



DOROTA PODGÓRSKA-JACHNIK

Uniwersytet Kazimierza Wielkiego w Bydgoszczy

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# **Liberation or dependency? The problem of language mediator and new areas of dependence in communication of people with disabilities**

**ABSTRACT:** Dorota Podgórska-Jachnik, *Liberation or dependency? The problem of language mediator and new areas of dependence in communication of people with disabilities* [Wyzwolenie czy uzależnienie? Problem pośrednictwa językowego i nowych obszarów niesamodzielności w komunikacji osób niepełnosprawnych]. Interdyscyplinarne Konteksty Pedagogiki Specjalnej, nr 12, Poznań 2016. Pp. 213–227. Adam Mickiewicz University Press. ISSN 2300-391X

W artykule przedstawiono problem osób niepełnosprawnych zależnych od pośrednika językowego w komunikacji alternatywnej i wspomagającej (AAC). AAC jest dla nich okazją do osobistego wyzwolenia z opresji izolacji, chociaż specyfiką tej komunikacji jest ograniczony krąg uczestników, a czasem uzależnienie od tłumacza lub facylitatora. Ten typ zagrożenia rozwoju można jednak ograniczyć przez świadome kształtowanie środowiska komunikacyjnego i kontrolowania rozwoju relacji: osoba z niepełnosprawnością – pośrednik językowy. Pokonanie bariery komunikacyjnej jest ważnym procesem wyzwiania się z ograniczeń wynikających z niepełnosprawności.

**Słowa kluczowe:** niesamodzielność, pośrednik językowy, komunikacja alternatywna, niepełnosprawność

Disability is a complex personal situation defined through different kinds of limitations originating in damages of biological nature and in their indirect and direct results. Hence, disability shows itself not only in biological functions of an organism but it can also be connected to every area of psycho-social functioning of a person. It is a factor that limits the possibilities to satisfy own needs or a full access to those areas of social life which are not additionally limited for people without disability – they have a full access to them and realize their recognized civil liberties and rights<sup>1</sup>. Some limitations can only be observed in particular areas and periods of life of disabled. Other limits are constant and omnipresent. Some can be equalized or compressed by shaping specific competences of a person with disability or increasing their effort in achieving goals equal to healthy people. Other limitations, unfortunately, require constant or temporary external aid from other people. In the second case we talk about dependent lives or an independence noticeably limited by disability. The dilemma – how to successfully help people with disability – is connected with the risk of secondary dependency from the help and unintentional increase of the level of dependency of supported people.

One of the secondary and most common results of numerous permanent kinds of disability<sup>2</sup> are communication disorders. The problems with communicating may be connected with intellectual, motor disability or sight or hearing defects. They occur as a symp-

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<sup>1</sup> L. J. Sibilski (2000), *Social Aspects of Disability: Social Movements, Social Organization and Legislative Action*, Wyd. "Śląsk", Katowice, s. 15 i 21-37.

<sup>2</sup> There are communication disturbances showing themselves not only in particular situations (e.g. mutism or non-fluency of speech i.e. stammer, communication of deaf people but only with hearing people who do not know sign language, etc.). Nonetheless, most of them should be treated as a long-term disturbances and regarding all or most areas of human activities connected to communication with other people. What is more, some effect of generalization of negative experiences may be expected in particular situations influencing all interpersonal contacts. That is why if we treat speech and communication as key elements in interpersonal relations, we should treat speech and communication disturbances as the biggest threats for the relations.

tom or an after-effect of various diseases, genetic syndromes, damages and vast developmental disorders. They appear e.g. in Usher syndrome, autism, cerebral palsy, aphasia, selective mutism etc. they may also co-occur with depression, anxiety states, emotional problems, neurotic and psychotic syndromes. The character of such disorders, the conditions and mechanisms differ and – as a result – the effectiveness of communication also differs.

The scale of communicative limitations connected with disability is also varied. It can be described using the following areas (continua):

- From slight disturbances to a complete loss of speech or even paying attention to a person trying to initiate a contact (e.g. visual);
- From minor cognitive and language gaps (slightly limited language competences) to a complete exclusion from a common communication code (the level of communication competences so low that it excludes from functioning within a particular language<sup>3</sup>);
- From compensatory abilities situated within common communication systems (e.g. replacing one form of communication with another – speaking with writing) to various forms of substitute communication (e.g. graphic systems understandable only to initiated users – sign language, cued speech, Bliss symbols etc.);
- From minimal and situational need of help (e.g. during dealing with official affairs, at school or at work) to a complete dependency from a translator, an interpreter or a facilitator (a constant need of a participation of others in contacts with other people; without any language mediator the communication process is not initiated or it is entirely ineffective).

This analysis refers especially to the latest one. It concerns the problem of independence *versus* dependency on various levels in the area of language and communication mediation.

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<sup>3</sup> It is a real situation during which it is extremely difficult to imagine a complete lack of any language competences in practice.

Interpersonal communication, speech and language are a very important tools of regulating relations of a person with social surroundings. They may be called social adjustment tools. Interpersonal communication in that context is mirrored by diagnostic tools to evaluate a general level of adaptive competences. A good example is well-known and used in Poland – *the scale of accommodative behavior of children, youth and adults*, and the authors – K. Nihira, R. Foster, M. Shellhaas i H. Leland – name the following detailed sub-scales:

- Independent functioning,
- Physical development,
- Economic activity,
- **Speech development**,
- The notions of number and time,
- House works,
- School/professional activity,
- Self-control,
- Responsibility,
- Socialization.

The speech function underlined above (understood as an ability to communicate and not only as an ability to form words) is an adaptive competence itself although it is obvious that it may influence the remaining scales (e.g. school and professional activity). In the context of the topic of this case study it is worth to pay attention to an external connection of *speech* scale with the scales of *socialization* and *independent functioning*. Although the achievements in these scales are evaluated separately, there are some noticeable lower results in socialization and independent functioning when also communication disturbances co-occur simultaneously. A. Smyczek points out that the ability to talk is dependent from not a functional organization of one area only (e.g. the agility of speech apparatus) but numerous brain processes responsible for sending a verbal communicate. The author places the group of children with cognitive development distortion, attention, perception, initiating contacts or behavior organization distortions among children especially endangered with communication disturbances. Disturbed eating

function correlates with speech disturbances on an especially high level<sup>4</sup>.

A very low level of communicative competences limits independence and self-reliance and decreases general adaptive resources of a human being. Independence and self-reliance are commonly treated as synonyms. Hence, the level of functioning of a person (not necessarily with a disability) may be situated somewhere within the dependency – independence continuum.

However, a simple and one-dimensional inference ends here. The process of searching for ways to increase the level of independence of a disabled person is neither simple nor universal and accepted solutions quite often contain elements of lowering functioning standards or a compromise (choosing so called “lesser evil”). The situation of people who need a translator or other language mediator is a special example. Special pedagogics consider such possibility when help – aimed at an increase of independence – may cause an increase of the dependency from the aid<sup>5</sup>. The threat paradox is that the more the help is needed and the more we help – the greater the threat of the dependence from helping person may become. It especially concerns people with disability and the level of disability is not meaningless as well. When we consider communication support for a disabled person in the categories of increasing their general adaptive potential we should also take into consideration a secondary increase of dependency from both the mediation person and the alternative forms of communicating.

The threat of an increasing dependence or even passivity and helplessness in interpersonal contacts of people using communica-

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<sup>4</sup> A. Smyczek, *Zastosowanie wspomagających i alternatywnych metod komunikacji (AAC approche) w terapii małych dzieci zagrożonych poważnymi zaburzeniami w porozumiewaniu się* [w:] J. Bleszyński red., *Alternatywne i wspomagające metody komunikacji*, Oficyna Wydawnicza „Impuls”, Kraków 2006, s. 74–75.

<sup>5</sup> D. Bacelewska, *Wsparcie emocjonalne w pracy socjalnej*, Wyd. „Śląsk”, Katowice 2005; D. Podgórska-Jachnik, *Rola psychologa w identyfikacji i likwidacji wewnętrznych barier osób niepełnosprawnych poszukujących pracy*. „Aktywizacja Zawodowa Osób Niepełnosprawnych” 2006, issue 3–4 (7–8) October.

tion mediation is described by S. von Tetzchner i H. Martinsen (2002). According to the authors, the phenomenon is relatively common among users of supporting or alternative forms of communication regardless of the nature of the support. Three groups of disabled people are usually named as those who need such support:

1. Group of a language expression – people who understand speech but cannot use it; the aim of this group is *"the aim of an intervention is to supply a form of communication that would become a permanent mean of expression – it could be used in various situations throughout the whole life of a disabled person"*<sup>6</sup>;
2. Group that needs language support – people who need a temporary communication alternative supporting the development of speech and language acquisition (developmental sub-group) or people who developed a speech that is not always understandable for everybody (situational sub-group). The people need a clear amplification of their utterances; according to the authors, *"the intervention aims at the ability to support speech, to monitor the understanding of a conversation partner and to apply various means and strategies in different situations"*<sup>7</sup>;
3. Group of alternative language – people who need a communication alternative throughout their whole life; with a slightly developed or a complete lack of speech with a simultaneous lack of chances to develop them in a foreseeable future<sup>8</sup>.

