UDC 376 : 316 .77

CHILDREN WITH PROFOUND AND MULTIPLE DISABILITIES AND THEIR COMMUNICATION NEEDS

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Key words: communication, inclusion, disability, persons with PIMD, special needs, enviornment , education.

Abstract

The concept of intervention for people with communication disabilities has been developing since the beginnings of the 70's, moving from a response to people who could not use speech as a form of communication, to a more integrated approach which stresses the need for natural approaches to support the development of functional communication.

The concept of Profound Intellectual and Multiple Disabilities (PIMD) refers to a specific population showing combinations of profound intellectual challenges combined with sensory and/ or motor disabilities.As a result of these combination, children with PIMD are not able to spontaneously and consistently explore environments, get involved in daily life activities and, attend to people in the environment.

Communication as a right and an educational resource for the population of PIMD is not consensual. An approach to communication with this population requires a change in paradigm regarding the goals for their education as well as a definition of the role of all team members involved with particular attention to their role as communication partners.

In this article we discuss a few theoretical contributions to the understanding of the needs of the new population of people with PIMD, the challenges of developing appropriate services to meet their needs, the role of communication in the process, and new trends in service provision.

Introduction

The ability to communicate is one of the most crucial requirements for participation within our individual environments and within the society.Without communication and rewarding interactions children's progress and development are severely affected. Families and family settings are the first environments which contribute to children's development in general and children's communicative behaviors in particular.

Communication is an early process in the life of a child and it is usually initiated by the contingent responses that mothers give to their children's behaviors (Keller, Lohaus, Volker, Cappenberg & Chasiotis, 1999). When such behaviors

are difficult to read, mothers tend to reduce and eventually stop this process.

This article concerns a population which has recently become the focus of attention and research, reflecting changes in the way children with profound intellectual and multiple disabilities have been addressed by services involved in their education and well being.This population has complex communication needs (CCN) which severely impact on their education, on their ability to understand and be understood, and on how they can express themselves to share their emotions.

The Profound Intellectual and Multiple Disability Special Interest Research Group (PIMD–SIRG) of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID) identifies children with PIMD as individuals with such profound cognitive disabilities that no existing standardized tests are applicablefor a valid estimation of their level of intellectual capacityand who often have profound neuromotor dysfunctions. (Nakken & Vlaskamp, 2002, 2007)

In addition to profound intellectual and physical disabilities, these children frequently have sensory and motorimpairments, as well as health problems. Individuals with PIMD are, therefore, a physically vulnerable group of persons with a high dependence on personnel assistance for everyday tasks, twenty four hours a day.

Along with such unique needs, the Complex Communication Needs presented by this population significantly reduce their ability to interact with people and environments.(Justice,2006). This means that these individuals cannot meet their daily communication needs through the current methods of communication, as a result of a variety of physical, sensory, and environmental causes which also restrict their independent functioning in society. Such needs can occur in all forms, in any environment, and with a variety of communication partners (Justice, 2006, op cit.).

This article addresses two questions. The first one relates to the changes we can identify in the present, regarding the way children with PIMD are addressed by services. The second one discusses what can we hope for the future, and how can these hopes reflect quality education for children with PIMD and increased well being

Method

For the purpose of this article, a search was conducted based on the following themes

a) concept of disability

b) profound and multiple disabilities,

c) complex communication needs,

d) staff training,

e) research in the area of profound and multiple disabilities and,

f) evidence based practice. A total of twenty one articles were gathered based on these themes.

Thematic analysis was used to analyze data (Braun & Clarke 2006). The analysis was performed at two levels: at a first level all documents were read and annotated using field notes (Wolfinger, 2002). At a second level both the documents and the filed notes were analyzed and categorized as a way to find themes

which contributed to the discussion of the orienting questions. An initial draft was discussed with a professional working in the field of PIMD. Following this discussion we were able to identify the following themes : i) the concepts of disability and the person-environment interaction; ii) the population with severe and profound disabilities in school, iii) the role of communication in daily life and education, iv)parents and team work v), improved sensory opportunities for children with PIMD, vi) Increased communication and access to social environments; vii) increased participation of the society viii) efficacy of interactions among all participants in children's lives; ix) research and evidence based practice. These themes set the basis for the discussion presented in the following topics of this article.

