Innovative methods and tools for professionals working in supported living services for intellectually disabled persons

Katalin GRUIZ[a,1]
[a]Hungarian Down Foundation, www.downalapitvany.hu

Abstract. Autonomy of mid-seriously and seriously intellectually disabled persons is encouraged both by legislations on human rights and the modern social care and services. The process leading to the maximum possible autonomy is illustrated by a developmental spiral in our model. Specialty of the development is that the personal educational projects are realized during everyday activities. The process requires conscious professionals with an empowering and motivating attitude, with adult relationship to the intellectually disabled persons and versatile skills and tools. In this educational relationship the social professional and the supported person are equal partners moving together along the spiral of human development. An innovative tool-battery has been developed aiding support-staff in the 'pedagogical' task embedded into everyday social services. The tool-battery and its first application in supported living services of the Hungarian Down Foundation are introduced in this paper.

Keywords. autonomy, adult relationship, coaching, Down-syndrome, empowerment, intellectual disability, mental accessibility, person centred planning, social services, supported living, the spiral of development

1. Introduction

The normalized and integrated life of disabled persons is a prerequisite of their autonomy, which is the main target of global human rights legislations and movements, and is facilitated by modern social services in the practice. Normalized and integrated life of disabled people means to fulfil their potentials. It needs person-centred professional support, in other way it does not differ from the 'normal', i.e. the average.

Reading such a sentence, most people raise the question: is this approach applicable for the seriously disabled persons, who will never reach full autonomy? The answer is yes! The target of as much as possible autonomous life maps the road ahead and the path toward autonomy. This path is the life itself, and the running speed and time to reach the stations are of secondary importance, and are very diverse for humans.

The model and the corresponding methods and tools introduced in this paper have been developed in a European adult educational project, and focus on social professionals working with intellectually disabled persons in social support services. The methods and tools focus on mid-seriously and seriously intellectually disabled persons, who need permanent support and care in their daily life and do not possess sufficient skills to

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[1] Corresponding Author.

autonomously manage their personal relationships. We selected this target group to justify the universal scope of the developed model and the coupled tool-battery.

Four organizations from Italy, Spain and Hungary have cooperated in the realization of the INV project [1] to develop the conceptual framework – a modern pedagogical model adapted to and embedded into social care – and the corresponding tools for the professional support of intellectually disabled persons in their independent living.

The 3 years long developmental work includes the complete innovation chain:
- scoping and planning;
- creation of the conceptual framework;
- developing the theoretical and practical pedagogical model and the tools;
- description of a training itinerary;
- testing of the embedded pedagogical model and its tools;
- implementing modifications and service-specific variables;
- the first full-size application and validation of the INV model and the tools.

2. The context and definitions

One targeted group of actors of the INV method are the ***social professionals*** of supported living and related services, such as care-takers, assistants, mentors, educators. The requirement toward their work quality is enormous, but most of them are not in possess of proper awareness and skills and no organized professional help is available for them in most cases. Result of these shortcomings may be inefficient work, indifference or burnout.

The other target-group is made up the ***people with disabilities***. Human rights of all disabled persons – including those who require more intensive support – are recognized by the UN Convention [2]. The developed model and the tools are based on the requirements of the convention to promote and protect human and citizen rights of disabled persons and ensure their autonomous life.

The relationship between the professional and the supported person is also in the focus of the model; it will be discussed in section 3 in more detail. A short overview on the most important contextual terms and the professional practice is given below.

2.1. Normalization, inclusion and supported living of intellectually disabled persons

Nirje [3,4] formulated the normalization principle as follows: normalization is "making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society".

Integration is closely related no normalization, meaning to interact with non-disabled persons to the fullest extent possible. Integrating people with developmental disabilities into mainstream schools, living and working environments by measures is not enough; the disabled persons should also feel being part of these communities: this is real inclusion. An integrated life is based on the experience of people with disabilities who, with the support of social professionals, live as contributing members of their communities.

Support in living and employment of intellectually disabled persons are the most important social services, accompanied by supported decision making and the supported use of civil and market services. Support is provided by assistants, mentors, care takers, guides, case-workers, coaches, educators, and other professional, who assist in self-care, living, working, recreation, travelling and social life of intellectually disabled people. Professionals apply versatile, mainly still largely undeveloped or underdeveloped tools, e.g. based on outdated medical, professional or charity and goodwill models focusing on the disability, the missing ability, on the unilateral professional-centred solutions, coupled with patronizing, disempowering and authoritarian attitude, instead of person-centred services based on the dynamically changing needs and claims of their clients.

2.2. The spiral dynamics of development and motivation

Spiral dynamics of human development and motivation symbolises that human beings continue to spiral through a helix of developmental stages depending on the biological, social, environmental, and psychological forces at work. Based on the spiral dynamics the development both of disabled persons, the professionals, and their relationship can be understand and handle better. The main spiral is an aggregated outcome of several sub-spirals and coupled spirals as it is shown in Figure 1. To explain the dynamics of social care in supported living of intellectually disabled persons, a simplified scheme is shown on Figure 1: life skills as upwards approximating autonomy and the cyclic professional support in order to become more independent after separation from family and moving into a supported living facility.
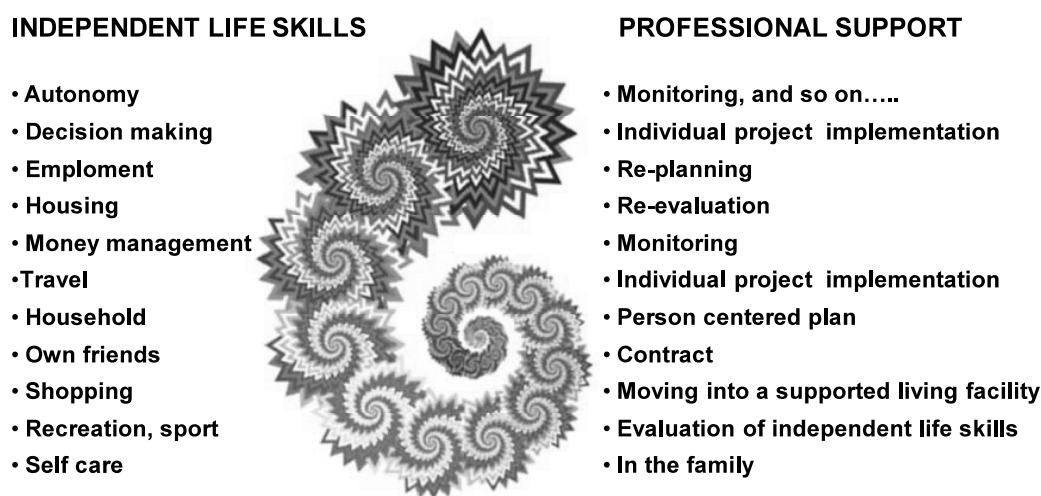

INDEPENDENT LIFE SKILLS

- Autonomy
- Decision making
- Emploment
- Housing
- Money management
- Travel
- Household
- Own friends
- Shopping
- Recreation, sport
- Self care

PROFESSIONAL SUPPORT

- Monitoring, and so on…..
- Individual project implementation
- Re-planning
- Re-evaluation
- Monitoring
- Individual project implementation
- Person centered plan
- Contract
- Moving into a supported living facility
- Evaluation of independent life skills
- In the family

Figure 1: The aggregated spiral of the life skills and the cyclic social support.

2.3. Social professionals and support services for intellectually disabled persons

Requirements toward quality professionals in support services are: high level knowledge, awareness, skills and experience, versatile tools and creativity as well as the right attitude. These together may help the social professional to become familiar with the person and support his or her developmental objectives, to motivate and empower, manifest expectations, but remain patient, support when necessary, but never over-support and to integrate the developmental support into the daily life activities. In addition the professional should be highly ethical, to consider and accept (even seriously) intellectually disabled persons as equal partners, as autonomous individuals, respecting and serving them, keeping away from competing and abuse.

To be able to fulfil all these professional and personal requirements, social support workers should be provided with intensive support in the form of trainings, team-meetings, case-discussions, team and individual supervision, coaching or other personality developing services. The developmental spiral of the social professionals and the supported disabled persons may proceed in close correlation with each other. The long-term knowledge management in social services together with the personal development of the professionals ensure quality services and prevents professionals from burn-out.

