained during the first talk with the person.
- The second part (diagnosis) completes the questions of the first part (about the situation of residence, health, employment...). It results in the actions of integration, needed by users and proposed to set up by the professional.
- The third part concerns the follow-up and the evaluation of the situation of the person, recording the actions carried out and the situation at the end of his accompaniment.

The work of interpretation of the data is made by the professionals, with a strong implication of the user, and takes place on several talks based on the talk guide.

This tool makes it possible to describe the evolution of the situation of:
- each user
- groups of users
- all users, showing their progress in quantitative and qualitative terms (analyzes data, definition of the individual profile and needs).

Finally, on the basis of this tool, the partnership records the production during 3 years of:
- quarterly and annual statistics
- annual qualitative analysis of these results, interpretation and conclusions about the actions, the situation of the users, and the co-operative work in partnership.

Difficulties recorded for the implementation of the tool
“EXIGENCE”

- It’s difficult to adapt the indicators of users’ evolution to the needs of the partners: their activities are very diverse in terms of production of results personalized by structure or action.
- The database does not make it possible to record exploitable information on the capacities and necessary socio-professional users’ skills for the working stations: it requires the use of other complementary tools of evaluation.
- In spite of the improvements recorded, compared to the software PARADA, the database/tool of evaluation EXIGENCE still does not appear rather easily and quickly flexible, adaptable to the changes of the environment.

Perspectives in 2005

On the basis of a software used by only one institution then by the database and tools of evaluation on line for a regional partnership (750 users concerned), after nearly 10 years of work and consideration:
- the evolution of the system of observation of targeted populations must still be developed so that it will become better adapted to the needs of the social actors.

But it already made possible changes in the mentalities of the professional users, by a clear evolution of the appropriation of the concept of “evaluation” and its results in terms of actions.

3 - FINALIZATION OF A SYSTEM OF CO-OPERATIVE INFORMATION ON LINE “OSUA”, FOR ADMINISTRATIVE, SOCIAL AND PERSONAL DATA USED IN THE TOTAL AND INDIVIDUALIZED USERS’ PROCESS OF ACCOMPANIMENT

Context

In this new work phase which begins in July 2005, the stress is laid on the importance of the rationalization of the information management to give better answers to the users.

According to the law 2002-2 (evolution of the medico-social institutions), the adapei of Besancon started a rationalization of its internal procedures by beginning quality actions, for which it obtained a certification ISO 9001 v.2000 in december 2005.

This is why it was recommended by the Center MTI@SHS to develop a data-processing solution, very flexible, able to absorb in an intelligent way these constant adaptations to the legislative, administrative, and social contexts.

Public aimed: mentally handicapped persons, poly-handicapped persons, and in a more general way people in great social difficulty of insertion.

In the long term, the information system developed will be able to adapt to all types of population in great difficulty accompanied by specialized services or structures.

Description of the co-operative information system

“OSUA”

- co-operative information system in line (19 sites of the Adapei are initially concerned, with opening to the external partners for a real coordination in the users’ project of total and individualized accompaniment).
- It integrates forms of follow-up of users’ situation evolution, at the arrival and at the exit of the service, with indicators and criteria of evaluation.
- It integrates notes and online help to ensure the accompaniment of the users.

This system, initiated and carried out by the Adapei of Besancon is a complete tool for collective use at disposal of any social actor of socio-professional insertion users’ project for:
- quantitative and qualitative evaluation of the efficiency of the actions carried out on the individual situations.
- quantitative and qualitative car-evaluation of the performance of the institutions.
- definition of the individual profile and needs.

The aim is to evaluate the process of socio-professional insertion.

The recommended solution is to generate a collection of information for any intervention with the user, as in the 2 preceding systems.

Objectives for the professionals:
- data acquisition.
- grant all the interventions concerning a user.
- navigate between the situations.
- consult the calendars, the statistics.
- publish the file of a user.
- communicate all information concerning the users between the various actors, complementary intermediaries in different fields, proposal for a meeting, transmission of a situation or detail of an intervention…
- calculate statistics based on the information recorded in the database.

These calculations will be carried out starting from simple and crossed requests, on the basis of clearly identified descriptors.

“It is a question of developing a common tool for the whole sectors of the association where each one will be able to find what he needs for his users.

Moreover, it will allow us to develop an individual estimation per user and also an estimation of activity of an institution.

It will also be used as a tool for the synthesis of actions by the coordinator in the individual user’s project of accompaniment.”

The solution consists of several modules to implement:
- Platform Web.
- Joint Base.
- Administrative Management of the user.
- Modules to be developed in association with the joint base, concerning health, mobility transport, education, employment, residence, leisure, finances,…
- Manager of contents.
- Integral search engine.
For a real flexibility, an optimum adaptation, and to take into account the technology selected, the system will be able to evolve easily, quickly, without intermediary and progressively with the evolution of the environment of the accompaniment of the users, or of the institutional or legal needs.

For this management of the contents, a procedure is developed, organizing the role of every actor in the system.

Today, we record a strong mobilization of the persons who work on this project, thanks to an awareness that the system in the long term represents the tool of accompaniment and coordination of the actions implemented for the users, in the respect of the new legislation (individual project of the users, internal and external evaluation of the structures).

**Work done today**
- definition and validation of the architecture of the system
- principal common validated data
- writing of the procedure of management of contents of the system
- launching of the technological development of the system

**Work still to do in July 2006**
- Glossary (common with project CAENTI, to adapt to the French national context)
- Deposit of the project with the CNIL
- Detail of the data necessary to the structures of Adapei
- Instruction manual and online help
- Development, experimentation, correction, training of the professionals to use the system

The system will be efficient as of the end of the year 2006 for experimentation, for nearly 1.000 users.

**CONCLUSION**

On the basis of tools and method CATALYSE, Adapei of Besancon conducted the following actions:
- 1994: reflexion about evaluation
- 1999: experimentation of the software PARADA conceived for only one service (350 users) within a difficult and long work taking into account the professional revolution which the use of data processing for the follow-up of the users represented,
- 2002: the database/tool of collective evaluation by intranet “EXIGENCE” allows for the opening of this practice towards a work in regional partnership (750 users)
- 2005-2008: the project profits from the conclusions drawn from these 2 experiments ; particularly from the points of view of mentalities, laws and norm ISO 9001 v.2000 ; but also from the point of view of the considerable technological advances recorded by the development of a system of co-operative work “OSUA” (1 000 users concerned).

It should be noted that the Adapei of Besancon sought a partnership for the widening and the diffusion of its product and method, for the enrichment of its reflexion, practices and tools with project CAENTI.
In return, the Adapei of Besancon contributes to project CAENTI by sharing the work completed during his projects. The association will show its expertise capacity related on the handicap and the people in very great socio-professional difficulty.

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