Changes in the present

The concepts of disability and the person-environment interaction

In the beginning of the 20th century children with PIMD were not visible. They were kept at home or in segregated institutions,and education was not a goal for them. They were considered ineducable. It was not until end of the 50's that this concept started to be reviewed. (Kirman,1958).

The literature shows that disability is more thanjustasa reduction of the persons' ability to show skills in one or more areas of development. (WHO, 2011). A progressive change from medical approaches of disability to ecological approaches brought to light the idea that it is not the cognitive, sensory or motor ability which defines the type of disability.Disability is viewed, now a days, as a reduced opportunity for interactions between the person and the environment, witha particular emphasis on theability toaccess, explore and participate in the environment and the ability to interact with people in diverse environments.

This person- environment interaction has been studied recently, bringing into discussionthe need for a broader theory of the various types of interaction (Jahier and Scherer, 2010) originated in factors such as the identity of the subject or the reactivity of the environment during interaction.The concept of disability results, according to these theories, from the mismatch between these variables. Education and rehabilitation should, taking this perspective, no longer try to change the person but, most of all,adapt the person's interactions with the environment by acting both on the person and on the environment.

The population with severe and profound disabilities in school

Several factors affect change in the population of people with special needs (Emerson, 2009):

1. change in birth rates in the general population;

2. change in the incidence of children being born with or acquiring PMLD;

3. change in infant and child mortality among children being born with PIMD

4. change in mortality among adults with PIMD.

The evolution of medical and care services have reduced the number of children with single disabilities but it has also increased the number of children

with complex needs in school (Carpenter, Cockbill, Egerton & English, 2010). Such changes raise the need for an in depth study of children with complex needs at school age level, as well as a reflection onwhat can school do to support their education.Inclusion, as a general strategy that allows all children to learn in the same place, is not always a useful approach to this population. There is a need to take into consideration children's individual characteristics, namely the variations in attention and behavior alertness,andtheir socio communicative engagement (Arthur-Kelly, Foreman, Bennett ,& Pascoe,2008) in the absence of effective means of communication.

The role of communication in daily life and education

The concept of Education for All (UNESCO 2000), defines goals to be achieved by 2015,namely education for all vulnerable groups and disadvantaged children,as well as an equitable access to appropriate learning and skills programs.

According to these goals all children, independently of their needs, should have access to appropriate education by 2015. Effective interaction and communication are an essential part of this education and a response to children's and families basic needs. Although many changes have been doneto accommodate children with severe disabilities including PIMDin education programs, we are far from having a general and consistent approach to the education of these children, including the role of communication in the whole process. There are no clear models of intervention and certainly still some confusion about goals to achieve (Carpenter, et al, 2010). The duality of functional versus developmental approaches, far from having clarified the routes to take,has brought an enormous amount of confusion when one has to define goals and priorities for children with PIMD.

The concept of complex communication needs (CCN),and how to support communication development in children with CCN, has also changed due to several factors. One is a better understanding of what are communication needs; the other is aprogressively clearer concept of communicationas a result of effective use of a language system between two (or more) people, as opposed to the ability to use speech.

We must respond to the communication needs of children who may never use a language system properly and who do not use speech to communicate. Children with PIMD have a massive lackof communication experience and their access to sensory information is reduced,fragmented and difficult to process.They havereduced opportunitiesfor interaction with different and meaningful environments,and no individual systemaimed at replacing speechcan be considered as an effective wayto address their communication needs.In many cases children with PIMD do not recognize adults or objects. Communication intervention must therefore start at a very early point in development, and its first goal should be to create ground for communication by developing early interaction skills as a starting point for further communication and learning.

Early intervention professionals are becoming more attentive to the

early communication behaviorsand they value quality interactions more than before. Most of all, and particularly when working with the population with PIMD, professionals learn to value any behavior as having a potential for communication(Sigafoos et al, 2000),and respond to early behaviorsas the initiation of an interaction process. Parentsand other communication partnersare therefore encouraged to interact with their children,encourage initiations,develop turn taking,and explore attention to people and objects, before they are asked to use any system to communicate with them.Parents tend to do this spontaneously with their normally developing child,but it turns into a quite difficult job when dealing with children with PIMD.

