

Anna Szemplińska¹,

Urszula Dębska²

Uniwersytet Wrocławski,

Wydział Nauk Historycznych i Pedagogicznych, Instytut Psychologii

Fundacja L'Arche

Supporting development of adult persons with intellectual disability living in the L'Arche in the *life-span psychology*

Abstract

We approach the problem of possibilities of intellectually disabled persons development in the context of a specific experience which is the life in L'Arche communities. Empirical references constitute the research of a narrative type. Theoretical foundations are based on Jeana Vanier's personalistic philosophy as well as in the context of development from the point of view of life-span psychology and development support.

Key words: supporting development, intellectual disability, L'Arche, Communities *life-span psychology*

Streszczenie

Podejmujemy problem możliwości rozwoju osób niepełnosprawnych intelektualnie w kontekście dostarczanego im specyficznego doświadczenia, jakim jest zamieszkiwanie we wspólnotach L'Arche. Odniesienia empiryczne stanowią badania typu narracyjnego. Podstawy teoretyczne bazują na personalistycznej

¹ u.debska@psychologia.uni.wroc.pl

² a.szemplinska@psychologia.uni.wroc.pl

filozofii w ujęciu Jeana Vanier'a oraz ujęciu rozwoju w perspektywie *life-span psychology* i wspomaganie rozwoju.

Słowa kluczowe: wspomaganie rozwoju, niepełnosprawność intelektualna, L'Arche, psychologia cyklu życia

Introduction

For a very long time, intellectually disabled persons were perceived as people with intellectual defects and with deviations from the so called norms in cognitive functioning. It resulted from the fact that mental disability was treated as irreversible condition caused by organic damages of the brain. Kościelska (1995, 1996) perceives these persons from a wider viewpoint. She understands disability as a psychological disturbance – a condition which results from an incorrect developmental process. Its specific property is a blockade of cognitive activeness and not an organic disturbance as it was defined earlier. She emphasises the importance of social bonds and relationships for the development. She also underlines the significance of combining the work of the brain, feelings and action. All this allowed for a personal reference to persons with disabilities and not treating them in a subjective way (Kościelska, 1995, p. 8n). A particular contribution to this personalistic approach was made by a philosopher Jean Vanier – the founder of 'L'Arche' and 'Faith and Light' communities. L'Arche community – as the first one – became a place where intellectually disabled persons found an opportunity to develop in a better way. Their approach became an inspiration for our research.

Theoretical bases

A theoretical basis for the study of development and intellectually disabled persons research living in L'Arche constitutes *life-span psychology* as well as development support and personalism by J. Vanier (Szemplińska, 2011). In *life-span psychology* approach, development is understood as a continuum of changes which take place during the whole individual life (Baltes, 1974; 1998; Straś-Romanowska, 2001). A phenomenon of progression is not limited to particular mental functions but it comprises transformations of a psychological organisation and takes place during the whole life (Łoś, 2010, p. 75). At a certain stage of development an individual actively joins this process (Łoś, 2011, p. 82; Straś-Romanowska, 1992). When in a certain sphere the development is hindered or even regress appears, an individual is able to achieve positive changes in another sphere (McAdams, 1994; 2001; McLeod, Balamoutsou, 1996; Grzegorek, 2003;

Łoś, 2010). Development in the aspect of *life-span* takes place in accordance with the following rules: it occurs throughout one's own life, it consists in biologically and culturally conditioned changes of adaptation abilities; it involves a dynamic proportion of mutually occurring increases and decreases; individual development shows great flexibility at each age and it may take many forms depending on living conditions; influences of biology and culture on development take place in ontogenetic and historical context of the three following categories of events: the ones connected with the individual's age, the ones connected with historical time and 'non-normative', i.e. those happening to a particular human being; it can be understood only in the multi-disciplinary aspect (taking into account also biology, medicine, anthropology or sociology); biological influences on individual development decrease along with the age. Together with the developmental advancement, there is a growing demand for cultural resources; it has three general functions: a/ growth, b/ keeping (including regaining) and c/ function of regulating decreases – a 'systematic entirety of individual development.' Along with the decrease of (internal) individual resources, allocation of resources to those free functions is subject to change; it takes advantage of complementary strategies of selection, optimisation and compensation. Each development is a composition of those three components (Baltes, 1998; Dębska, in print).

Understanding development in the light of the *life-span* approach allows for seeing intellectually disabled persons in a broader perspective than only their developmental, cognitive and social limitations. Apart from deficiencies, man and his possibilities are perceived (Dębska, 2011; Szemplińska, 2011).

Multi-aspect support is significant and indispensable for the development of intellectually disabled persons. Its theoretical basis derives from an observation that 'man acting in the world of his life remains in a continuous relation with the world, he learns about himself and changes himself and the world or its chosen areas' (Kaja, 2010, p. 26). During intentional impingements, the people from the surroundings try to make it possible for a supported person to tackle tasks and solve life problems on his own. Support is employed when the development and accompanying processes (e.g. education, socialisation) occur in an incorrect way and when difficulties disturbing this development appear in man's life because of various reasons (Kaja, 2010).

Chosen social factors supporting the development of intellectually disabled persons

Factors such as presence of close relatives, created family bonds and other social relations are of fundamental significance for correct development of man (Bowlby,

2007; Czapiga, 2007). For many parents the fact that their child is disabled can be very difficult to accept. Loving such a child will be even more difficult. The child will not be able to fulfil many of their hopes. Possible consequences of parents' disappointment are lack of acceptance and creating no positive bonds, reducing relationships to the minimum or total rejection. The lack of acceptance, love or rejection of the child, which does not fulfil parents' expectations, enlarges the area of its disability, functioning disturbances and exclusion (Kościelska, 1995). One's own image and a positive attitude towards oneself is conditioned by a sense of safety and one's own value, which are created in the relationships with close relatives (Łaguna, 1996; Witkowski, 1996). This image is created by a set of information concerning one's own features, possibilities, skills, appreciated values and guides all actions of an individual (Brzezińska, 1973; Janiszewska-Nieścioruk, 2000). It steers an individual's behaviour, controls it, makes references to the surrounding world, stimulates an individual to act, determines the level of aspirations and motivations in achieving established goals, decides about good or bad mood as well as about quantity and quality of built up contacts (Otrębski, 1997; Majewicz, 2002). Social experiences, everyday relations, tension between an individual and the social environment are reflected in changes in the self-assessment (Oleś, 2011, p. 303; Vickery, Evans, Lee, Sephiri, Jabeen, 2009). Perceiving oneself as a wronged, worse, not loved, not wanted individual shall result in impaired functioning (Kościelska, 1995; Łaguna, 1996; Czapiga, 2007; Dębska, 2011).

On the other hand, excessive care is equally harmful and limits the child's development. Parents, who for example feel guilty about their child disability or want to reward the child its imperfection, often become overprotective towards the child. But at the same time, a child with disability – similarly to healthy peers – must 'touch' the reality and experience it on one's own. Weaker cognitive functioning and weaker I (ego) requires clear messages and situations, an experience that will help a child to understand them. Should this not happen, a child will have the right to feel that people lie to it and it will never trust another man – similarly to a healthy child (Vanier, 1988). As a consequence, the above mentioned examples and other mistakes made in the process of development and education of many intellectually disabled persons, a self-image unfavourable for the development will be created: a sense of inferiority, a sense of lower value due to lower ability, efficiency, usefulness, effectiveness or rejection (Kościelska, 1995; Zasepa, 2008; Dębska, Szemplińska, 2011).

Intellectually disabled persons are characterised by considerable openness and readiness to communicate with others; they look for and wait for contacts; unfortunately, they often do not find a positive response from the people around (Gałkowski, 1979; Kościelska, 1995; Zasepa, 2008; Dębska, Szemplińska, 2011;

Szemplińska 2011). However, by noticing their specific value, which they can introduce into the society they live in, we can restore their dignity. Behaviours, which take into account deserved respect for them, result in situations in which their level of 'disability' and exclusion becomes lower and at the same time their sense of value increases.

On the basis of research on disabled persons Kościelska claimed that the examined persons – since their childhood – experienced a sense of disability, dependency, being worse, lack of love. They were forced to conform to the society, to take advantage of other people's help, they held views which were useful in order to become similar to significant persons. All this resulted from their weak **I** which stopped their development, blocked their possibilities to become self-dependent. Lack of cognitive activeness limited their acting in the world and made them socially disabled. This caused images about themselves as dependent and disabled persons and at the same time it blocked the development of **I** autonomy. A triad was created: handicapped **I**, handicapped mind and handicapped life (Kościelska, 1995, p. 39). We can assume that by preparing appropriate conditions for intellectually disabled persons and by reinforcing their weak **I** by means of positive experiences in social relationships, we can achieve an opportunity to improve their own image of themselves, self-assessment and functioning. L'Arche Foundation³ is a place where such methodological steps were taken probably for the first time. Vanier's philosophy emphasises an incredible value of a disabled person who brings the values of heart, openness, honesty, trust and faithfulness into the world of 'able' people. The purpose of the communities which were established by Vanier is to help disabled persons experience their hu-

³ L'Arche Foundation, called Arka in Poland, was established when Jean Vanier started to live together with two disabled persons in a small house in Trosly-Breuil near Paris in 1964. At present, 137 communities on the model of the first house function in 35 countries all over the world. Communities were established on five continents, both in rich countries such as the USA, France, Canada, Australia and in some of the poorest countries such as Honduras, Haiti, Bangladesh and Zimbabwe. L'Arche Federation has about five thousand members, including 2278 intellectually disabled persons who live in the houses kept by them. Additionally, 1315 persons with disabilities take part in activities in the workshops prepared and run by the Federation (<http://www.larche.org.pl>). In Poland there are also several houses of the Federation. The Polish region accepted the legal name L'Arche Foundation with its seat in Śledziejowice because in 1981 the first house on the model of French Trosly was built in Poland. The Polish Foundations comprises four branches situated in Krakow (Śledziejowice and Wieliczka), Poznan, Wroclaw and a project in Warsaw. The legal aspect of L'Arche in Poland results in responsibility towards local governments or national institutions for the quality of care over the disabled people who are entrusted to it (Szemplińska, Śmigiel, 2009).

manity in many aspects of the existence and accept their own values and beauty, help them believe in themselves, their possibilities of the development and abilities to do good things (Szemplińska, Śmigiel, 2009).

L'Arche model to support the development

In 1993 L'Arche Federation General Assembly approved 'L'Arche Charter'. This document precisely outlines the goals and principles of the Federation communities. The Charter clearly declares that L'Arche is a place of special development for its residents. One of the items referring to the principles underlying the community provides as follows: *In order to develop their skills and gifts as well as to feel accomplished each person needs an environment that is conducive to one's development. Each person needs bonds with other members of the family or the community. Each person needs a life in trust, a sense of safety and mutual love. Each person needs acceptance and support through warm and real relations* (L'Arche Charter, 1993 <http://www.larche.org.pl/idea-larche/karta-larche.html>).

It is explicitly emphasised that for the best development of L'Arche residents the care of building an appropriate **growth environment** is necessary. In L'Arche, it is essential to accept the fact that all persons constitute one group of people and each person has equal rights and duties, if possible. Another equally important aspect of supporting the development of L'Arche residents is connected with **bonds**. The main idea behind L'Arche communities is to create bonds which do not object to the distinctness of another person, but rather accept this person as a partner. With time, partnership becomes one of the elements guaranteeing mutuality understood as an exchange of gifts as well as mutual support in the face of revealed weaknesses and traumas. 'L'Arche Charter also emphasises that a climate of **trust** is conducive to the residents' development. The communities constitute places where it is particularly important that persons with intellectual disability should be perceived as gift and their distinctness must not be seen as a problem or a source of fear or exclusion but as a tool of transformation. Therefore, **warm relations** enable us to discover exceptional gifts of the community residents. The mission of L'Arche is to show talents of intellectually disabled people, which are revealed in mutual relations, and to provide support for these people so that intellectually disabled people could discover their value (Szemplińska, 2011).

In L'Arche homes usually 5 to 7 people live who have intellectual disability and some assistants who accompany them in their everyday activities. The process of accompanying starts at the break of the day from the morning reveille, then it constitutes preparing and consuming meals, going to work together and generally spending time together. L'Arche communities also have their own workplac-

es – occupational therapy workshops where intellectually disabled persons along with workshop assistants have an opportunity to take up work. There are various workshop studios such as painting, carpentry, candle manufacturing, weaving and cooking workshops. All the suggested activities are aimed at development of residents and helping them restore their sense of value. It is also important that the intellectually disabled persons assume responsibility for themselves and others (Szemplińska, 2011; Śmigiel, Szemplińska, Andrzejczak, 2010).

Synthesis in L'Arche – summary of the development

A method of carrying out the aforementioned programme in L'Arche communities is the Synthesis which constitutes a conscious reflection on the development of the particular persons with intellectual disability. The Synthesis is used to sum up the development, to verify the level of satisfying needs, to reveal occurring problems and to help with formulating a strategy of methods of reacting to them. Its methodology includes weekly meetings of home assistants with the one who is responsible for the home during which they discuss and share observation results concerning the development of residents with a mental handicap. On the other hand, the basic Synthesis constitutes a yearly assessment of the development, which summarises the entire experience referring to a given person. Apart from the evaluated person, all the residents participate in the assessment, namely, assistants and also colleagues, friends or family members as well as a pedagogue and psychologist employed in L'Arche. There are interviews conducted relating to the person who undergoes the Synthesis (according to an appropriate questionnaire), and also information is collected on functioning of this person, the person's revealed needs and problems. The whole process is focused on affirmation of the person, revealing his/her gifts and talents and defining the areas which require support. The conclusions which are drawn from the conducted Synthesis, defined as 'planning around a person', are supposed to help assisting the persons with a mental handicap. The entire Synthesis process is aimed at defining the areas which are important for a given person and methods of supporting this person in implementing his/her plan. The Synthesis can be perceived as a meeting during which the invited persons along with a mentally handicapped person have a chance to discover some aspects which are important for personal development during the Synthesis process and in the future (Śmigiel, Szemplińska, Andrzejczak, 2010).

L'Arche – a place of development – from an empirical point of view

For the purpose of narrative type research, nine residents of L'Arche community with various levels of a mental handicap were invited. They were chosen randomly in order to maintain methodological correctness. Taking into account a wide range of the collected material, it is possible to quote only some selected fragments of the research. Real names of the participants were changed for ethical reasons. A research method constituted dialogues and narrations of L'Arche residents. An original instruction was *'tell me your story'*. However, as some of the participants found it difficult to understand, it was verbalised in another way, namely, *'tell me something about yourself'*. During the research, I also asked additional questions in order to direct the story or dialogue and to have a look at some particular aspects of being a L'Arche resident, for example, the awareness of having a mental handicap such as Down syndrome. Some of the participants of their own accord attempted to change the subject by directing the conversation to their own topics which were not necessarily a part of the research problem. It was hard to carry out the research due to frequent speech impairments of the participants, brachylogies, perseverations as well as changes of word meaning which had to be disambiguated. In the course of research I could notice a need for a bond of the participant with the examiner expressed by revealed trust of its lack. This proves that research reliability requires more time spent individually with the subjects which is conducive to the atmosphere of trust and acceptance. One of the cognitive goals was to look into narrative skills of mentally handicapped persons. Based on the material collected we can draw conclusions as to great significance of interpersonal relations in their lives. Throughout the research we noticed that the atmosphere of trust, safety and support which the participants found in L'Arche communities – indispensable for personal development – is realised by the subjects and perceived as a positive value (Szemplińska, 2011). The fragments cited below are only brief examples and their purpose is to show possibilities of having conversations with the participants about important issues. They show indirectly that experiencing life in L'Arche serves the purpose of their development. The conversations reveal the dreams and feelings of the subjects and represent their awareness of changes.

Exemplary statements of the subjects:

Michał – with Down syndrome, level of retardation – severe, aged 55

Michał appeared in L'Arche community when he was 31 years old, after his grandmother died and his mother was unable to look after him. Michał had prob-

lems with social adjustment, he could not look after himself and he was scared of everything. His behaviours were obsessive. A sense of security acquired in the community contributed to his development; first of all, he learned basic rules of hygiene and looking after himself. Everyday work in occupational therapy workshops taught him regularity and built a sense of his own value. Living in the home resulted in the formation of social behaviours generally accepted to be appropriate and formed his sense of responsibility for a place of living. Michał talks about himself:

I was a different human being then, totally different from my present life now, everything somehow changed, it comes with age, everything just changes, like I was in a totally different life, eh? I was such a small baby like all other babies, yes, of course I was really born with such a strange syndrome, like you said, with Down syndrome, of course. You know how I came to know about it? Perhaps it was in L'Arche that I learned that something like this exists. I don't know if it was a problem for me then, I didn't realise I had it, that it was possible, very strange, isn't it? It seemed to me something completely different, like an illness or not an illness, like Down syndrome, I didn't know what it was. Nobody talked to me and that's the way it was. After some time, I was at home then and attended school, of course a different school, it was called a special school which was situated at Raclawicka Street. At the beginning, my mother thought that she wanted me..., she wanted the best for me, of course, like all the others, each Mum says that...she thought that she would order me around and she wanted me to be in L'Arche probably. I don't know, maybe she wanted to get rid of me but it didn't work, ordering me around because finally I ended up in L'Arche, you know why in this way? I didn't like it here at all and so since then I bore a grudge against her for some time because she did it.

J: Did you prefer to stay with her?

M: Eeee I didn't want anything from life then, nothing at all.

J: So, L'Arche was not your choice? And what, you came to L'Arche and a new chapter in your life started?

M: Eee at first Mum thought that I was all thumbs but only when she saw me here she changed her mind as to me, what do you think about it?

J: Did you discover our talents here?

M: I learned many things here. My Mum had a bad opinion about me.

J: Bad?

M: You see, it was only in L'Arche that I started having a new life, it's like this until today, I am happier than I used to be.

J: Although life here is not a bed of roses.

M: But because of all this my history is so strange, God could shape me in a spiritual way, I am chosen by God, my heart is richer now. I was given life wisdom and I was shaped spiritually, I am more independent, it seems that angels carry me everywhere (he is crying), I didn't know that Jesus had such a plan, I don't know should I laugh or cry, I can laugh through tears too, what do you think? This is my story. Now I told you the whole story of my life.

Ela – mild level of retardation, aged 26

Ela came to the community directly from an orphanage – her family had an alcohol-related problem. L'Arche community was not her personal choice; however, because of her life situation she was not able to take up an independent life. L'Arche community homes accept persons with moderate, severe and profound levels of retardation, thus, the fact of accepting Ela was the community's readiness to adapt the girl for an independent life. Ela always wanted to become independent and start a family. At the moment the L'Arche Foundation is building a house in which Ela will be able to live in a protected flat. It seems that living in L'Arche community substituted her lack of family life and it provided her with help and the hope that she would be able to build her future independently or with a little support. The community helped Ela find a job apart from the occupational therapy workshops where Ela with her level of retardation was unable to work. L'Arche also formed a support group for the girl so that she could share her fears and joys with them. At this home Ela discovered her numerous talents, with satisfaction she shared with assistants her cooking skills, ability to receive guests and build permanent relations with the persons surrounding the community. Her main problems now are management of money and naivety in contacts with men. Ela is aware of her problems and very sincerely discusses them with her leading assistant. Ela talks about herself:

The problem with my Mum was that she fell ill and she couldn't stand us, no way, so she had to leave us and it was too difficult for her. She was epileptic and so alcohol, I don't know about these things. Something like this, it's difficult for me

to talk about it because I didn't see it, I once saw her when she had an epileptic fit, my heart trembled and on the street, I didn't know what to do, I was depressed and surprised, it was just like this. Yeah, I have good memories from the orphanage, all the time I think about it, I would like to go back there, if there was such a possibility, if there was no L'Arche I could go back there. /.../

I ended up in L'Arche on 6th December.

J: But why did they say that you should live in a home like L'Arche and you cannot live on your own?

E: Because they are afraid that for example if I lived on my own, something bad would happen, like a gas explosion, or that I would forget to pay for water, they wouldn't trust me, if I can cook, wash, switch off everything, not to make a fire. No, they are afraid of this most. I just can on my own because I can do everything but I am afraid of OSH. If it hadn't been for L'Arche I wouldn't have a job and I would stay at that orphanage. This is m experience that I can do everything, I'm going to the workshop to see how others manage with it. Well, I sometimes quarrel in L'Arche because I don't like something and I want it m way.

J: So L'Arche was not your choice?

E: No, no.

J: If L'Arche is not your choice, tell me what you would like to do?

E: Maybe have a husband, live with a husband, somehow make a living.

J: So, perhaps it is good that you are in L'Arche because who knows what would your life look like?

E: You know, I have told other people what I did and I'm not ashamed to hide it and that

J: Well, if you were on our own, other people could abuse you, don't you think?

E: I am what I am. It's good that a home like this was built for me, if it weren't there, I would end up with some grannies and what would I do, I would escape, I wouldn't be able to stand it there.

Kryisia - 37 years old, with Down syndrome, level of retardation – severe.

Kryisia was placed in the community by her mother who became seriously ill. The situation of her illness forced the woman to make decisions connected with the future of her disabled child. Kryisia arrived in the community when she was 25 years old, she was cheerful and did not cause any problems. In L'Arche she seems to have grown up. She started taking up works connected with everyday life, regularly attended workshop activities and began to assume some degree of responsibility for herself. At the moment Kryisia appreciates a lot the community aspect of her place of living.

J: So you're saying now that you are satisfied with your life, are you happy?

K: Yes.

J: And why are happy here in L'Arche?

K: I have friends.

J: And that for example you have a job?

K: Yes, work is more important.

J: It is important too?

K: Yes.

J: Do you like your job?

K: Yes.

J: And what gives you most joy in L'Arche?

K: Yyy, I have... joy of being with others.

J: ... and that you are not alone?

K: Like in a family.

J: Does it ever happen, in the community, that you feel lonely?

K: No, I never felt lonely, I always talk with my friends, when I need it I talk to someone /.../

J: Wouldn't you like to exchange the community for another life now?

K: The way it is here, it's good now.

(...) I contact my Mum from time to time, I ring her or visit her at home. In Katowice it is very boring, there's no work, no friends. Here in the community I have found my place. (...) On Saturday I am going to see my parents, but only until Monday, then I'm coming back to paint my cards. Zosia asked me to do it, I always do it. I like living with these people, I chose L'Arche myself. Sometimes my family comes to visit me, I also like going to my parents to live in luxury for a while but I like talking with the people here, although sometimes I don't know how to get along (laugh). You can always talk to people, see the duty roster for instance.

Summary

Our research results showed a significant impact of a community life on individual development, functioning and life satisfaction of persons with mental handicap. Living in L'Arche homes confirms that it is possible to see intellectual disability in a positive aspect. Our research proves that persons with mental handicap do have a sense of their autonomy, distinction, self-awareness and awareness of change as well as their own world of personal meanings. They discover their identity and learn about their distinctness that other people do not want to know or talk with them about. They have their dreams and desires and first of all they want to be loved, accepted and noticed. They learn about their hidden possibilities: gifts and abilities. The atmosphere of the community helps them overcome their own weaknesses and gives a possibility to grow. By starting interpersonal relations they notice their potentials. They come to perceive themselves as persons who have something to offer for others and be helpful. They no longer see themselves as individuals who take from others, remain on the margin and are excluded. According to their possibilities, they assume responsibility for the community and can feel accomplished in the tasks entrusted to them (Dębska, Szemplińska, 2011). During our research, also some negative aspects of the participants' lives were revealed. The safe atmosphere of L'Arche allowed them to reveal their sufferings

as Different people – ‘marked’ with, for example, Down syndrome or generally with intellectual disability (Szemplińska, 2011).

Of course, we cannot be convinced that the stories told by these intellectually disabled persons contained the truth or they were just an effect of their fantasising. The person carrying out the research has been involved in creating L’Arche communities for sixteen years and for some time she lived in L’Arche homes herself. Everyday observation and experience in contacts with mentally handicapped persons enable her to accept the aforementioned cited statements as reliable. The studies on intellectually disabled persons carried out earlier by Kościelska also confirm the validity of exploration activities of this type (Kościelska, 1995).

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