The dynamic character of the support involves special methods and tools and a close relationship between the supporter and the supported persons. Some keywords are listed here, to demonstrate the dynamic nature:

- The long-term goal is the normalized life of the intellectually disabled persons;
- The short term/daily goals are highly versatile;
- Increased frequency of interactions increases the needs;
- The once assessed status and needs are continuously changing;
- Decision-making is a daily task, given that generally several options are available;
- Interaction between the supporter and the supported person is influenced by personal and environmental factors and is changing in time;
- Motivation works for dynamic changes, the difference between the present and the targeted situation is the working force;
- Long-term goals – i.e. the autonomous life – defines the path and the direction. The velocity is relative, awareness helps to notice and accept minor and slow changes;
- Social and built environment, legal background, 'mental accessibility' [5] and other external factors have significant impact on the developmental process. Progressive legislation, universal design (easy to use for all) and an intellectually accessible environment (understandable for all) accelerate the development;
- The support is cyclic: assessment, evaluation, planning, interaction, monitoring, evaluation, re-assessment, re-design and so on; repeated at higher and higher levels.

In the above described dynamic and individualized social care, the relationship between the professional and the supported person must be put in focus. Mutuality is the basis of this relationship, meaning that both parties are equal, and the relationship is personal – not hierarchical. External (regulatory, organizational and family context) and internal factors (age, personality, communication, emotions) have an impact on the relationship.

3. A pedagogical model embedded into social services

The developed INV model is a combination of open learning (an innovative model of education) and the person-centred social services. The embedded model has been designed for professionals involved in social services, such as supported living and employment of persons with an intellectual disability, including serious disabilities.

According to the basic approach of modern social work, the everyday life of intellectually disabled persons is identical with learning and developing; social care and support is identical with education and development; the daily self-care is learning and developing, household, recreation, all compartments of living require continuously growing knowledge and new skills. The same is true for every single human being, and especially applies for intellectually disabled persons, who forget faster.

The model aims at achieving the goals:

- Taking education as an essential factor for the construction of paths towards autonomy, capacity planning and citizenship of each person;
- Addressing professionals as a fundamental tool of the growth paths of people with disabilities, in order to provide them with stimuli and tools for reflection and a change of perspective (in relation to their vision of the person with an intellectual disability);
- Focusing on the educational type relationship between the person with disability and the professional;
- Increasing awareness of the professionals.

3.1. The model

The embedded pedagogical model is based on two main categories:

3.1.1. The category of intentionality. The professionals should activate intentionality in their educational activity [6]. Intentionality consists of:

- The awareness of the educational act; on the part of the professional with respect to the initiatives, activities and care that stimulate and orientate the process;
- Awareness regarding the person of the professional, the principle 'working instrument', who must therefore know him or herself, what he or she wants, what his or her fears are, paradigms, reference values, and must know how to evaluate his or her limits and motivations and how to treat emotions;

3.1.2. The category of otherness. Instead of frightening, using schematic rigidity, routine action and the loss of achievable horizons towards which the other can tense, the value of otherness should be emphasized. Beginning with the assumption of responsibility, the professional will be able to reflect and construct by means of caring (taking care of) the ethical relationship that unites him/her to the Other, who nonetheless maintains his/her own difference. Assuming responsibility and constructing an ethical relationship contrast with the 'pedagogy of the model' and recall the need of the 'pedagogy of the occasion'[6]. Therefore, the Model does not want to advise or prescribe certain activities, but acts in the context of daily life and normal activities such as personal assistance, housekeeping, etc.

3.2. The relationship, its axioms and phases

The relationship of the social professional and the supported person is explained along the axioms. All axioms are accompanied by explanatory tales and videos in the handbook to make clear the influencing factors and increase professionals' awareness:

- Relationship is behaviour; it follows a precise mental map. Homologation, demonization and normalization are differentiated and explained.
- The relationship depends on me: I am the only variable of the relationship, the other is a free subject;
- The relationship implies a unilateral risk;
- The relationship has enemies: fear, lucidity (too much knowledge), power, old age;
- The relationship demands a metamorphosis: the professional must assume the attitude of a child who starts over every time;
- The relationship implies taking on responsibility.

