

Title : Assessment of a population of disabled children : method, main results and discussion of ICF-CY

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Abstract :

The authors have built a Global Autonomy Assessment Schedule (GAAS) for disabled children hosted in French specialized institutions. This schedule, based on ICF, has been tested by social workers, physicians, psychologists, physiotherapists, speech therapists, occupational therapists, and teachers within a 59-children sample. Even though the authors' approach was based on ICF's methodological principles, their experiment brought them to modify substantially the proposed model and to adapt it. Hence, among the hundreds of available categories, they selected the most relevant ones to describe the aimed population, adding precisions in the definitions and complementary variables. They also developed an operational use of the generic scale to quantify difficulties and differently questioned environmental factors (in regard to their specific interaction with each dimension of a life situation and to their definitions).

In this paper, the authors will present the Global Autonomy Assessment Schedule, its field testing and the results of its implementation in regard to ICF and ICF-CY and compared to WHO-DAS-II.

INTRODUCTION

Before introducing the tool we have built from the ICF and comparing it to other tools associated with this international nomenclature (ICF for Children and Youth, WHODAS-II), I would like to give some contextual elements on the organization of social protection in France.

In France, there is a legal obligation to provide an education for children from 6 to 16. But, when their learning capacities are too limited or when conditions of reception in their nearby school do not satisfy their needs (buildings with problems of accessibility, lack of trained staff, etc.), children go to a specialized institution. These institutions are to fulfil three missions simultaneously:

- a pedagogic mission, by organizing a teaching adapted to the needs of every child,
- an educational mission, by proposing some actions that aim at developing communication and socialization of children,
- and a therapeutic mission, by providing them with necessary care and rehabilitation.

This triple concern leads these institutions to intervene in the different life dimensions of the child and to work with professionals who belong to different disciplines (physicians, social workers, teachers, psychologists, speech therapists, etc.).

This characteristic of the French institutional organization has led us to question the necessity, inside these institutions, of using a language common to the multi-disciplinary team in order to collectively design a life plan for the child. The ICF had this advantage of not belonging to any particular discipline and to explore the person's characteristics in his/her different life dimensions. Moreover, because it takes into account the environmental factors in the analysis of life situation, this could encourage medico-social institutions to better identify potential partners outside of the institution and to think about the conditions of inclusion of a child in ordinary school and settings.

AIMS OF THE TOOL

The construction of our *Global Autonomy Assessment Schedule* takes place within the scope of several research works our body is commissioned to make. The last order came from a French department composed of more than one million of inhabitants, that wanted to equip itself with a continuous observation tool of disabled children hosted in specialized institutions of its area (about 2000 children). It was a matter of collecting updated information on these children's life situation in order to adapt provisions programming to the evolution of needs and to improve the inclusion of disabled children in ordinary settings.

METHODOLOGY

If the development of this data collection grid leans on ICF principles (a multidimensional approach of a disability situation and interactive with the environment), we had:

- first, to select among ICF hundreds of variables those that were most discriminating to describe this population (if necessary, by rewording certain items or by adding variables);
- second, to define a more reliable way of coding the difficulties (by giving a definition of the different levels of difficulties for each variable)
- third, to propose an adaptation of the interactive reference model, by differently linking the notions of capacity, performance and environmental factors.

It is important to underline that the construction of this data grid, with the contribution of professionals who work in specialized institutions, was meant to be a basis for an operational information system that would help policy makers to adjust their social policy. This is this result-oriented requirement that has guided our theoretical and methodological choices.

The selection of the variables was based on the following criteria:

- variables had to allow a description of the disabled children's situation in their different life dimensions (every day life activities, involvement in social life, communication and relationships, mobility, learning, etc...)
- variables servicing a shared and non-clinical observation. The collection of information was not meant for professionals to establish diagnoses or to decide on therapeutic modes (or adapted pedagogic material; etc.), but rather to identify the characteristics that are fundamental for designing a global strategy of intervention (a life design). For example, we did not select ICF variables that describe affective components of the mental process (e.g. *Regulation of emotion* – b 1521: "mental function that control the experience and display of affect – sorrow, love, anger"). This information can be part of the psychiatric or psychological diagnosis definition but is too precise and refers to a too specific clinical approach to be part of a collective reflection that aims at developing a life design. So, we rather chose to assess the disabled children's difficulties in regulating their behaviours within interactions (d 7202). The child's difficulty to master his/her emotions, drives, verbal or physical aggressivity within interaction, depending on circumstances and respecting local norms (this wording has been established by professionals of specialized institutions) is not identified only by mental health professionals and is not taken into account only in the "therapeutic" dimension of the helping process. This is a major issue in the collective reflection aiming at developing an individual design or setting up a program of adapted measures. This difficulty can occur at school, while playing, during school meals or during a professional training session, and therefore it conditions the present and future answers proposed to meet the child's needs.
- Variables that are common to all the disabled children hosted in French specialized institutions and fit the large variety of the concerned children's profiles. This data collection grid must discriminate as much for children

with hearing problems who have some difficulties in learning and communicating, as for children with multiple disabilities who experience an extreme autonomy restriction in every dimension of their life situation.

The adjustment of this data collection grid required the conception of a way of coding the difficulties that would mean the same thing to everyone who might be in charge of filling it up (assessment must be reproducible). The ICF generic qualifier comprises five levels of difficulty in performing activities: no problem, mild problem, moderate problem, severe problem, complete problem. But it does not provide any precise interpretation of these different levels, only does it invite researchers to find a way of developing assessment procedures for a quantification to be used in a universal manner (ICF, 2001, p. 22).

Therefore, we set up a technical note for each variable with a specific definition for each level of difficulty. For example, having "some difficulties" in eating (d 550) refers to a situation where the person can eat by her/himself but either needs help from a third party to do complex manipulations (such as opening a sugar bag, removing a cookie from its packing), or needs to be stimulated (e.g. in order to begin eating, to get organized to take one's meal, etc.). These technical notes provide a better assessment's reproducibility since the persons who fill up the data grid have more precise criteria to complete the forms. However these technical notes do not provide for a universal coding mode. It is designed for a specific population and based on the representation of a scale of values common to professionals who work in the same branch of activity (with common theoretical and cultural background). Moreover, this codification schedule was reduced to 4 levels instead of 5. We changed "no problem, mild problem, moderate problem, severe problem, complete problem" to "no difficulty, some difficulties, many difficulties and complete difficulty". Because, if all the professionals have a common representation of the highest and lowest values, that is to say total absence of problem (i.e. no limitation of performance) and conversely complete problem (i.e. total limitation of performance), the intermediate values might be interpreted much more differently. In that respect it seemed more operational to eliminate the notion of moderate/medium difficulty ("moderate problem") because professionals do not have any particular representation of it (moderate understood as "medium" does not represent a reference point within their scale of values). On the other hand, among the intermediate values, the notion of "mild" difficulty and the one of "many" difficulties were kept, both referring to the highest and lowest values.

The application of ICF principles to this particular object has led us **to adapt the interactive model by differently linking the notions of capacity, performance and environmental factors.**

Our proposition of adaptation comes from two main findings.

First, it seemed impossible, when working on concrete situations, to measure someone's capacity or ability without taking account of life contexts in which he/she evolves. Because the notion of "standard" environment is not precise enough to allow the measurement of the "supposed" performance of the person in this "neutral" environment. It is not possible either to measure the effects of environmental factors on a life situation (mild barrier, moderate,

severe, etc.), which implicitly means comparing performance with and without the very environmental factor that is supposed to impact on the situation.

Second, the ICF assesses the effects of environmental factors on the whole person's life situation, without precisising which dimension(s) these effects particularly impact on. In order to optimise the child's autonomy, it is important to determine which activities are more sensitive to environmental conditions.

From these observations, we made the following methodological choices.

⇒ First, we limited our assessment to the performance of the child, observed in a real context of life, that is to say in the specialized institution.

⇒ Second, in order to pick out the effects of the environmental factors, we chose to analyse environmental factors for each domain of life.

⇒ Third, if it is not possible to determine the level of impact of environmental factors (mild barrier, moderate, severe, complete, mild facilitator, etc.), however it is essential to assess whether the effects are "negative" or "positive" and more generally, to work at identifying, for each life situation, environmental factors or specific means that have to be taken into account in order to optimise the child's autonomy. This methodological approach consists in three questions to fill out for each main dimension of a life situation:

- what is/are the environmental factor(s) that contribute currently to the difficulties of the child?
- what is/are the existing environmental factor(s) (or also some specifically mobilized environmental means) without which the child would have lesser performance?
- what are the specific environmental means that are new or in a greater amount which would be necessary in order to improve the child's performance?

The three questions related to the interaction between the person and his/her environment seem to be operational enough to define an action plan that would enable to reduce barriers, to support facilitators or to mobilize environmental factors to enhance the child's autonomy.

TOOL'S TESTING

This data grid was tested in 5 institutions that host children with very different disability profiles. The multidisciplinary teams of these institutions filled in a questionnaire about the situation of a random sample of 59 children. Psychiatrists, psychologists, nurses, teachers, social workers, speech therapists, physiotherapists, occupational therapists have taken part in this work.

The test results showed that this tool fits the diversity of children hosted in specialized institutions (selected variables were discriminating and relevant). It showed that this new approach of the child's situation changed professionals' practices. By distancing from the clinical approach and by offering a common language to the multidisciplinary team, this tool showed particularly useful, on one hand to assess complex situations and on the other hand to analyse situations on which team members did not agree. Moreover, taking to account

environmental factors favours the opening toward ordinary settings and allows to better identifying potential partners.

But the test has showed that this tool was not adapted to young children (less than 6). It showed that it requires a stage for the team to get familiar with the methodology and that the description of each situation takes much time. Finally, this tool does not include any particular partnership with the parents within this assessment process, even though nothing keeps the team from inviting them to take part or to have some exchange with them on its results. It would be all the more possible that the proposed common language, disconnected from any specific discipline, is particularly adapted to an assessment that has nothing to do with the establishment of a diagnosis but aims at knowing the conditions necessary to maximize their child's autonomy. It does seem, from a methodological and ethical point of view, that it is more adapted to ask the parents to give their opinion and to express their expectations on a "shared" and "global" assessment of their child's life situation rather than on clinical elements based on specific professional knowledge and skills.

DISCUSSION

→ Can this tool be considered as an ICF application to a particular object in spite of the model's numerous adaptations? Can this study be used for further work, for example, on the codification of the levels of activities performance? Is this implementation interesting only in the French institutional context? In any case, even though the operational goal of this work led us to turn around methodological and theoretical difficulties in a pragmatic way, difficulties that without any doubt, need to be closely studied, this work gave us the opportunity to put a theoretical model to the test of concrete and immediate concerns.

→ Our use of ICF is part of a shared observation process and in any case does not intend to address any clinical concern. From our point of view, ICF is interesting as a nomenclature that does not refer to any particular discipline and that is not based on any specific corpus. On the contrary, it provides another point of view on life situations, distant from a clinical analysis since it does not aim at the same objectives. It is a matter of understanding the possibilities of and barriers to people's inclusion in ordinary settings and institutions of society and not of establishing a diagnosis on their intellectual and psychic functioning in situations of learning, etc. From this point of view, our tool and our approach differ from the ICF-CY's approach. This ICF for Children and Youth describes a life situation by putting together clinical criteria coming from different professional corpuses and not from a common language. It seems ICF-CY gathers the main clinical indicators of different nomenclatures (medical, pedagogic, speech therapists', ...). What is the objective of this classification? In which way does the Other professional need to get familiar with My clinic to intervene on his own field? On the contrary, in order to determine a global intervention strategy, or to design an adapted life plan, it seems important for the multidisciplinary team to be able to exchange about the disabled person's potential in social and daily activities and about the conditions that have to be gathered to enable him/her to live a life with some autonomy and as a citizen (shared observation). That is why we question the reference to the clinical approach in ICF-CY.

→ Comparing our data grid with the WHODAS-II shows that we selected approximately the same variables among the hundreds that make the ICF. Did the WHODAS-II have the same goal as our tool? How can it be concretely applied to disability situations description? Has it been tested? Which was the way of codification used? How was it coded? How does it question environmental factors?