Parents and team work

There have been important changes in the way families get involved and participate inthe lives of their children with disabilities. There is greater awareness of the needs of such children and important changes in children's image werebrought by the Unesco Education for All Act (UNESCO, 1990), giving parents a stronger background to fight for the rights of their children. Parents associate now a days to fight for such rights.

Last but not least, the changes observed in professional team work have been improving the way families are addressed by services.The way teams have been supporting and cooperating with parents to help them fully participate in the decisions about their children encourages change, giving parents a sense of being part of a group who takes care of their children and a positive image of themselvesin the process.

Communication, as one of the areas which parents are repeatedly concerned about, is getting into the agenda of the professionals as a topic which requires their specific attentionand certainly more training (Marvin, Montano, Fusco, Gould, 2003). It is no longer enough to identifylow or high technologyto help children express themselves. Good intervention needs:

to support the development of effective interaction skills, including in itiation and turn taking a comprehensive way to support understanding and interaction with activities in meaningful environments effective means of communication to support both comprehension and expression. Such intervention should include the training of partners who can communicate with children at their level of attention and interests, and who can properly plan intervention in the communication domain. (ACN, 2009)

Hopes for the future

Improved sensory opportunities

Limitations in the amount and qualityof the sensory information received, as well as difficulties in processing such information, severely impact on children with PIMD. To these days, education has not been able to properly assesshow differences in the way information is presentedinfluences persons with PIMD and contribute to a better understanding of the world around them. Such difficulties severely affect communication.When the sensory input is not properly interpreted there is little chance that children

can understand the world,whichseverely impactson their interactions and communication opportunities. They do not understand realityand therefore cannot express themselves aboutthe reality around them.

Research which looks at physiologic responses to sensory stimuli (Lima, Silva, Amaral, Magalhães, &de Sousa, 2011) leads us to understand that even in the absence of detectable behavior responses, children with PIMD respond differently to different stimuli, and there can be made an appreciation of the pleasantness and unpleasantness of such stimuli. Such a line of researchmay help professionals identifythe quality and quantity of stimuli that best fits each child.

The measurement of brain activity for Event Related Potentials (ERP) has also proved to be a useful assessment instrument (Brinkman, 2009). An important advantage of the ERP Methodist heability to assess sensory and cognitive information processing independently from behavior.

Increased communication and access to social environments

For children with PIMD communication is a particular challenge.Their limitationsin movement and in cognitive ability result in less involvement in meaningful activities, reducing opportunities for diversified experiences which, in turn, may support concept development. Due to their unique abilities, most potential communication partners do not know how to approach these children properly.

Empirical evidence shows that communication interactions with these children are often short in the number of turns, fragmented, limited in the diversity of topicsand with an important lack of concepts behind. Often children are exposed to a large quantity of oral language which they have no way to understand (Amaral, 2002). Varge (2006) showed that the communication behaviors of partnersare not consistently directed to the child and are often reducedto statements or commands.It also shows that many attempts to talk to the childare not contextualized.

Still, it is our beliefthat children benefit from effective interactions and involvement in meaningful activities, during which communication happensat their level of interests and needs.

Hopes for the future, therefore, include:1) a new vision of communication for children with PIMD,which looks at interaction and communicationas unique for each child, 2) the use ofcontextualized person to person interactions and diversified experiencesas a support for communication3) the need to select concepts to develop before using labels to name it; 4) the need for effective communication partners and,5)a careful identification of the environments which are part of the life of each child in particular.

A vision of total inclusion may not be the best way to address the education of children with PIMD. These children deserve to be included in environments which they can recognize, which make them feel safe and happy,and which contribute to the development of their skills.This may not go beyond the family house and the school environment, along with one or two community environments which become frequent be-

cause the family or the school uses it often. Each of these environments should become meaningful both because of the activities children are involved in, and also because of the personal interactions they develop in such environments.

By making sure that children feel comfortable, safe and involved with the environments at their own level of interests and abilities we can contribute to an increased well being.

Increased participation of the society

Many of the children with PIMD are still invisible. The community in which they liveis, often, not too involved in their lives.Although experiences may be different according to different cultures, in many cases these children attract pity and a feeling of helplessness.Inclusion is adesirable strategy but schools must change in the proportion of these children's needs.Participation in school activities is helpful, but often there is not enough staff to help support participation of children with PIMD in everyday activities. Actions for changing this situation include a movement from awareness of the disability to active involvement of the community in the life of children with PIMD. The community must change, not only the child. Therefore we must look carefully at person-environment interactions and activity opportunities, and provide for effective environment adaptations including choice opportunities and training of communication partners, if we want to contribute to an active involvement of children with PIMD in their communities.