In the case of the first group, the authors show a risk of a spontaneous usage of their abilities<sup>9</sup>. Many researchers underline the

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<sup>6</sup> S. von Tetzchner, H. Martinsen H., *Wprowadzenie do wspomagających i alternatywnych sposobów porozumiewania się*, Stowarzyszenie na Rzecz Propagowania Wspomagających Sposobów Porozumiewania się „MÓWIĆ BEZ SŁÓW”, Warszawa 2002, s. 63.

<sup>7</sup> Ibidem, s. 64.

<sup>8</sup> Ibidem, s. 65. Simultaneously, the authors stress the difficulties of estimating a complete lack of chances for speech development giving examples of people who achieved that very late – at the age of 40 and more.

<sup>9</sup> Ibidem, s. 88.

“laboratory” character of utterances of children with damaged hearing who just copy the patterns learned during rehabilitation – didactic classes in a schematic way with no attempts to change them in a creative way<sup>10</sup>. The structures acquired during such classes are just an inefficient prosthesis of communication and their repertoire defines the range of communication abilities. They are the range of communication dependency and people who do not move to the next level of language competences stick to them very tightly. It is, in fact, a contradiction of communication as an interactive process of reaching mutual understanding. Other special area of the dependency is the attempt to express oneself and applying bad communication habits when attempting to introduce new means of auto-expression<sup>11</sup>.

In the group of language intervention a studied helplessness is pointed out<sup>12</sup> and it is suggested that it may come from a lack of strengthening the attempts of communication and feedback. This results in the situation that the same attempts may be successful in contacts with particular people and unsuccessful in contacts with other people. The lack of a coherent experiencing communication successes may, in turn, result in doubtfulness in regards to one’s communication competences and helplessness in contacts with people. A mediator seems to be a guarantee of a successful contact.

There may occur a noticeable dependency from communication help of other people in both the language support group and the alternative language group. *“Quite often children with delayed speech development ask their parents to talk for them in presence of other people even if they are usually understood by others. When the possibility of a movement of a child is not limited the lack of initiative in a conversation is especially visible. Autistic children who are not able to talk attempt to*

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<sup>10</sup> D. Bouvet, *Mowa dziecka. Wychowanie dwujęzyczne dziecka niesłyszącego*. WSiP, Warszawa 1996; E. Domarecka-Malinowska, *O ograniczeniach językowych uczniów głuchych*. „Biuletyn Audiofonologii” Tom III, 1991, 1–4; Cz. Dziemidowicz, *Dziecko głuche i język ojczysty*, Wyd. „TANAN”, Bydgoszcz 1996.

<sup>11</sup> S. von Tetzchner, H. Martinsen, *Wprowadzenie...*, s. 88.

<sup>12</sup> *Ibidem*.

*initiate a conversation very rarely. They miss the readiness to react and initiate a contact – a person responds only when is talked to and they take initiative when they are forced to do so*<sup>13</sup>.

The observations of von Tetzchner i Martinsen confirm the concern about an excessive increase of dependency of disabled from the help in communication. Nevertheless, they seem not to cover all detailed threats of communication disturbances coming from the participation of a language mediator. The attempt to regulate various situations leads to enumerating the following threats:

1. Risk of intentional or unintentional meaning distortion (dependency from competences and intentions of a mediator).
2. Risk of mediator's dominance in the process of communication (mediator takes the communication initiative sometimes with a permission or expectation of one or both sides of communication – *"Please, explain"* communicate).
3. Risk of initiating communication only in presence or through mediator (dependency from facilitating presence of mediator; people do not initiate communication with the usage of available communication abilities).
4. Risk of a "social filter" (amplifying or weakening of some parts of verbal or non-verbal communicates through the barrier of mediation in the natural process of reception-sending of indirect communicate).
5. Risk of "protective umbrella" and isolation (mediator is an element of protection but also isolates a disabled person from others).
6. Risk of lack of personal relations (instrumental treating of language mediator; instrumental dependency, depersonalization).
7. Risk of excessive attachment (personal dependency).

Described situations and problems come as a result of a long-term observations and feedback from deaf students from Wyższa Szkoła Pedagogiczna in Lodz (Pedagogical Academy in Lodz)

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<sup>13</sup> Ibidem.



where more than 65 deaf students have been studying between 2005 and 2015. They were supported by 6 sign language interpreters – some of them bilingual, using Language-Sign System (in Polish: *SJM – system językowo-migowy*) and natural Polish Sign Language (in Polish: *PJM – polski język migowy*). The author of this paper has been a spokesperson for students with disabilities. She had organized professional support and language interpreters service for students with hearing impairment as well as conducted research on problem of deaf people's emancipation through education<sup>14</sup>. The observations and analysis of the problems of disabled people who need help from a language mediator showed numerous dilemmas connected to such form of help that change the place of the people to a continuum between independence and dependence.

### **Communication of people with disability – old and new areas of dependence**

Simultaneously, it should be rethought to what extent the problems of communication are ahistorical and to what extent they are situated in a particular time context (that may be treated as a cultural or even civilizational context).

When searching for the answer, old areas of communicational dependence will be connected with general regularities of the process of communication and with interpersonal interactions and regularities of the communicational competences development process. They are of a universal character and to a large extent they are the subject of this case study. Nevertheless, here we can also see a sign of times – *signum temporis* – when a reference to new communication systems or technical means completely changing communication perspectives and new cultural contexts that modify the area of strategic decisions connected to the process of choosing communication means occur.

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<sup>14</sup> Podgórska-Jachnik D., *Głusi. Emancypacje*, Wyd. Naukowe WSP, Łódź 2013.

New areas of dependence regard those aspects of communication and development that are placed in the "here and now" context – both in cultural and technical contexts. They are connected to changing communication media and the role given in the process of education and rehabilitation as well as – simply – psycho-social functioning of a contemporary human being. It is a separate, very broad discussion subject and that is why I will only signal the most important areas spotted that may bring hope of independence or strengthen the feeling of dependence from others.

What comes to mind in the first place is the technical compensation means. Their communication role in contemporary society is unquestionable. For disabled people modern technologies are a chance for communicational independence or even with functional abilities close to zero (e.g. in motor sphere for people with major motor disability or visual perception sphere for people with vision disturbances or blind). Technical possibilities modern prostheses of sight, hearing, speech synthesizers open communicational channels with particular sense modalities. Will technique eliminate communicational dependence? It creates chances to limit it and, simultaneously, draws a painful line of accessibility to such solutions. We may expect a sad contrast of relative independence and radical communicational dependence between people who have access to newest "technique miracles" and others who do not have such access; those who live in countries or societies with high technical culture and high income rate and those from poor regions. Hence, the problem is not only an inequality of chances of disabled people but also securing the stability of technical support. It may be said that a new kind of dependence or disability occurs: the lack of competences or the lack of access to modern information technologies and the most powerful medium – the Internet.

Technological solutions are not the only aspects of modern times that influence the level of communicational independence. The increase of communicational potential and the level of independence will surely depend from modern rehabilitation and education techniques of disabled people. They also change with time and scientific

knowledge on the effectiveness of influence in these spheres is constantly actualized. We perceive the increase of chances for higher level of functioning and independence through the earliest possible initiation of prophylactic and compensative actions – early support and developmental intervention. Life results as well influence the decision about the optimal communication option – that has already been a subject of consideration.

The level of communicational dependence is also influenced by changing social standards e.g. communicational styles. In the XX century, interpersonal communication entered a central spectrum of interest of many sciences: psychology – especially social and clinical psychology (communication disturbances), psycholinguistics, sociology, sociolinguistics, management theory or pedagogics. The role of knowledge on communication and communicational competences in working teams has been recognized, a new fashion of non-verbal communication, negotiation and mediation, assertiveness, group trainings and group management processes – including group communication – occur. The knowledge may also be used by disabled people and increase their independence in two ways:

1. By increasing personal resources – using knowledge on effective communication to broaden personal communicational potential of disabled people;
2. By increasing communicational resources and interpersonal sensibility of a society and people potentially communicating with disabled (i.e. everybody); if the social awareness on communicational processes increase it should be mirrored by higher effectiveness of communication with people with limited communication abilities; it is consistent with the contemporary social approach to the disability problems.

The latter aspect may be perceived through the problem of changing social attitudes and approaches towards disabled people. Social ideologies define the rules and conditions of participation of disabled – their segregation or integration. It is social solidarity that forces to take co-responsibility for results of disability and strains connected to it. Social stereotypes and breaking them defines roles

of disabled. Social expectations and demands will increase or decrease the standards of expectations towards disabled. Social support may help in meeting those standards and a lack of such support may be the reason for marginalization and exclusion. Social relations defined, define and will be defining the areas of dependence and independence. Former, current and future areas.

