Neurodevelopmental disorders and development of project of life in a lifespan perspective: between habilitation and quality of life

Roberto Cavagnola[1], Laura Alzani[1], Davide Carnevali[1,2], Giuseppe Chiodelli[1], Serafino Corti[1,3], Francesco Fioriti[1], Maria Laura Galli[1], Mauro Leoni[1,2], Giovanni Michelini[1,2] and Giovanni Miselli[1]

[1]*Dipartimento delle Disabilità, Fondazione Istituto Ospedaliero di Sospiro Onlus, Sospiro (Cremona), Italy*
[2]*Sigmund Freud University Milano, Milan, Italy*
[3]*Università Cattolica del Sacro Cuore, Brescia, Italy*

Abstract
For some years, the term "project of life" has become widely used in the field of neurodevelopmental disorders, and, at the same time, it has begun to make its way in many social and health planning documents. However, beyond its relatively widespread use, this term does not yet possess an adequate and shared frame of the main underlying decision-making processes. In particular, there is a need to identify the crucial questions for orienting the choice of goals within the adolescent transition, which represents the complex hinge between childhood and adulthood. Moreover, adulthood, which is often completely devoid of culturally and socially shared references, is still critical precisely because of the lack of future direction prompts usually represented by the stages of development. In this case, the themes of quality of life functioning as a guiding compass appear pertinent and much more relevant. The present contribution is, therefore, an attempt to present, in a unitary manner, the decision-making processes and questions at the basis of a construct of "project of life" shared within the scientific and associative communities.

PROJECT OF LIFE DURING DEVELOPMENTAL AGE: INTRODUCTORY CONSIDERATIONS

When analyzing the project of life in children with neurodevelopmental disorders, it is necessary to introduce an important distinction between childhood and preadolescence: they may roughly correspond to the transition period between the end of primary school and the beginning of secondary school respectively.

This distinction seems appropriate precisely in relation to the concept of project of life. As regards childhood in the strictest sense and, in particular, what is sometimes called first and second childhood, (from birth to the first five years of life), we believe that the project of life has, and should have, specific habilitation-based features closely related to the different developmental stages. Indeed, it is during the developmental stages that anything "potentially" relevant for the future life of the child is pursued. In a broad sense, therefore, we speak of project of life as a way of bridging the gap between the skills possessed by the minor and what is typically observed in minors of the same age. The project of life clearly aims to find a connection with the outcomes that the person will have during the course of their life but, on the level of habilitation contents, it is based on "cusp" [1] and "pivotal" skills [2-4]. These skills are important in order to guarantee greater possibilities of development, promotion, and quality of existence in the periods immediately following, such as the one starting with pre-adolescence. Indeed, it is precisely during this period that it is more appropriate to speak of a project of life because what was previously purely potential, now begins to be translated into numerous links which effect what ideally will find full actualization in adulthood, i.e. an existence made up of inclusion, commitment, active recognition within society, and achievement of personal outcomes.

Therefore, the keyword for childhood is "habilitation".

Child habilitation is, by definition, extended to all areas of development. However, primary attention should be given to some repertoires that objectively play a criti-

Address for correspondence: Roberto Cavagnola, Dipartimento delle Disabilità, Fondazione Istituto Ospedaliero di Sospiro Onlus, Sospiro (Cremona) Italy. E-mail: Roberto.cavagnola@fondazionesospiro.it.

cal role in the whole process of growth and that, consequently, have an educational centrality.

The relevant areas of intervention in the educational habilitation process can be briefly summarized as follows:

- inter-subjectivity;
- game and free time;
- communication;
- personal hygiene;
- basic autonomous behaviors.

The assessment tools that can adequately support this habilitation practice and emphasize the above-mentioned areas are: Vb Mapp (Verbal Behavior Milestone Assessment) [5], Pep 3 (Psychoeducational profile) [6], Denver Model Curriculum Checklist [7], Ablls (Assessment of Basic Language and Learning Skills-Revised) [8].

In general terms, what may be said about first and second childhood intervention, can be effectively summarized within the so-called triad of intervention.

Firstly, the intervention is defined starting from *precocity*. The precocity of intervention is now considered to be the necessary condition to exploit learning opportunities and maximize the chances of success of the intervention. At the same time, precocity prevents the consolidation of "maladaptive" learning behaviors within the main contexts of interaction.

A second characteristic of the early childhood intervention is the *intensiveness*, which refers not only to the quantitative dimension of the treatment (minimum number of hours per week necessary to support the change), but also to the contextual dimension. Intensiveness indicates the extent of the habilitation action not only centered on the child, but also extended to the context in which the child lives. Special attention is given to the child's family engaged in learning and experimenting with new effective models of interaction. For these reasons, the educational planning implies, from the beginning of the intervention, a guided involvement and participation of the family members in order to create the most favorable conditions to transform every daily moment with their child into an authentic opportunity for learning in a natural environment.

The *curricular character* of the treatment is the third salient feature and it refers to the articulation of the goals linked to the developmental processes. Therefore,

this type of intervention must be supported by specific assessment tools, such as those mentioned above, capable of aligning the assessment plan with that of the intervention. The curricular plan must also be pursued with educational procedures that are supported by clear evidence. Hence, we are referring, in general terms, to the complex and articulated contribution offered by behavioral science with ABA and the Denver Model. As already mentioned, it is believed that the project of life begins to acquire shape from the pre-adolescent and adolescent phases. The two main elements that markedly note the distinction between the planning of the first and second childhood are: first, a more precise and punctual identification of concrete and specific community contexts within which to allocate educational interventions to promote the development of the child. Secondly, a stronger emphasis on the set of transitions viewed as a shift to increasingly diversified and specific social roles. The minor begins to enter the peer group, to participate in a more active community life (volunteering, places of entertainment, etc.), to develop the need to move independently in the territory, and to have a more active and collaborative role within the family and domestic context.

If the keyword for childhood was "habilitation", for the adolescent and young adult the keyword becomes "transition". Thus, the assessment process must reflect this change of perspective and adopt this transition to new roles and new areas as a central element of the evaluation.