The relationship in the INV model is divided into a pre-educational and an educational phase. Further sub-phases are differentiated and characterized within both main phases with a broad description and several useful tools. Here we show just the framework.

3.2.1. Pre-educational phase is typically the launch of the intervention, when the disabled person makes use of the service for the first time.

- *Connection*: initiating the relationship and getting to know the person by
  o Welcoming: explaining the service, listening to, exploring potentials;
  o Invitation: first steps towards constructing the reciprocal trust.
- *Taking care*: assuming responsibility, reducing asymmetry by
  o Entrustment: activating the person's desire to address their needs;
  o Intimacy: establishing a relationship based on the mutual intimacy, rituals.

3.2.2. Educational phase aims at the promotion of the growth, the development and the social integration of the person in a citizenship perspective.

- *Accompaniment*: the professional considers the other as an active subject and this does not conform to the level of severity of disability of the person. It means following, observing, and ensuring security but understanding when to intervene in a more direct way as well as identifying the right moment for applying the "interrupted gesture", an important tool in this phase.
  o Educational contract: after the well-established relationship, the professional is able to design the individual project together with the supported person and fix it;
  o The individual project is the implementation of the agreed educational project (embedded into social services) and its continuous monitoring;
  o Checking the result: monitoring the concrete skills in the practice, discussing the result with the supported person and celebrate the success together.
- *Social integration:* the goal of this sub-phase is to foster the exercise of the right to citizenship of the person with intellectual disability. The professional has to accept the adulthood of the supported person.
  o Personal networks: reinforcing personal network, to insert the person into a relational network of time, space, and other relationships of normal life.
  o Partnership: an adult relationship between the professional and the person. The professional has to know how to keep his or her role as stimulus and facilitator of other equally significant relationships.
  o The professional must support the relationships with several privileged stakeholders who in turn can enter into a partnership with the supported person.

3.3. Trainings of the professionals

The training allows the professionals understanding of themselves as a complex, plural entity in relation to the Other complex and plural equal entity. Goals of the training are:

- Encouraging the exploitation of the Pedagogical Model by the professionals working in services for people with severe disability,
- Enhancing the professional experiences;
- Encouraging the change of perspective and the vision about people with severe intellectual disabilities, "free" from the schemes and routine;
- Promoting a different vision of oneself as a professional who is able to work from the viewpoint of "the pedagogy of opportunity".

The INV model is taught for the professionals by trainers. The contents of the course have been organized based on at least five meetings approximately of 7 hours each. The training itinerary [7] gives advice for the trainers how to proceed with trainings and which exercises to make with the trainees. The role of trainings can be changed later on, and operate as team meetings, case discussions and team or individual supervisions.

4. The tools

The INV model is aimed at implementing several new and adapted tools. Part of the tools serves as assessment and monitoring tool to follow the development of the intellectually disabled person. Other part of the tools supports self observation and self-evaluation of the social professional her- or himself during interaction with the client to follow the relationship, her or his attitude and personal development. The third type of tool supports the trainers in conducting and reporting the training.

4.1. Tools for assessing and monitoring the supported intellectually disabled person

4.1.1. The initial survey has the role to define the point of departure in the individual educational project of the intellectually disabled person. It collects personal data and basic information on diagnosis and personal history. The entry sheet includes the outline of a conversation. In addition to the entry-sheet it is helpful to acquire the dynamic-functional profile which will be verified and further elaborated during the person centred project.

4.1.2. The service log is a general tool employed in service sectors to transmit information that is useful for workers on the next shift. The INV Model reinterpreted the log as a tool of participative observation and shared elaboration, and is used as an instrument for collective reflection and training. In the Down Foundation it exists physically as an IT cloud. The logbook is applied for staff meetings as a basis for discussion.

4.1.3. Observation of the development of the supported intellectually disabled person. It is an assessment tool for practical skills necessary for living and working. It is an adequate selection from well-known pedagogical and social assessment tools, adapted to the level of mid-seriously intellectually disabled persons. The observation sheet is the synthesis of direct observations during activities and serves as basis for planning individual projects.

4.2. Tools for self-observation and self-evaluation of the professional

4.2.1. The self observation register seeks to offer an instrument of self-observation and monitoring for the professional. It is useful for keeping one's emotions under control, understanding them in order to reflect, to learn from one's errors as well as from the unexpected successes, to foster awareness of possible conditioning by past experiences. Two versions of self-observation templates have been developed in the project, a simpler version for "beginners" and a more advanced one. The content of the self observation registers can be used for case discussions and for professional supervision.

4.2.2. The self evaluation tools together with the self-observation tool support the professionals to become more conscious and being able to assess their own behaviour and attitude within the relationship to the intellectually disabled person. Some conventional tools have been selected and adopted for our purposes. Both tools make the professionals able to follow the development of their personality and their relationships. The use of the self-evaluation tools are taught and exercised during the trainings.

4.3. Tools for the trainer

4.3.1. Training itinerary for staff trainings, aims to get familiar with the new pedagogical model as well as to communicate and cooperate with colleagues and leading professionals or supervisors. The training itinerary defines the reasons and objectives of the training course, the role of the trainer and gives methodological notes on the way to use the course for the education of professionals working in the field of social care. It recommends a schedule for the meetings and introduces the tools useful for the trainees.

4.3.2. Evaluation of the self-observation registers is aided by the trainers report template.

4.3.3. Evaluation of the trainings and meetings by the trainer is supported by a specific template for the minutes of staff meetings, case discussions and/or team-supervisions.

4.4. Exploitation of the innovative INV model and its tools

The complete *toolbar* is ready for widespread application, and it is available in four languages – English, Italian, Spanish and Hungarian. It is recommended for social service providers, supporting living and working of intellectually disabled or autistic persons. The tools have been tested and successfully demonstrated so far by 120 professionals in social and adult educational services of the four participating organisations. In Hungary, the Down Foundation has started with the application of the INV methods and tools for 100 professionals in 14 different services and transferred the complex methodology and its tools for the supported living of people with autism. Adaptation for parents is under way.

Acknowledgement

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Evidence-based development and first usability testing of a social serious game based multi-modal system for early screening for atypical socio-cognitive development

Miklos GYORI[a,1], Zsófia BORSOS[a] and Krisztina STEFANIK[b]

[a] *Institute for the Psychology of Special Needs, ELTE University, Budapest, Hungary*
[b] *Institute of Special Education for Atypical Cognition and Behavior, ELTE University, Budapest, Hungary*

Abstract. At current, screening for, and diagnosis of, autism spectrum disorders (ASD) are based on purely behavioral data; established screening tools rely on human observation and ratings of relevant behaviors. The research and development project in the focus of this paper is aimed at designing, creating and evaluating a social serious game based multi-modal, interactive software system for screening for high functioning cases of ASD at kindergarten age. The aims of this paper are (1) to summarize the evidence-based design process and (2) to present results from the first usability test of the system. Game topic, candidate responses, and candidate game contents were identified via an iterative literature review. On this basis, the 1st partial prototype of the fully playable game has been created, with complete data recording functionality but without the decision making component. A first usability test was carried out on this prototype (n=13). Overall results were unambiguously promising. Although sporadic difficulties in, and slightly negative attitudes towards, using the game occasionally arose, these were confined to non-target-group children only. The next steps of development include (1) completing the game design; (2) carrying out first large-*n* field test; (3) creating the first prototype of the decision making component.

Keywords. Autism spectrum disorders, early screening, evidence-based design, eye-tracking, serious game, usability test.

1. Introduction

Autism spectrum disorders (ASD) are defined and diagnosed on the basis of limitations in reciprocal social interactions including social communication, and in adaptive, flexible organization of behaviors and interests, including atypical sensory sensitivities in a part of cases. Symptoms as well as support and educational needs are present from early childhood on, and persist throughout life [1]. Now-standard interventions are evidence-based, complex psycho-educational approaches, used in highly individualized

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[1] Corresponding author, Institute for the Psychology of Special Needs, ELTE University, Ecseri road 3, H-1097 Budapest, Hungary; E-mail: gyorimiklos@elte.hu.