The issue may only be solved by controlling and certifying the quality of work of interpreters with simultaneous caring for their high ethical level and the feeling of responsibility. The approach of an interpreter – regarding a particular situation or a text – is a decision that needs great responsibility. It assumes the declaration of a sufficient level of language and non-language competences to produce an effective interpreting. In many countries the process of certification of interpreters and giving rights to teach any alternative methods of communication is formalized. In Poland, there are some communication systems which are under a very strict specification e.g. Pictograms<sup>15</sup>, Makaton<sup>16</sup>, Bliss system<sup>17</sup>, Cued speech (Polish version: Fonogesty)<sup>18</sup> or sign language<sup>19</sup>. There are numerous, sometimes multileveled trainings and courses organized or studies cov-

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<sup>15</sup> *Centrum Metod Alternatywnych w Szczecinie, Portal* [online], available in Internet, [access: 2016.02.19], <http://www.piktogramy.com.pl/>.

<sup>16</sup> *Program Rozwoju Komunikacji Makaton, Portal* [online], available in Internet, [access: 2016.02.19], <http://www.makaton.pl>.

<sup>17</sup> Centrum Rozwoju Komunikacji - Ośrodek Bliss przy Zarządzie Głównym Towarzystwa Przyjaciół Dzieci (TPD) z siedzibą przy Szkole Podstawowej nr 327 ul. Radomska 13/21, 02-323 Warszawa, [online], available in Internet, [access: 2016.02.19], <http://warszawa.tpd.org.pl/pl/organizacje-wspopracujce-z-tpd.html>.

<sup>18</sup> *Polskie Stowarzyszenie Metody Fonogestów, Portal* [online], Lublin, dostępny w internecie [access: 2016.02.19], <http://www.fonogesty.org>.

<sup>19</sup> Sign Language Interpreters Certificate (T-1) and fluent Sign Language Certificate (T-2) are issued by Centrum Edukacyjne Języka Migowego (CEJM) Polskiego Związku Głuchych (PZG) (*Centrum Edukacyjne Języka Migowego, Portal*, [online], available in Internet [access: 2016.02.19]). To be allowed to teach sign language (language-sign system SJM) one needs to get didactic powers during courses organized by PZG and/or graduating postgraduate studies *Sign Language Educator* (such selective – because of the highest level of language competences required – are organized, inter alia, in Wyższa Szkoła Pedagogiczna in Łódź).

ering the issue of various communication methods<sup>20</sup>. The latter solution seems to be the best regarding receivers' needs: it is crucial to choose the method individually that is the most appropriate for a particular user and not adapted to fragmental competences of a particular therapist or a language mediator<sup>21</sup>. The certification system is a sign of responsibility for the standardization of popularized communication methods.

Alternative and augmentative communication is an opportunity for personal liberation from the oppression of isolation. However, the specifics of this communication has a limited circle of recipients, sometimes addicted to interpreter or facilitator. What is important on the one hand, is a systematic development of a genuine communication environment around the people using it, is important. On the other hand, to be guided by a holistic perspective on social relationships of supported communication unit, including paying attention to whether or not there is the secondary personal dependency on language mediator. What was supposed to be a chance – can not become a new source of oppression. Communication – also in its

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<sup>20</sup> E.g. Postgraduate studies project "Supporting and alternative ways of communication" prepared by "Speak with no Words" Association at Samodzielny Publiczny Ośrodek Terapii i Rehabilitacji dla Dzieci (SPOTiR) in Kwidzynie or a program of three-leveled logopaedic workshops "supporting ways of communication", realized in cooperation with Polish Logopaedic Association (*Stowarzyszenie na rzecz Propagowania Wspomagających Sposobów Porozumiewania się „Mówić bez Słów”, Portal [online], available in Internet [access: 2016.02.19], <http://www.aac.org.pl>*). SPOTiR in Kwidzyn cooperates with International Society for Augmentative and Alternative Communication (ISAAC), what may be a sign of keeping international standards of communication support for disabled people. From the very beginning, i.e. 1993, it works actively to adapt and popularize various systems of alternative communication in Poland (since 2001, Picture Communication System (PCS) (K. Kaniecka, 2006, *Alternatywne i wspomagające metody komunikacji [w:] J.J. Bleszyński red., Alternatywne i wspomagające metody komunikacji, Oficyna Wydawnicza „Impuls”, Kraków, s. 358*).

<sup>21</sup> S. von Tetzchner, H. Martinsen H., *Wprowadzenie do wspomagających i alternatywnych sposobów porozumiewania się, Stowarzyszenie na Rzecz Propagowania Wspomagających Sposobów Porozumiewania się „MÓWIĆ BEZ SŁÓW”, Warszawa 2002, s. 63.*

alternative form – should become a factor which release from oppression. Makes it possible to speak and influence their own affairs, which in turn is the basis for emancipation processes.

## RECOMMENDATIONS

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**WWW index**

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