Useful tools in this perspective are: the Teacch Transition Assessment Profile (TTAP) [9], Community Based Skill Assessment Checklist [10] or the Transition Checklist contained within the VB Mapp [5]. These tools focus, in particular, on the skills needed to adequately perform the complex tasks required by the transitions. The relevant work areas within this life cycle are described in *Table 1*.

In an attempt to summarize in key words the paradigm of the project in a lifespan perspective, it could be stated that the project of the person with neurodevelopmental disorders ideally represents an arc. The starting point of this arc coincides with a strict *habilitation* phase, which is then followed by a planning phase during which the *transitions* represent its main feature. These transitions are the ones that accompany the per-

Table 1

Adolescent and young adult task area required by the "transition" phase

Area	Description
Career and employment	Opportunities to learn all the skills needed to enter the world of work in a fulfilling and productive way, while respecting the personal skills and interests, or attitudes
Self-determination	Ability to be the primary causal agent of one's choices, and at the same time, the knowledge of how to protect oneself from possible exploitation or deception
Health and Safety	Ability to manage one's sexuality, to adequately manage possible pharmacological therapies or practices of self-medication, or know how to move safely in the home
Community active participation and access to services	Participate to the wide range of possible activities related to personal satisfaction, such as the cultivation of friendships, the development of hobbies, sports activities, etc. Furthermore the use of public transport is crucial to attend community
Role within one's own household	Acquiring an active role, which is that of contributing to the management of the various daily life actions and to the care of the home environment

son to adulthood where the project takes on a markedly existential connotation.

THE PROJECT OF LIFE IN ADULTS WITH NEURODEVELOPMENTAL DISORDERS AND DEFINITION ISSUES: INTRODUCTORY CONSIDERATIONS

The previous paragraph has given us a glimpse, in its essential terms, of what could be defined as an itinerary for the development of a project for people with neuro-developmental disorders in the developmental age. Perhaps, a good starting point is the precise definition of the differences between a project of life for people with neurodevelopmental disorders in adulthood and in the developmental age.

First of all, the project of life for the adult person, especially when compared to the developmental age project, implies fewer shared social expectations. The developmental age consists in stages of development where, regardless of whether the specific child will follow this evolutionary sequence, there is a social consensus on what is important to acquire. At a certain age, a child is typically expected to start speaking, to develop sphincter control during kindergarten, to start learning literacy at the age of six, and so on. Something similar does not exist for adulthood. The cultural and social link that can be the basis for choosing goals for the project of life in adulthood is much more evanescent and nebulous. This becomes vaguer when the functioning of the people with disabilities is low, they require a high degree of support, and there are no credible pathways to employment. Hence, we enter a gray area where "what society expects" appears to be an even more random reference. All this leads us to affirm that, at times, when selecting goals for the adult person with disabilities there are specific reasons why certain goals were chosen to the apparent detriment of others.

Secondly, in simple terms, the project of life for adults should be characterized by a different emphasis within the range of goals. Gardner [11] proposed and distinguished between the following outcomes:

- *clinical*, are the outcomes of interventions aimed at ensuring both good physical health and the reduction of "challenging behavior". Both the former and the latter interfere with the full exploitation of the opportunities offered by the community;
- *functional*, are the outcomes of programs aimed at improving the person's functioning in terms of socially relevant behaviors;
- *personal*, are the expression of what is interesting and desirable for the person.

If we adopt this tri-partition of goals stemming from expected outcomes, we can affirm that planning in the developmental and adult age differs precisely because of the different saliency of these three categories within the individual project. In particular, in a project of life for adults, the functional goals, though still present, will be decidedly less marked than those found in a project for the developmental age. This is not only because of less brain plasticity, but also, and especially, because the greatest concern in adulthood is to enhance and emphasize the learning that occurred in the previous years. This means making the object of learning functional and avoiding maintaining the subjects at the existential register of eternal schoolchildren. Conversely, in adulthood all those paths that put the person in contact with personally relevant and rewarding outcomes will necessarily have to find more space, which is not different from what all adults pursue when attempting to realize their desires and expectations. The potential presence of health issues or behavioral and psychopathological problems may facilitate both in the developmental age and in adulthood, the presence of clinical outcomes *(Figure 1)*.
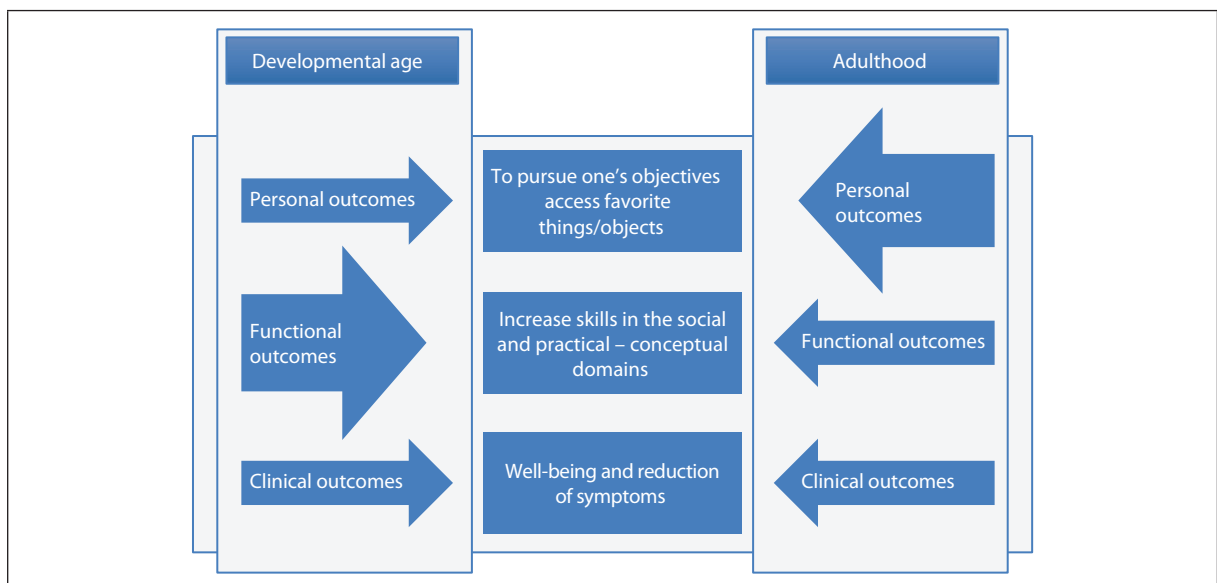

Figure 1
Model of the "Project of life" outcomes differentiated by the age of the subject. The size of the arrows indicates the greater/lower emphasis that should be given to personal, functional, or clinical outcomes in the different ages.

Thirdly, we believe that another difference between projects in the developmental age and adulthood lies in the different timespan that characterizes them. Indeed, the goals contained within a project for minors have, legitimately so, a very close temporal projection. On the contrary, those present in a protocol for adults require much more time for their realization. This depends on two factors: the first, which is well known and cited, is the greater brain plasticity during the developmental age, which necessitates intensive and early intervention, with different and operational short-term goals. The second is linked to the common and ordinary ways in which, typically, adults plan their lives. Indeed, the ways to build a career, an independent life, an emotional project are goals that may occupy many years and involve countless and intertwined paths. Thus, a project of life for adults will necessarily require an adequate temporal span within which to unfold and should not have significant repercussions in the short term [12].

The assessment of the project of life

In terms of assessment, it may be useful to start from the five dimensions that characterize intellectual disability and autism according to the multidimensional perspective proposed by AAIDD [13, 14]. This multidimensional approach requires that a comprehensive assessment of a person with neurodevelopmental disorders include five dimensions to be assess:

1. intellectual capacity;
2. adaptive behavior in its three fundamental factors (conceptual, social, and practical);
3. health, physical, and mental condition;
4. participation, interactions, and social roles;
5. the person's life context.

For each of these five dimensions, there are different tools depending on the function the evaluation intends to perform. The functions can be:
- diagnostic;
- classificatory;
- aimed at the programming of plans and individual support systems [14].

For the purpose of this contribution, we think that the main purpose of an evaluation process is to better identify the necessary support systems:
- improve functioning;
- improve outcomes (in terms of quality of life);
- encourage the implementation of individual choices;
- guarantee human rights.

Within the five dimensions, the assessment tools will thus be varied and the short list below has the sole function of indicating, in a concise manner, some of the most useful ones for the development of a project of life. As far as health conditions are concerned, the CIRS (Cumulative Illness Rating Scale) [15] is an easy, but effective tool for the quick identification of the active pathological frameworks and comorbidities present in the individual. The CIRS is a standardized scale for obtaining a measure of somatic health. The questionnaire requires the healthcare professional to identify the clinical and functional severity of 13 categories of pathologies based on clinical history, objective examination, and symptoms. Then, the professional defines the level of severity for each of the categories and a comorbidity index is drafted. With regard to the health condition, the presence of other potential psychopathologies necessarily requires appropriate tests to detect the associated psychiatric pathology, such as SPAIDD-G (Systematic Psychopathological Assessment for Persons with Intellectual and Developmental Disabilities - General screening) [16] or DASH II (Diagnostic Assessment for the Severely Handicapped revised,) [17]. However, it is critically important to have instruments of functional analysis of behavior and, in particular, of experimental functional analysis [18, 19]. Indeed, these may detect the functions of behavior and, consequently, may be the basis for the identification of iso-functional, adequate and effective behaviors, which need to be reinforced in order to replace problematic and dysfunctional behavioral repertoires. As far as the adaptive dimension of behavior is concerned, in addition to the Vineland II Scales [20] – which represent a normative tool – an excellent contribution for the construction of a project of life is provided by other sets of criterion-based tests such as the TTAP (TEACCH Transition Assessment Profile) [9], the EFL (Essentials For Living) [21], the AFLS (Assessment of Functional Living Skills) [22]. In terms of the intelligence dimension, we believe that tests of a normative nature such as the WAIS (Wechsler Adult Intelligence Scale) [23] hardly satisfy the function of programming plans and individual support systems. If the main purpose of this particular type of assessment is to define the project of life, then it may be important to use assessment tools that improve the evaluator's ability to focus on basic learning skills, such as ABLA (Assessment of Basic Learning Abilities) [24] or communication skills, such as the Speaking and Listening scales in "Essentials For Living" [21].

The assessment of the remaining two dimensions, namely participation, interactions, social roles, and the context of life, emphasizes the need to make use of criterion-based and non-normative tools, such as ecological questionnaires to investigate the ecosystems of the person's life and scales for the assessment of support. Furthermore, at least two types of assessment can also be extremely significant: the quality of life and the preferences expressed by the individual. With regard to the theme of quality of life, there are many scales designed for such assessment in people with neurodevelopmental disorders [25-31]. In our working practice, we make explicit reference to the meta-model proposed by R. Schalock [32], who insists on eight domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being and mental health, material well-being.

As it has already been anticipated, a second type of assessment plays a crucial role in the development of the project of life. This assessment consists in a set of procedures normally defined as "preference assessment". The assessment of preference is of fundamental importance for a project of life that emphasizes the prominence of personal outcomes, the access to the

world of stimuli and, more generally, the events preferred by the individual. This type of assessment can be performed indirectly, that is, the source of access to preferences is not the direct observation of the person with disabilities, but a survey conducted by caregivers who know them best (or by people with disabilities themselves if they are linguistically competent), for example questionnaires such as RAIDS (Reinforcement Assessment for Individuals with Severe Disabilities) [33], the Reinforcement Inventory for Children and Adults [34] or the "values interview" [35]. In general, however, the hierarchies of preferences produced by indirect assessments do not always align with those resulting from direct assessments. Another modality, which could be defined as direct observation, is that of the "free operant" [36], characterized by giving the subject free access to objects or activities and the amount of time spent in contact with the objects (manipulating them, looking at them, paying attention to them) constitutes the criterion for constructing the person's hierarchies of preference. The framework of preference assessment procedures is completed by systematic preference assessments that can range from single-stimulus assessment [37], to paired-stimuli assessment – which is perhaps the most precise way to build a hierarchy of preferences [33, 38] – multiple stimuli assessment with repositioning [39], where the stimulus selected as preferred is reinserted within the range of choices, and lastly the multiple stimuli procedure without repositioning [40], where the selected stimulus is removed from the selection set, thus "forcing" the person to assess the preference within the remaining stimuli. It goes beyond the intent of the paragraph to compare the validity of the different preference evaluation procedures. In the present work, it should be highlighted that there are, in the literature, different ways of assessing preferences and assessment acquires an unprecedented importance in the evaluation phase of the project of life for adults. A person-centered plan without an assessment of what is important and preferred by such individual risks consigning the choice of activities to a philosophical, rather than empirical, principle and this can give rise to innumerable biases [41, 42].

FROM ASSESSMENT TO ECOLOGICAL BALANCE

The observational and evaluation phase conducted so far should offer the assessor a substantial amount of data and information regarding the five dimensions presented in the previous paragraph. Thus, having a great deal of information available is a potential benefit for a more project-based evaluation, but such an amount of information may be difficult to summarize and it could pose some problems for the development of the project of life. Indeed, assessment is valuable insofar as the data and information collected are instrumental and usable for the development of the project [12]. In order to align the data of the evaluation with the goals and goals of a project of life, it is therefore necessary to have an intermediate process capable of filtering the set of information and data. Such process

questions the results of the overall assessment and draws significant information for the development of the project of life.

Consequently, with this intent, we have outlined some questions that could be viewed as special lenses through which to investigate the varied information produced by the assessment. These questions, in line with the initial assumptions, lead to an ecological analysis involving the person and the main ecologies of life within which the person lives (family, service, places, and community services). This analysis should involve all the main caregivers, and, where possible, the people themselves, with the aim of finding a balance among the various ecologies/ecosystems. The questions, which are at the basis of the ecological balance are a means to develop input for the project. The ecological balance is composed of six questions:

Preferences and wishes of the person with disabilities (things that are dear and important to the person with disabilities)

At this level, reference is made to the results of the survey conducted previously with the person with disabilities about their complex system of preferences obtained through the choices assessment procedures. The hierarchy of preferences expressed by the person must represent the fundamental reference point in the definition of the project of life. This hierarchy must then be concretely declined according to the resources and opportunities available. During this process of declination, it is also appropriate to provide for interventions that can change the contexts and beliefs of the ecosystems of life of the person with disabilities. Thus, the questions feeding this category are: "what does the person want?", "what does the person like?", "what does the person declare to be important for them?". A further question that could be proposed at this level is related to the difficulties that this person might encounter in acquiring their favorite things or in achieving what is important to them.

What is important for the person (from the point of view of caregivers and the person's background)

This question leads us to investigate the parts of the assessment related to contexts. Understanding what the different contexts of the person's life represent for them means understanding the expectations and rules of the primary network (e.g. family) and all other networks of support and belonging of the person (friends, services, volunteering...). The choice to investigate the expectations and rules of the networks that constitute the social and affective context, in addition to the person's expectations, stems from the fact that the preferences and desires of the person with disabilities are not always exhaustive of what is important for that individual. It is a trivial consideration, but it implies both ethical and deontological consequences. There are many classes of behavior that appear to be central to ensuring a good quality of life and which, however, are not among the person's preferences and priorities. The answers to this general question can be sustained by a series of other questions, such as: "what do we consider important for

this individual?", "what skills are important for this individual in order to improve their quality of life?", "what skills would be useful to improve their quality of life?". It is important that the formulations collected are always expressed in a positive form and not in a negative one. The assessors will therefore express themselves starting from statements such as: "increase their communication"; "increase their personal autonomy skills"; "make them more capable of managing their emotions". The following formulations are not correct: "we would like him not to disturb", "we would like her not to always get into trouble...".

The first question of the ecological balance directly interrogated the set of evaluation procedures related to the preferences of the person, but there is no similar question regarding the process of choice and targetization of goals and objectives. Even in the absence of such a precise reference, however, it is possible to orient this choice by means of a series of further critical questions about activities and goals. These questions can refine the statements stemming, at first, from the different contexts. The following questions draw on two major sources of the literature: on the one hand, the contributions offered by behavior analysis [43, 44, 2] and, on the other, the quality of life studies [32].

Do the identified goals represent an essential skill?

McGreevy [21] has listed eight potential "must have" skills also suitable for adults. The lack of these skills could be a factor of serious hindrance for the development of other more important functional and adaptive skills. The skills that are reported at this level are the following:

- making requests;
- knowing how to wait for the delivery of a reinforcing stimulus;
- accepting the delivery of a reinforcement and/or the interruption of a preferred activity;
- knowing how to complete learned tasks;
- accepting a negative answer ("no");
- following health and safety related instructions;
- completing daily life skills related to health and safety;
- tolerating health and safety related situations.

Is the behavior or activity likely to produce reinforcement in the person's life context?

The question leads us to reflect on whether the achievement of a goal and/or the performance of a certain activity will have reinforcing consequences for the individual. In this case, an objective or activity is significant and important because of the person's primary interest. When can these circumstances occur? We believe that at least two different circumstances meet the "primary interest of the person" requirement:

a) the first can be considered satisfied when the objective or activity produces automatic reinforcement. In other words, the activity is self-reinforcing. For instance, though they are very different, "reading" or "manipulating stimuli" that produce pleasant tactile sensations are two examples of this;

b) the second refers instead to the possibility that, while the person is carrying out an activity, or at the end of a teaching process, they can get in contact with reinforcements in their natural environment.

Is this behavior (or activity) a prerequisite for a more complex functional ability?

Some behaviors are not significant except for the fact that they are prerequisites of functionally important and relevant skills: for example, grasping a soap bar placed in one box to put it in another could be a meaningless activity if it is not given any function other than changing the location of objects. However, it could be a valuable activity to build prerequisites if it intends to develop the grasp of soap that is an absent behavior within a task such as "washing your hands". In this case, it is worth underlining that if some prerequisites represent the target of the intervention in the context of a project designed for adults, they must be directly connected to a socially relevant skill and not be generic remote prerequisites.

Does this skill increase the person's opportunity to access environments in which other important behaviors can be acquired and used?

The question enquires whether the chosen behavior is a behavioral "cusp". To understand what a "behavioral cusp" is, it is worth citing the author who first used these words: it is "a change of behavior that has consequences for the body beyond the change itself, some of which can be considered important" [1]. A classic example, borrowed from the developmental age, is that of a child learning how to walk. The acquisition of the walking skill allows the child to access new contexts and new experiences that can be both reinforcing and a source of new and significant learning. In the developmental age, we can certainly set ourselves a behavioral objective of this kind and be reasonably sure that walking will put the child in contact with countless stimulating contexts. Nothing else is needed. The targetization of a behavior or the selection of an activity, in an adult person with neurodevelopmental disorders, should, in our opinion, imply a greater commitment to identifying the contexts to which we want, realistically, the person to have access. Therefore, the potential cusp function of a behavior does not seem sufficient to target an objective or select an activity without, at the same time, identifying the specific contexts within which the person will experience new sources of reinforcement.

Will changing this behavior predispose others to interact with the person in a more appropriate and supportive way?

In this case, the target is not of direct and immediate interest to the person with disabilities. Cooper, Heron and Heward [43] produce a good example of a potential communication target which is suspended in favor of another related to the management of living places (tidying one's own room and helping with the housework) in order to reduce the workload (and stress) of parents. In this case, the authors state that it may be appropriate to teach such skills precisely because the reduced dependence of the children will predispose parents to interact, more and better, with them, also from the point of view of communication itself, which

was the initial target of the educator. This question has a certain relevance for people with disabilities in adulthood, whether they are with the family or part of service programs. Indeed, the frequent reduced number of staff creates a condition of real "flooding", that is, the tasks of care significantly saturate the time of the staff. Similarly, this phenomenon tends to reproduce itself in the family, often characterized by a high level of stress resulting from the burden of care of the relative. In this case, a reduction of the burden could turn into a flywheel able to increase the availability of staff or parents, promote training or, more simply, a shared time slot within which to develop more fun and strengthening relationships. The question guiding targetization certainly has its relevance and legitimacy, however, it also presents potential risks. In the previous example, there were two clear aspects:

a) behavioral objective which the educational figure considered of direct utility for the person (e.g. communication);

b) behavioral objective which is primary for other significant people (e.g. parents).

This means that a reduction in the care burden should be matched by an increase in the commitment to the behavioral target of direct interest to the person. In other words, an indirect target should always be paired with the identification of a target of direct interest. Otherwise, there is a risk of identifying targets that completely diverge from the priorities of the person with disabilities.

Is the behavior or activity generative?

The generativity of the target behavior occurs when the learned behavior produces changes and evolutions in other behavioral classes without being directly taught. The concept of generativity has been reviewed several times in the analytical behavior literature. It is on these behaviors that the concept of "pivotal behavior" [2-4] focuses, for example, as a skill that produces modifications or covariations in other adaptive behaviors not necessarily taught. For instance, teaching an autonomous and independent approach to other people represents, according to the authors, pivotal behavior because it correspondingly increases other classes of behavior such as "asking questions" or the "quantity" and diversity of speaking and dialoguing with others. There are many activities that develop potentially pivotal behaviors [44]: if one is taught how to play bingo, they will learn a variety of skills beyond the simple game: listening, verbalizing, interacting, taking turns and sitting together with others. It is easy to see how mastering all the fundamentals of a seemingly simple game like bingo could translate into skills needed for other areas of life.

Likewise, the concept of generativity, which is interesting because it creates potential developments that are not the object of direct teaching, thus widening the repertoire of the person, requires specific attention when applied to adulthood. Though it is true that a certain behavior has in itself the potential to broaden a person's repertoire of abilities in certain areas of life, the opposite can be said when that new behavior or activity is not accompanied by an increase in the opportunities needed to activate the generative process. Indeed, it is not uncommon to witness situations in which certain activities are selected for some intrinsic pivotal potential, but, in terms of opportunities offered, the person's life does not change at all and the so-called "other areas of life" simply do not exist. For this reason, developing activities or promoting pivotal behavior must include explicit planning of new opportunities to offer to people with disabilities.

Does the behavior or activity represent an iso-functional alternative to challenging behavior?

This question emphasizes the "constructive" approach versus the "eliminatory" approach [45]. Indeed, it is simply unfeasible to eliminate a challenging behavior when this behavior, though socially challenging and dysfunctional, has proved to have at least one or more functions for the person who exhibits it. For this reason, Bosch and Fuqua [44] suggest alternative behaviors as a new frontier of cusp behavior. In this sense, some activities, which apparently may not have any meaning, acquire significance precisely because they are socially and personally more adequate responses to the problems present in the person's repertoire. Behaviors and activities at this level can be very different depending on the level of functioning of the person and the type of challenging behavior subject to intervention. They can range from mand training to manipulation of soft materials to surrogate tactile sensibility stereotypies.

Is this behavior age-appropriate?

The question refers to two assumptions. The first is philosophical, so to speak, the second is linked to the actual probabilities a behavior or activity has to be reinforced naturally in the natural context. The philosophical principle is based on the famous concept of "normalization", which emerged during the 1970s. The recommendation is to conduct activities "as culturally normal as possible" [46]. The term "as far as possible" indicates that the principle of normalization should be understood more as a continuum rather than a category. There are different ways to answer this question and, among what is feasible, there is the use of age-appropriate material. Indeed, it is also possible for people with profound multiple disabilities to perform sensory activities with brushes capable of stimulating their touch, rather than with cloth puppets.

Does the activity or behavior aim to improve important parameters of a person's health?

Sometimes the activity or behavior to promote is not aimed at the person's immediate behavior. Weight reduction or glycemic values are examples of this. However, activities can contribute to the achievement of adequate physiological parameters through the teaching of a diet, exercise, or other activities that can normalize the parameters. Health issues, which are frequently related to neurodevelopmental disorders, are therefore of co-primary importance within a person's project.

Is the behavior or activity a direct response to improving some domains of quality of life?

An expression is often used in reference to behavioral targets: "socially significant". This definition indicates, like that of normalization, what is socially expected, in particular, for an adult person. However, there is a potential range of goals which are not only attributable to socially expected behavior, but also encompass the improvement of quality of life and general well-being. A reference to this level can be represented by R. Schalock's meta-model [32] which, as seen in the previous paragraph, identifies 8 fundamental domains for a good quality of life for all people. This question leads to the identification of "contents" that can be used as the basis of the targetization process. In this regard, it is worth underlining that there are not only goals aimed at increasing adaptive skills, but also others intended to increase the indicators of happiness or, conversely, reduce pain indexes within clinically necessary activities [47, 48], thus generally improving well-being. It should be noted that in adulthood the dimension of personal outcomes should be emphasized and the identification of potential goals balanced by trying to respond to the complex of the eight domains. The breadth of the domains requires that the goals relating to improving the quality of life are clearly defined in terms of expected outcomes and do not constitute generic phrases capable of justifying any activity.

Challenging behaviors for the environment and concurrently dysfunctional behaviors for the person (which challenging behaviors limit their active participation?)

This question requires the assessor to investigate the existence or non-existence of behaviors that the person exhibits which are challenging for their ecosystems and, at the same time, dysfunctional for the same individual. This operation involves two different moments:
a) the collection and listing of the different behaviors experienced in a challenging way by the contexts;
b) the assessment of challenge severity and hierarchy.

The collection of challenging behaviors must include the contribution of all people who, in different ways, have an important relationship with the person with disabilities. The selection "judges" the degree of challenge, thus including some of these behaviors (which will then be the subject of intervention) and excluding others. The process of selection and hierarchy can be facilitated by the use of questionnaires that can help caregivers to share the judgment of challenge and produce a hierarchy.

In order to understand and evaluate the degree of challenge of some behaviors, it would be better to resort to some subjects before starting any intervention. The first of these should be whether the behavior produces damage to the subject or to other people or things. A positive answer to this should clearly dispel any kind of doubt: the behavior that the person exhibits is truly challenging. The second enquires whether that challenging behavior is an obstacle to the development and well-being of the individual. Indeed, there is a wide range of behaviors that are not

"dangerous" either for the person or for others, such as stereotypies.

However, a considerable exhibition of such behaviors can be detrimental to the learning of new skills. In some cases, the frequency of stereotypies is so high that it even seems to shield the subjects, thus making them hostile and extraneous to any proposal. In this case, too, an affirmative answer would legitimize an intervention. Finally, some considerations should be done on "milder" behaviors, configurable as strange or bizarre attitudes. The assessor needs to evaluate whether such behaviors tend to consolidate the social stigmatization and therefore the marginalization of the subject. This evaluation is important because the risk is that of "normalizing" the behavior of the person by annulling what could be defined as the typical dimension of the subject in light of a conformist vision of attitudes and behaviors. Only a pondered and shared positive response among all the people and contexts with which the user is in close relationship can provide a sufficient basis for an intervention.

The person's performance/skills are not actualized (required) by environmental contexts

This specific question leads to the isolation of the set of skills that the person already possesses within their repertoire and that, for various reasons, are not requested and experienced. It is not a matter of selecting these skills, if there any, and inserting them sic et simpliciter within a new project. However, it is important to understand how much of that person's learning history has settled in order to assess how many of these skills can be appropriately included in an intervention program for the person. The term "appropriately" refers to the role these skills could play in improving one or more domains of the person's quality of life.

Therefore, at this level two steps must be taken: on the one hand, the set of these skills needs to be identified, on the other the skills that are considered "important for the person" for a good quality of life should be selected.

The questions that could feed the information contained in this category are the following: "does the person have any skills that are currently unexpressed?"; "are there any skills that we have seen in the past, or that emerged during the assessment, that are currently not valued?"; "In the person's history, are there any skills that our environment has no longer exercised or requested?".

Balance between personal performance and ecosystem demands (what significant abilities does the person already express?)

This ecological analysis question attempts to isolate the "balance points" between the abilities expressed by the person and the demands of life ecosystems. Referring to the "old" WHO document, the ICIDH (International Classification of Impairments Disabilities and Handicaps) [49], where there is a balance between environmental demands and skills expressed by the person there is no "handicap". It is ultimately a question of investigating, in the different contexts of a person's life, the strengths of that individual, what makes them par-

ticularly "capable" of responding to certain aspects of their daily life in their environment. The questions that call for an investigation in this direction can be: "are there any skills that the person already exhibits that we consider particularly useful in the life they lead within that specific system (family, service, aggregation); "what strikes us most positively among the skills exhibited by the person?"; "what are the skills that make them more adequate and capable than what is typically required in their daily lie?".

Health conditions that can influence the search for the best quality of life (which health conditions could limit the active participation of the person?)

The sixth category of the ecological balance requires the identification of disease conditions that may impair the achievement of a higher quality of life. It is therefore not so much a question of listing all the pathologies of the person, but of understanding which ones seem to have the most direct impact on quality of life. In particular, we are referring to physical health, since mental health aspects should have already been investigated (in behavioral terms) in the previous analysis question on "environmentally problematic and dysfunctional behaviors for the person". This part of the analysis should examine: the active pathologies present at that moment; the risk factors (with particular reference to lifestyles) that could give rise to potentially serious disease patterns detrimental to a good quality of life; and the presence of iatrogenic problems arising from the use of psychotropic pharmacology.

FROM THE ECOLOGICAL BALANCE TO THE PROJECT OF LIFE

The ecological balance we have seen so far should lead to a summary of the salient and representative aspects of the people's desires and choices, and the different contexts and systems within which the subjects find themselves living.

The ecological balance should provide the "material" with which the "project of life" will be developed and its results represent what could be defined as real project inputs. From this perspective, the "project of life" is a set of propositions elaborated by the multidisciplinary team and shared with the person, their family, and other significant contexts. Therefore, the project of life must clarify the "general purposes" that inspire the work of the whole team and its different goals must be declined within the eight domains of the already mentioned meta-model of quality of life [32]. As already noted, the project of life must be promoted within an adequate temporal span. This means that the different goals contained in it can guide the educational and clinical work for periods that can be as long as a few years. This does not mean rigidifying the planning or not considering events that can modify the educational clinical and care framework. It only means that the planning, sometimes, should be configured as a necessarily long-term process, similarly to normotypical adults.

In general, this translates to having articulated and coordinated plans that can lead to expected outcomes in a period that is not necessarily measured over a cal-

endar year. It is worth pondering, for a moment, what it could mean to habilitate a person to an independent life, or to activate a path of reintegration in the community of a person suffering from severe challenging behavior. The Project is therefore valid as long as the five dimensions of the evaluation, on which the ecological balance was conducted, do not present significant changes. If this were to happen, for example in the case of an onset of dementia, a major psychiatric problem, or the disappearance of one of the nodes in the person's network (e.g. the family), this picture would change substantially and the project of life would have to be extensively redefined.

THE INTERVENTION PROGRAM

The intervention program represents the full operationalization of the goals contained in the project of life and its translation over a short period of one year. The goals contained in the project are, as was said, operationalized and transformed into work goals. The intervention program, precisely because it is inscribed within a complex and articulated project of life, must necessarily develop from different types of objectives. In particular, within the Intervention Program we can distinguish the following five objectives:

1) *constructive type*, that is, the formation of new skills (or increase of the parameters of the same) previously absent from the person's skills repertoire;

2) *decrease*, aimed at reducing challenging behaviors or behavioral excesses;

3) *maintenance*, intended as actions towards classes of responses, already present in the person's repertoire, through functional exercise and monitoring. On the one hand, the maintenance goals will therefore welcome the constructive goals that have been achieved and that will have to be included in a functional exercise and monitoring register. On the other, they will be fed by inputs contained in the ecological balance when, for example, the points of "balance between the performance of the person and the demands of the ecosystems" are identified;

4) *environmental change*, as actions directed towards environmental ecosystems in order to make an environment more appropriate to the well-being of the person, and their personal and functional characteristics. The concept of environment used within these goals is "extensive" as it includes physical, organizational, cultural, and relational aspects. In other words, this particular type of goals does not focus on a person's behavioral repertoire, but rather on the modification of certain aspects of the environment in order to update the skills possessed, increase well-being, or reduce the burden of discomfort and pain;

5) *bio-medical*, are the set of actions and interventions mainly aimed at normalizing parameters (treatment), preventing pathologies linked to specific risk factors, and monitoring the effects of the treatments themselves with the aim of reducing possible iatrogenic conditions.

Each of these objectives clearly has specific ways of articulation and a number of steps that must be fol-

lowed in order to implement them. However, an analytical examination of these processes within the individual types of objectives goes beyond the scope of this chapter, which has only attempted to outline a possible path for the development of a project of life for a person with neurodevelopmental disorders.

Conflict of interest statement
The Authors declare that they have no competing interests.

Submitted on invitation.
Accepted on 19 March 2020.

REFERENCES

1. Rosales-Ruiz J, Baer D. Behavioral cusp: a developmental and pragmatic concept for behavior analysis. JABA.1997;30:533-44.
2. Koegel RL, Frea W. Treatment of social behavior through the modification of pivotal social skills. JABA.1993;26:369-77.
3. Koegel L, Koegle LK. Generalized responsivity and pivotal behavior. In: Horner RH et al. Generalization and maintenance: life-style change in applied settings. Baltimore: Paul Brookes; 1988.
4. Schreibman L, Kaneko W, Koegel RKL. Positive affect of parents of autistic children. A comparison across two teaching techniques. Behav Ther. 1991;22(4):479-90.
5. Sundberg ML. Verbal behavior milestone assessment. Edizione italiana a cura di Moderato P, Copelli C. Brescia: Vannini Editrice; 2012.
6. Schopler E, Lansing MD, Reichler RJ, Marcus LM. PEP-3. Edizione italiana a cura di Villa S, Micheli E. Brescia: Vannini editrice; 2006.
7. Rogers SJ. Early start Denver model curriculum checklist for young children with autism. New York: Guilford Press; 2010.
8. Partington JW. Assessment of basic language and learning skills-revised (ABLLS-R). Pleasant Hill (CA): Behavior Analysts; 2006.
9. Mesibov G, Thomas JB, Chapman M, Schopler E. TEACCH Transition Assessment Profile. Firenze: Giunti; 2010.
10. Virginia Commonwealth University. Checklist Community Based Skill Assessment; 2014.
11. Gardner JF, CQL, Designing Quality. Responsivity for the individuals, Towson; 1999. Available from: www.c-q-l.org/base.aspx?id=768.
12. Cavagnola R. Il piano educativo per l'adulto con ritardo mentale. Trento: Ed. Erickson; 2000.
13. AAMR. Mental Rretardation. Definition, classification, and systems of supports (10th ed.). Washington DC. [Ritardo mentale. Definizione, classificazione e sistemi di sostegno, 10° ed.]. Gussago (BS): Vannini Editrice; 2005.
14. AAIDD. Intellectual disability. Definition, classification, and systems of supports. 11th ed. Washington (DC); 2010.
15. Parmalee PA, Thuras PD, Katz IR, Lawton MP. Validation of the cumulative illness rating scale in a geriatric residential population. J Am Geriatr Soc. 1995;43:130-7.
16. Bertelli M. Systematic psychopathological assessment for persons with intellectual and developmental disabilities. General screening. Firenze: OS Giunti; 2019.
17. Matson JL. The diagnostic assessment for the severely handicapped revised (DASH-II). Baton Rouge (LA): Disability Consultants, LLC; 1995.
18. Beavers GA, Iwata BA Thirty years of research on the functional analysis of problem behavior. J Appl Behav Anal. 2013;46(1):1-21.
19. Hanley GP, Sandy Jin C, Vanselow NR, Hanratty LA. Producing meaningful improvements in problem behavior of children with autism via synthesized analyses and treatments. J Appl Behav Anal. 2014;47(1):1-21.
20. Sparrow S, Cicchetti DV, Balla DA. Vineland Adaptive Behavior Scales-II – Second Edition – Survey Interview Form. Firenze: Giunti; 2016.
21. McGreevy P, Troy F, Cornwall C. Essential for living. 2012.
22. Sundberg W, Mueller MM. AFLS Assessment of functional living skills. Behavior Analysts, Inc. & Stimulus Publications; 2012.
23. Wechsler D. WAIS-IV. Wechsler Adult Intelligence Scale – Fourth Edition. Technical and Interpretive Manual. Pearson Assessment; 2008.
24. Casey L, Kerr N. Auditory-visual discrimination and language prediction [Monograph]. Rehabil Psychol. 1977;24:137-55.
25. Brown I, Renwick R, Raphael D. Quality of life instrument package for adults with developmental disabilities. Toronto: Centre for Health Promotion, University of Toronto; 1997.
26. Schalock RL, Keith KD. Quality of Life Questionnaire. Worthington: IDS Publishing Corporation; 1993.
27. Petry K, Maes B, Vlaskamp C. Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: first results. Res Develop Disabil. 2009;30(6):1394-405.
28. Stancliffe RJ, Parmenter TR. The Choice Questionnaire: a scale to assess choices exercised by adults with intellectual disability. J Intellect Develop Disabil.1999;24:107-32.
29. Lyons G. The life satisfaction matrix. An instrument and procedure for assessing the subjective quality of life of individuals with profound multiple disabilities. J Intellect Develop Disabil. 2005;49(10):766-9.
30. Cragg R, Harrison J. Living in a supervised home. A questionnaire on the quality of life. West Midlands Campaign for People with Mental Handicap. Wolverley: Kidderminster; 1986.
31. Van Loon JHM, van Hove G, Schalock R, Claes C. POS-Personal Outcomes Scale, Adattamento italiano di Coscarelli A, Balboni G. Brescia: Vannini Editoria Scientifica; 2017.
32. Schalock RL, Brown BR, Cummins RA, Felce D, Matikka L, Keith KD, Parmenter T. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities. Report of an International Panel of experts. Mental Retard. 2001;40(6)457-70.
33. Fisher W, Piazza C, Bowman L, Hagopian L, Owens J, Slevin I. A comparison of two approaches for identifying reinforces for persons with severe and profound disabilities. J Appl Behav Anal. 1991;25:491-8.
34. Institute for Applied Behavior Analysis. Behavior Assessment Guide. Reinforcement Inventories for children and adult. Los Angeles (CA): IABA; 1993. Available from: www.aba-instituut.nl/back-site/upload/content/reinforcementinventory.pdf.
35. Miselli G, Berna S, Paci C, Cavagnola R. Il colloquio sui

MONOGRAPHIC SECTION

valori per le persone con disturbi del neurosviluppo. Brescia: Vannini Editrice; 2018.

36. Roane HS, Vollmer TR, Ringdahl JE, Marcus BA. Evaluation of a brief stimulus preference assessment. J Appl Behav Anal.1998;31:605-20.

37. Pace GM, Ivancic MT, Edwards GL, Iwata B, Page TJ. Assessment of stimulus preference and reinforcer value with profoundly retarded individuals. J Appl Behav Anal. 1985;18(3):249-55.

38. Davis CJ, Brock MD, McNulty K, Rosswurm ML, Bruneau B, Zane T. Efficiency of forced choice preference assessment: comparing multiple presentation techniques. Behav Anal Today. 2010;10:3440-55.

39. Windsor J, Piche L, Locke PA. Preference testing. A comparison of two presentation methods. Res Develop Disabil. 1994;15;439-55.

40. DeLeon IG, Iwata BA. Evaluation of a multiple-stimulus presentation format for assessing reinforcer preferences. J Appl Behav Anal.1996;9:519-33.

41. Green CW, Reid DH, White LK, Halford RC, Brittain DP, Gardner SM. Identifying reinforcers for persons with profound handicaps: staff opinion versus systematic assessment of preferences. J Appl Behav Anal. 1988;21(1):31-43.

42. Reid DH, Everson J. Green MCC. Systematic evaluation of preferences identified through person-centered planning for people with profound multiple disabilities. J Appl Behav Anal. 1999;32(4):467-77.

43. Cooper JO, Heron TE, Heward WL. Applied behavior analysis (2nd ed.). Upper Saddle River. New Jork: Pearson; 2007.

44. Bosch SR, Fuqua W. Behavioral cusps: a model for selecting target behaviors. J Appl Behav Anal. 2001;34(1):123-5.

45. Snell ME, Brown F. Instruction of students with severe disabilities. Pearson; 2006.

46. Wolfensberger W. The principle of normalization in human service. Toronto: National Institute of Mental Retardation; 1972.

47. Green CW & Reid DH. Defining, validating, and increasing indices of happiness among people with profound multiple disabilities. J Appl Behav Anal. 1996;29:67-78.

48. Green CW, Reid DH. Reducing indices of unhappiness among individuals with profound multiple disabilities during therapeutic exercise routines, J Appl Behav Anal. 1999;32(2):137-47.

49. WHO. International classification of impairments, disabilities and handicap. Geneva: World Health Organization; 1980.