

THE PERSON WITH DOWN SYNDROME AND THE JOB WORLD. THE BIOPSYCHOSOCIAL MODEL FOR SUCCESSFUL JOB INCLUSION

LA PERSONA CON SINDROME DI DOWN E IL MONDO DEL LAVORO. IL MODELLO BIOPSIOSOCIALE PER UN'INCLUSIONE DI SUCCESSO

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Abstract

This work aims to clarify how it is possible to structure a path of personal and professional growth for people with Down syndrome with a biopsychosocial model (Engel, 1977). It also tries to explain how disability can be defined as the consequence or the result of a complex relationship between an individual's health condition and the context in which he or she lives and works.

The biopsychosocial model is a theoretical orientation that considers the individual and his health conditions dependent on physical, but also personal and environmental variables. Every condition of health or illness is the consequence of the interaction between biological, psychological and social factors.

The ICF, International Classification of Functioning, Disability and Health (OMS, 2001), in line with this model, introduces specific environmental factors that can describe the same environment with respect to which the functioning itself is evaluated.

Bronfenbrenner's Ecological Systems theory (1979), Lewin's writings about Field Theory (1951) and the Environmental psychology opened a horizon in the analysis of how the interaction between an individual and the environment affects human functioning.

The functioning of disabled or not person is the result of a relationship between individual features and context. According to ICF conception, the context acts as a barrier or facilitator of functioning.

Following BPS model as expressed in the ICF, the approach to individuals and their health problems aims to give a global view of the person, not only of his disability, while enhancing skills and creating a favourable context.

The educational proposal of the team of the restaurant "21 grams®" in Brescia is based on these innovative aspects. This situation differs from other similar ones on the national territory thanks to the theoretical model that supports the training of users, as well as a team of professional educators and professionals in catering, coordinated by a psychologist. The team also makes use of an innovative evaluation sheet, divided in two parts: how to be and how to give.

Individual, context and community are the main objectives on which the team of the "21 grams®" is focused.

The development of individual identity and abilities (Cottini, 2016) by the construction of facilitating tools that allow autonomy work (Bruner, Wood, Ross, 1976, Vygotskji, 1934); the awareness of the context, which can be both a facilitator or a barrier, by training employees and customers and introducing even physical changes to the job environment (Soresi, 2016); the community by creating a network of companies that recognize disability and diversity as added critical value for their competitiveness.

The team needs highly ecological assessment methods, congruent with people's life contexts. His intervention aims to define the customized project on the basis of an operating profile, which allows you to organize the work, define entity, resources and roles to be put in place. This allows to remodulate barriers and support facilitators over time.

It is clearly a matter of developing an innovative evaluation method.

Questo contributo ha l'obiettivo di illustrare come sia possibile strutturare un percorso di crescita personale e professionale per persone con sindrome di Down, di stampo biopsicosociale (Engel, 1977) e cerca inoltre di spiegare in che modo la disabilità può essere definita come la conseguenza o il risultato di una complessa relazione fra la condizione di un individuo ed il contesto in cui vive e lavora.

Il modello biopsicosociale è un orientamento teorico che considera l'individuo e le sue condizioni di salute dipendenti da variabili non soltanto fisiche, ma anche personali ed ambientali. Ogni condizione di salute o di malattia è la conseguenza dell'interazione tra fattori biologici, psicologici e sociali.

L'ICF, Classificazione Internazionale del Funzionamento, della Disabilità e della Salute (OMS, 2001), coerentemente con la visione di questo modello, introduce una specifica componente di fattori ambientali che possono descrivere

lo stesso ambiente rispetto al quale il funzionamento è valutato.

La teoria dell'approccio ecologico di Bronfenbrenner (L'ecologia dello sviluppo umano, 1979), gli scritti sulla teoria del campo di Lewin (Field theory, 1951) e la psicologia dell'ambiente, hanno aperto un orizzonte nell'analisi delle modalità con cui l'interazione individuo ambiente influenza il funzionamento umano.

Il funzionamento della persona con disabilità e non, è il risultato di una relazione tra caratteristiche individuali e contesto. Nella logica concettuale dell'ICF, il contesto agisce come barriera o facilitatore del funzionamento.

Con la presa in carico del modello BPS espresso nell'ICF, lo scopo dell'approccio agli individui ed alle loro problematiche di salute diviene quello di dare una visione globale della persona e non della disabilità. Si punta alla valorizzazione delle abilità e alla creazione di un contesto ambientale favorevole.

Sulla base di tutti questi aspetti innovativi si fonda la proposta educativa dell'équipe del ristorante "21 grammi®" di Brescia. Tale realtà si differenzia dalle altre simili presenti su territorio nazionale grazie al modello teorico che sostiene la formazione degli utenti, oltre ad un'équipe coordinata dallo psicologo e composta da educatore professionale e figure esperte della ristorazione. Il team, inoltre, si avvale di una scheda di valutazione innovativa che si divide in due parti: area del saper essere e area del saper fare.

I principali obiettivi su cui si basa l'équipe del "21 grammi®" sono la persona, il contesto e la comunità.

La persona: lo sviluppo della sua identità e delle sue capacità (Cottini, 2016), grazie alla costruzione degli strumenti facilitatori che permettono autonomia lavorativa. (Bruner, Wood, Ross, 1976, Vygotskji, 1934). La sensibilizzazione del contesto, che può essere facilitatore o barriera, attraverso la formazione dei dipendenti, dei clienti e l'introduzione di modifiche anche fisiche agli ambienti di lavoro (Soresi, 2016).

La comunità ovvero la creazione di reti di aziende che hanno riconosciuto la disabilità e la diversità come valore aggiunto e decisivo per la competitività d'impresa.

L'équipe necessita di modalità di valutazione marcatamente ecologiche, in grado cioè di risultare congruenti con i contesti di vita delle persone. Il suo intervento mira a definire il progetto personalizzato sulla base di un profilo di funzionamento, che permette di organizzare l'operato, definire l'entità, le risorse ed i ruoli da mettere in campo. Questo permette di rimodulare le barriere e sostenere i facilitatori nel tempo.

È chiaro che si tratta di sviluppare una modalità di valutazione innovativa che propone una rivoluzione culturale, partendo dalla valorizzazione della diversità dell'altro.

Keywords

Biopsycosocial, Context, Evaluation Sheet, Multi-Professional Team.

Biopsicosociale, Contesto, Scheda Di Valutazione, Equipe Multiprofessionale.

Introduction

We can say that the meaning of work inclusion is asking to ourselves how the environment is prepared to welcome people with intellectual disabilities.

So, we have to proceed by trying to make inclusion a workable reality, focusing on the reason that make it necessity, and on the ways to obtain it.

1. A new vision, the biopsychosocial model and the job inclusion. The importance of the context.

The educational method and job training for people with DS taken into consideration in this work are based on the biopsychosocial model (Engel, 1977), which is a health derived model, characterized by being contextualistic, relational, systemic and ecological, congruent with people's life context and opposed to the classic biomedical model, which is focused only on the injured part of the patient.

In fact, the BPS model starts from the awareness of the different biomedical model weaknesses, which ignores the psychological, social and environmental factors and doesn't read the conditions of health and disease as a consequence of the mutual interaction between the person, with his biological (organs, tissues and cells) and psychological (cognition, emotions, motivations) system and the social system (community, family and society), which are in a continuous and mutual influence.

Giving up the focus on cognitive and executive functions recovery and including patients personal, relational and environmental dimensions, the BPS model is a strategy of holistic approach to a person, developed by Engel in 1980, based on a multidimensional idea of health,

described in 1947 by the WHO (World Health Organization).

The BPS model, adopted by the WHO with the publishing in 2001 of the ICF (International Classification of Functioning, Disability and Health), provides a new meaning to disability: disability is made by context. In this perspective, we can't speak of disability as a pathological condition, but it depends on the interaction between the person and the context in which they live and work.

The approach to individuals and their health problems has the purpose of giving a global vision of the person and not of the disease, focusing on skill enhancement and the creation of a supportive context. Proposing the integration of the biological, psychological and social aspects, characterizing each individual in a different way allowed for the first time the understanding of the importance of multisystemic interventions in this field. The care of the patient according to the BPS model, is therefore holistic, aiming to give him the best possible functionality. The biopsychosocial model approaches health according to epistemologist Bertalanffy's General Systems Theory, which has emphasized the global knowledge aspect, the structural whole complexity, the interactions existing between the various phenomena and organisms, arguing interdependence relationships between different variables.

According to this view, a person is an open system, in continuous evolution and exchange with the surrounding environment and the cognitive subsystems of which it is made: physical and emotional.

If we consider, in fact, the same representation of health and disease, we can see how susceptible it is to changes even in a lifetime, to changes in basic biological processes, to emotional, cognitive and personality dynamics, to social norms and expectations, activity and levels of participation in relationship.

The keystone of the BPS model is the ICF: the context where a person lives and works can act as a facilitator when it emphasizes skills, or as a barrier when it limits the activities and represses the person's skills. The ICF gives us a positive view: You go from focusing on handicap and disability to focusing on functioning.

This is useful to understand that the opposite of "disability" is not "good health", but how to function like others and with others. With ICF, the WHO proposed an international model able to describe components of health that contribute substantially to define an overall picture of a person through a positive perspective, avoiding to focus attention only on deficits.

Consequently, the ICF cannot be regarded as a diagnostic tool, but as an analysis of the functioning with personal and environmental factors as context.

The environmental factors taken into consideration are all those elements that can influence the participation of the individual as a member of society and his daily activities.

What a disabled person can do in practice in everyday life contexts does not depend only on his abilities but also on contextual factors, which can reduce an ability (in that case they are barriers) or emphasize it through one or more facilitators.

On an educational level, the most direct consequence is the possibility of combating the disability arising from physiological impairments through positive action by environmental factors.

ICF model refuses the belief that those born with a disability or impaired cognitive ability and function cannot acquire skills or develop resources.

2. The "21 grams®" and its team.

The educational action aims to enable a person through the creation of contexts that enhance the existing capacities.

This is one of the aims of "21 grams®" and its team.

"21 grams®" is a restaurant opened in Brescia in February 2016, where adults with Down Syndrome can work or have an internship: the final aim is to show that the combination between disability and work is possible and advantageous. Recent market surveys show that companies with people with intellectual disabilities in their staff have a more motivated staff, less absen-

teism, but above all they have proved to be more open to demands and changes of the market itself.

The restaurant team has three focuses: person, context and community.

Concerning the person with SD, there is a strong belief in their skills and their possibility to be active and have a role in the society. The team tries to create an identity, making the person with SD feel like normal people: a citizen with rights and duties. Achieving this goal increases effectiveness and self-determination. These experiences give real skills that can be used in the job market. Planning individual paths for skill development goes through different phases: studying, programming and creating tools that make the worker with SD autonomous and independent.

The training studied by the “21 grams®” team starts from knowledge of the knowledge of how the person with Down Syndrome functions, from their strengths and weaknesses, then goes on with the analysis and structuring of the environment. By environment we mean the physical aspect, but also the relationships with colleagues and customers.

Focus 1: Person.

An environment with barriers, or without facilitators, will limit the individual performance; other more facilitating environments may instead promote it. Workstations inside the restaurant are all supported by job descriptions and other facilitating tools, to support impaired skills and enhance cognitive and executive functions to support impaired skills and enhance cognitive and executive functions, skill development, learning consolidation and barrier elimination. The neuropsychological skills of SD subjects, involve better visuo-spatial skills and processing of non-verbal information. Starting from this assumption, the tools designed and used are:

- the job description: an illustrated book that describes the single operations carried out by the user and the related procedures, step by step. Each description matches with a related demo photo. There must be one simple phrase that explains the photo in one single page; there must be just one action per page.
- the check list with all the ingredients used in the kitchen, which must be prepared on the bench. Initially the ingredients are placed inside the refrigerators: the user, with a written list, which can also be checked, takes the ingredients and puts them in order on the work bench.
- the check list with all the ingredients used for a single plate. One of the tasks of the kitchen is the preparation of salads. For each single salad, the check list shows name and all the single elements in it, with a square that the user can tick once the ingredient is inserted. Thanks to this the user can check all the ingredients without memory efforts. Each check list has a photo of the final product, which is a model and an example.

The tools are therefore in support of the compromised skills in the SD (attention, memory and perceptive discrimination) and they promote autonomy and consolidate learning.

Focus 2: Context.

Over the years, the staff of the restaurant has also been the subject of training to acquire the right knowledge and skills to be able to welcome and train people with Down syndrome.

The customers of the restaurant are a useful presence and do not just enjoy the restaurant service, while they also become trainers and training recipients.

Awareness of the context addressed to colleagues, volunteers and customers, to erase their prejudices, is very important. Today, normal employees, volunteers and customers no longer feel uncomfortable in front of a waiter or bartender with SD because they understand that observations help the relationship on equal terms; above all they can see who the employees with SD are: men and women at work, regardless of SD.

Focus 3: Community.

The third focus is about creating networks. On February 2019, the team planned a conference where some managers of companies that recognized disability as an advantage for their business competitiveness, shared their positive experience with managers of other companies.

Work inclusion does not depend only on the ability of the disabled person to adapt, but it above all depends on the organizational capacity of the company to make the person productive.

Positive effects for all employees, increased brand awareness and economic performance of the company, a more open to change and more resilient work environment, more motivated human resources, less absenteeism, better distribution of roles and development of new organizational forms: these are some of the advantages reported by companies, increasingly numerous, open to disability management and more generally to diversity management.

The “21 grams®” team is made up of a psychologist, who coordinate the educational projects, an educator and two tutors, one for the dining room and one for the kitchen.

It is a necessarily multiprofessional team, because variables such as the biological, psychological and a holistic management is: an overview of needs that talks about the person as a whole and all their variables, without losing focus on cognitive factors.

Working to increase the autonomy of disabled people, strongly ecological assessment methods are required, that is methods capable of being congruent with people’s living contexts.

Spending energy and resources to this kind of methods is important for several reasons:

- from a scientific point of view, it is important to test the effectiveness of the procedures used to decide whether or not to proceed with further interventions to replicate them by working with people with similar difficulties.
- from a deontological point of view, it is necessary to verify if the work done is really efficient.

According to the biopsychosocial Teamwork module focused on the person functioning should help the team “think positively”, allowing the identification of factors that act positively (to be supported) and negatively (to be removed or reduced) on the functioning of a person.

The work focuses specifically on a pedagogical dimension, with the primary intention to identify educational paths that can encourage each person to play an active role, to make choices that affect their own development, thus creating the best conditions for life quality.

To understand how to operate on potential abilities from an enabling perspective, we need to refer to Vygotsky’s studies (1987). According to the author, the gain of a new skill is possible through a process which he describes as a passage from the phase called “current development zone” (the stage in which the user is before acquiring the new capacity and which describes the skills that he already has), at the “proximal development zone” phase.

The “proximal development zone” therefore represents a learning area of a new capacity, on which we are working with a reinforcement action on the skills already possessed, with the aim to develop that specific ability. As long as the user remains in the proximal development zone the support action offered by the educator needs to continue. Then this support must gradually decrease, until it disappears when the user becomes capable. At that point, the learned ability becomes part of the current development area which is enhanced by the new exposure.

Bronfenbrenner’s (1986) discoveries, his so-called “ecological approach”, as well as Lewin’s writings (1951) on the “field theory”, opened a new horizon in the analysis of how the interaction between the person and the environment influences human functioning. From their studies, in particular, some fundamental guidelines for education, even of a special type, come up.

For example, the ecological approach clarifies that it is not possible to fully understand a problem of human behaviour, if the environmental variables from which it generates and to which it responds are not clear. This assumption also characterizes Lewin’s “field theory”, which however clarifies that an individual’s behaviour, although influenced by stimuli that come from the environment, should never be meant as a response determined by them. According to Lewin, the subject is always an active part, never a passive one, because he himself is

an element of that set of forces, tensions, relationships and processes that build up the “field”.

With specific reference to Bronfenbrenner and therefore to his theory on human development, it can be useful for the educator looking at the meaning of environment in the different interpretations offered by the theory of ecological systems.

In the perspective of environmental psychology, the environment is not considered only as a physical space, but above all in its social and political dimension, looking at the general characteristics of the social areas in which daily life takes place.

The customized project drafting, made by the Team.

The personal project must be considered as the set of resources that are invested in the improvement of a situation and it is evaluated according to the changes promoted. It will lead to positive changes of the situations, allowing to evaluate how the cooperative strategy and the resources used would be, in comparison to the result achieved.

Defining the personal project on an operating profile base allows you to organize interventions and to define the extent and the types of resources and roles to be deployed, in order to limit the barriers and support facilitators over time. The functioning profile of the same person, described at different moments in time, provides the elements to read the effects of the intervention and to evaluate its results.

3. The work prerequisites form.

The team uses, just inside the restaurant, as the main evaluation tool, the work prerequisites form, which is still being studied and tested, in collaboration with the University of Bologna.

Based on the Biopsychosocial model and the International Classification of Functioning, Disability and Health (ICF), this evaluation form is used for monthly observation of the users, for training planning and its control.

Its use defines what would be essential to know about the person, to guide their placement under care and their personal project.

This form is filled in by the educator and the psychologist and represents a true revolutionary tool. The form allows all operators to speak the same, technical and accurate language shared by all.

The form can also be used as a presentation and description of the user to the psychologists of the ASST, the local health authority.

Just like the ICF, the form is split in two parts as well: the analysis of the person and the analysis of the environment.

- Part 1 Functioning and Disability

- a) body functions and structures
- b) activities and involvement

- Part 2 Contextual factors

- c) environmental factors
- d) personal factors

The form focuses also on the performance as the involvement in a life situation or living experience of people in the context in which they live.

Each performance is assessed through a qualifier, which shows the difficulty of the person doing things in relation with the environment; it is a numeric code that states:

- the extent and severity of the functioning or disability in a specific category
- the level at which an environmental factor can be a facilitator or barrier.

Items have no meaning without a qualifier.

While evaluating functioning and barriers, qualifier 0 expresses the best condition while qualifier 4 shows maximum seriousness.

Evaluating facilitators instead expresses with 4 the best condition.

The first part, Functioning and Disability, is split in:

- “how to be” area, that is role-playing skills, what the person learns to be in their job environment
- “know-how” area, which is about skills acquisition and the learning consolidation.

The second part, Contextual Factors, focuses on the environmental factors that refer to the external world and build the context of personal life, having an impact on functioning and performance. Environmental factors include: physical environment and its characteristics, other people (colleagues, family, customers), attitudes, values, society, rules.

The environmental factors also concern: transports used to reach the workplace, times and duties assigned, structure of workplace, work tools, relationships with colleagues, attitudes of the family, availability of colleagues, staff and employees. flexibility of the company.

The form ends with notes about changes made to the environment to improve the performance.

The items are assessed through qualifiers ranging from 0 to 4; the average being the evaluation of personal evolution.

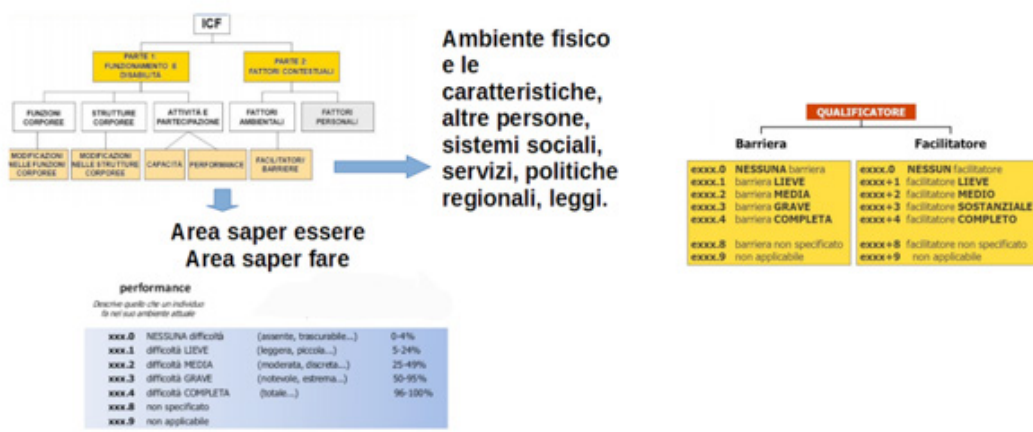


Figure 1. struttura dell'ICF e qualificatori rapportati alla scheda di valutazione dei prerequisiti lavorativi.

Conclusions

Seeing disability according to the Biopsychosocial model allows to avoid simplifications or reductionisms, respecting the complexity of the phenomenon. The Biopsychosocial paradigm lets us to understand the interdependence between the different areas/dimensions that make human functioning and offers a key to understanding the concrete experience of disability, that helps the educator understand causes and conditions through an integrated and systemic reading.

The ICF introduces a specific component of environmental factors that can describe the environment in which functioning is evaluated. According to BPS model as expressed in the ICF, the purpose is to approach to individuals and their disability with a global vision of the person, not only of their handicap, aiming to the enhancement of skills and to supportive context. Environmental factors are able to mark this difference, to make the action of the biological component less limiting, or to emphasize it by offering new learning methodologies.

In this perspective, assessing disability means focusing on the interaction between the person and their environment,

identifying those aspects of both (person and environment) to be improved towards inclu-

sion purposes.

Evaluating the interaction between the person and their environment, integrating the knowledge of both dimensions, is the most interesting and complex question in scientific and methodological terms, to reach the development of an innovative evaluation method. Fundamental values such as the construction of own identity and the realization of the self are fully involved into the work activity and they are fundamental to restore equal rights and opportunities for the person with disabilities.

It is important to understand how a social variable of environmental kind could decisively upgrade the functioning of a user with a disability. Understanding that, necessarily needs a change of perspective in the analysis of the causes of educational problems: the educator has to overcome the idea that user's problems and difficulties are just an effect of their individual and specific incapacities. Scientific research has now demonstrated that isolating a problem from a context does not help its real understanding. The accessibility of a job place becomes instead a real opportunity of a higher quality of life for those who have an intellectual disability, such as that of Down syndrome.

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