Efficacy of interactions among all participants in children's lives

Children with PIMD require a large amount of servicesand staff to help make their lives meaningful, safe and comfortable. In many cases, the amount of people involved with this population can be quite large, and parents often feel lost, moving from professional to professional, from hospital to hospital, in hopes they get the answers they need. The information they get is not always coincident, leaving them frustrated and discouraged.Team work andcooperative teamsneed to stand strong near parentsand fight for better interactions among professionals.This helps families reduce their feeling of loneliness and helplessness, and it also contributes to help families understandthe needs of their childrenand be sensitiveto their role in theirlives. Comfort, confidence and a sense of being able to cooperateare very strong allies for good communication between parents and their children with PIMD.

Research and evidence based practice

For the last ten years, a sound amount of studies have come to light, looking at various problems related to the development, communication and education of children with PIMD. (Arthur-Kelly, Foreman, Bennett &Pascoe,2008).

Research centers still resist conducting research with limited numbers of casesand often the limitations imposed by ethic committees create serious difficulties to researchers (Boxall, 2010). Still, if we want to move forward and

contribute to a better understanding of the needs and abilities of children with PIMD there is need for more research, particularly in what concerns communication.We do not know how far can children with PIMD develop in their communication abilities but we certainly know that this depends on qualified and sensitive partners as well as challenging environments.

We also do not know yet how to help some children move from a person to person interaction to a joint attention interaction in which they pay attention to environments and interact with it.This is crucial for communication and development and certainly moves children from an emotional person to person interaction to interactions about activities, places and people around them.

There is also not enough researchon the level of language understanding of children with PIMD who have normal hearing. That is particularly importantas we need to define what level of language should partners use when working with each child in particular.

Research needs to address such questions, so that intervention can be supported by evidence which, in turn, clarifies assessment results and helps identify adequacy of methods used.

Conclusion

We reviewed some of the concerns posed by the population of children with PIMD who is now a days coming to schools and centers. Families trust professionals to be able to provide support and help their children progress in development, learning and quality of life. But none of these goals can be achieved without the development of an effective communication between the child and the parents or other significant partners, as well asa well-designed communication plan for the child.

Encouraging research helps us understand that this population can benefit from adapted intervention which helps create a meaningful life in stimulating environments.We need more research and we certainly need more teams interested in bringing upfront their experiences, their achievements and their questions, so that research can be encouraged and better education opportunities provided for children with Profound Intellectual and Multiple Disabilities.

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РЕЗЮМЕ

КОММУНИКАЦИОННЫЕ ПОТРЕБНОСТИ ДЕТЕЙ С ГЛУБОКИМИ И СЛОЖНЫМИ НАРУШЕНИЯМИ РАЗВИТИЯ

И. Амарал

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В статье обсуждаются теоретические подходы к пониманию коммуникативных потребностей лиц с глубокими и сложными нарушениями, проблемы их развития и соответствующее обеспечение их потребностей, роль коммуникации и новые тенденции в предоставлении им профессиональных услуг.

ԱՄՓՈՓՈՒՄ

ԾԱՆՐ ԵՎ ԶԱՐԳԱՑՄԱՆ ԲԱՐԴ ԽԱՆԳԱՐՈՒՄՆԵՐՈՎ ԵՐԵԽԱՆԵՐԻ ՀԱՂՈՐԴԱԿՑՄԱՆ ՊԱՀԱՆՋՄՈՒՆՔԸ

Ի.Ամարալ

Սեփուբալի ճարտարագիտական ինստիտուտի պրոֆեսոր, փիլիսոփայության դոկտոր, հաղորդակցման խանգարումների մասնագետ, կրթության խորհրդատու, Պորտուգալիա

Հոդվածում քննարկվում են զարգացման ծանր և բարդ խանգարումներով անձանց պահանջմունքների ընկալման տեսական մոտեցումները, նրանց զարգացման խնդիրները, հաղորդակցման դերը և տրամադրվող մասնագիտական ծարայությունների նոր մոտեցումները: