Quality indicators in the education of children with Profound Intellectual and Multiple Disabilities

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Resumo

Todas as crianças, independentemente das suas necessidades, deveriam ter acesso a uma educação de qualidade e a serem incluídas nas suas famílias e comunidades. Esta afirmação inclui as crianças mais vulneráveis, em particular as crianças com dificuldades intelectuais e multideficiência. Os resultados da investigação sobre a educação de crianças com dificuldades intelectuais e multideficiência ainda não produziram até ao momento informação suficiente que possa ser usada para desenvolver indicadores de qualidade para a avaliação das práticas e dos serviços. A investigação nesta área é limitada por constrangimentos éticos, dificuldades na determinação de amostras e desafios metodológicos, sendo reduzido o número de estudos capaz de produzir a informação necessária. Este artigo tem como objetivo discutir fatores que contribuam para a qualidade do envolvimento de crianças com dificuldades intelectuais e multideficiência em atividades educativas, com base na experiência das autoras e na informação disponível que tem sido publicada sobre este assunto. Com base nesta discussão é sugerido um conjunto de indicadores que poderão ajudar os profissionais a dirigir as suas observações para a qualidade da oferta educativa e para aspetos significativos dos desempenhos das crianças quando envolvidas em atividades curriculares.

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Abstract

All children, independently of their needs, should have access to appropriate education and be part of their families and communities. This includes the group of most vulnerable children, particularly those with Profound Intellectual and Multiple Disabilities (PIMD). Data on the education of children with PIMD has not, as yet, provided enough quality information which can be used to develop effective quality indicators for assessment of services and practices. Research in this area is limited due to ethical constraints, sampling difficulties and methodological challenges, reducing the number of studies which could properly provide information. Still, the need to provide evidence based practices which effectively contribute to the assessment of development and learning offerings for children with PIMD requires more in-depth discussion of both the goals of education for these children and the contents of assessment instruments that help to identify the quality of the education provided. This article aims to discuss factors which contribute to the quality of involvement of children with PIMD's in educational activities, as a result of the authors' experience and the available information published around the topic. Based on this discussion, a set of quality indicators is suggested, which may help professionals to direct their observation into the quality of the educational offerings and meaningful aspects of the child's performance while involved in curriculum activities.

Keywords: Profound intellectual and multiple disabilities, participation, communication, activity based intervention, quality indicators.

Résumé

Tous les enfants, indépendamment de leurs besoins, devraient avoir accès à une éducation appropriée et faire partie de leurs familles et communautés. Cela inclut le groupe des enfants les plus vulnérables, en particulier ceux ayant un polyhandicap sévère. Les données sur l'éducation des enfants avec polyhandicap sévère n'ont pas encore fourni d'informations de qualité suffisante pouvant être utilisées pour développer des indicateurs de qualité efficaces d'évaluation des services et des pratiques. La recherche dans ce domaine est limitée en raison de contraintes éthiques, difficultés d'échantillonnage et défis méthodologiques, réduisant le nombre d'études qui pourraient correctement fournir des informations. Pourtant, le besoin de présenter des évidences basées sur des pratiques qui contribuent efficacement au développement et à l'évaluation de l'offre d'apprentissage pour les enfants polyhandicapés nécessite une discussion plus approfondie à la fois des objectifs de l'éducation pour ces enfants et du contenu et des instruments d'évaluation qui aiderait à identifier la qualité de l'enseignement dispensé. Cet article vise à discuter des facteurs qui contribuent à la qualité de la participation des enfants atteints de plolyhandicap sévère à des activités éducatives, à la suite de l'expérience des auteurs et des informations disponibles publiées sur le sujet. A partir de cette discussion, un ensemble d'indicateurs de qualité est suggéré, celui-ci peut aider les professionnels à diriger leurs observations sur la qualité de l'offre éducative et les aspects significatifs de la performance de l'enfant participant à des activités pédagogiques.

Mots-clés: polyhandicap sévère, participation, communication, activité basée sur l'intervention basé, indicateurs de qualité

INTRODUCTION

Children with disabilities, particularly those with Profound Intellectual and Multiple Disabilities (PIMD) have the right to appropriate treatment and education, in safe and welcoming environments which contribute to their quality of life. Providing adequate education and quality of life for children with profound intellectual and multiple disabilities is, therefore, in the agenda of all developed countries.

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 applicable for a valid estimation of their level of intellectual capacity and who often have profound neuro-motor dysfunctions". In addition to profound intellectual and physical disabilities, it has been demonstrated that individuals with PIMD frequently have sensory impairments. These children are a physically very vulnerable group of persons with a high dependence on personal assistance for everyday tasks, 24 hours a day (PIMD-SIRG) (Nakken & Vlaskamp, 2002; Nakken & Vlaskamp, 2007).

As a result of progressive changes from medical oriented to ecologically oriented approaches, the concept of disability is no longer defined just as the result of the degrees of cognitive, sensory or motor abilities. Grounded in Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1979), the concept of disability is regarded, nowadays, as a reduced opportunity for interactions between the person and the environment (Buntinx & Schalock, 2010), with a particular emphasis on the ability to access, explore and participate in diverse environments, including the ability to interact with people in those environments. Disability is, therefore, not inherent to the individual and his or her medical condition, but arises as the result of interactions between the person with impairments and features of the socioeconomic environment in which the person lives (Nakken & Vlaskamp, 2007). Despite the challenges of their disabilities these students should, therefore, be involved in the family life, participate with peers in school activities, and have opportunities to participate in activities of the community."

Research on person-environment interactions (Jahiel & Scherer, 2010) discusses the need for analysis of the various types of interactions subsequent to both the identity of the subject and the reactivity of the environment during interaction. This carries along the need to describe and to assess, not just children's characteristics and abilities, but also the results of children's interaction with the environments in which they are immersed. Education of children with PIMD should therefore, and following this concept, consider the need to assess and evaluate children's and environments' abilities to interact with each other, bearing in mind that it is not the level of stimulation that is relevant, but the degree of responsiveness to the user and the context in which it occurs (Barber & Goldbart, 1998) that supports participation.

Several questions rise from these changes, one being the *type of educational curriculum* and *educational setting* for children with PIMD. If these children are to be included, schools need to define the type of inclusion that supports, not just development and learning, but also the levels of happiness and quality of life.

Two concepts seem to be useful to design approaches and identify curriculum activities, while discussing the inclusion of children with PIMD in school settings. One is the concept of a Universal Design for Learning which includes multiple means of representation allowing various ways of acquiring information and knowledge and multiple means of expression to allow alternatives for demonstrating knowledge, (Orkwis & McLane,1998), as well as multiple means of engagement to challenge appropriately, to motivate, and to allow learners to express and participate in their interests (Rose & Meyer, 2002). A second important concept is the concept of Functional Curriculum for PIMD (Lyons, 2003) which holds education responsible for supporting involvement and participation in meaningful activities, along with an investment in quality of life and happiness for these children,

Another question relates to the *type of inclusion* which best benefits these students. Lyons and Arthur Kelly suggest that of all the types of inclusion offered in schools, a pathway to quality of life inclusion is recommended (Lyons & Arthur-Kelly, 2014), ensuring that children have: 1) opportunities for meaningful participation in family, school and community activities, 2) an appropriate education which responds to their individual needs and, 3) ongoing support built around quality person to person interactions.

Based on the identification of such guidelines, another question emerges, related to the need to identify the *quality of life and levels of happiness* of children with PIMD in school settings. Although extensive research demonstrates that all children can learn better if they are happy and motivated (Green & Reid, 1996; Singh et al., 2004), not all programs for students with disabilities, particularly children with PIMD, aim at increasing the quality of life and happiness levels of the students they serve.

A final question relates to the *interactions developed between children with PIMD and their partners.* Children with PIMD require ongoing support, which means that professional and committed trained people must interact with these persons on a daily basis, as mediators who encourage interactions between them and the activities in which they participate. This requires abilities in person to person interactions which call for specialized training (Singh et al., 2004). In any case, there is a need for quality indicators which help to assess educational offerings and to improve education, providing children with quality educational options and life style.

Quality indicators in education usually examine a range of factors which include *contextual factors* such as the politics of education, *input factors*, such as the quality of teacher qualifications or the accessibility to instructional materials, *process factors*, which relate to activities provided by the school or the quality of planning, and *output factors* which describe students achievements and results., (EQAO, 2015).

This article presents an effort to identify quality indicators aimed at analyzing *process factors* through the analysis of educational activities included in educational programs for children with PIMD. In doing so, we considered the following topics: 1) children's needs, 2), engagement and participation in activities and, 3) activity management. Based on a

theoretically grounded discussion of these topics we present a set of quality indicators which may contribute to assessing the quality of school activities provided to children with PIMD and, eventually, set the basis for future research in the quality of educational offerings for these students.

CHILDREN'S NEEDS

Children with PIMD are included in the larger group of children with Multiple Disabilities, which represent a heterogeneous population with concomitant intellectual and sensory, communication, motor, behavior and health impairments who often lack effective communication skills, expressed by the use of idiosyncratic behaviors or have problems with understanding spoken language (Orelove & Sobsey, 1991). Their motor disabilities require ongoing appropriate positioning, and they experience difficulties with personal care activities like eating, grooming, dressing etc. They have difficulties in generalizing skills and transferring information from one situation to another. They may exhibit self-stimulatory behaviors (e.g., repetitive body movements) and self- injurious behaviors. Some of them have problems in visual or auditory functioning or combined. Sometimes medical problems like epilepsy, or respiratory problems are present. The combination of these problems identifies the need for ongoing, extensive support within their daily routines. Such combination results in specific educational/learning needs some of which are summarized in Table 1.

Table1 - Children with PIMD's educational needs

Predictability and consistency	Functional goals embedded in meaningful activities	Optimal level of support	Learning in natural environments
Organized environment	Effective communication system	Meaningful outcomes	Meaningful topics
Opportunities for generalization	Enough time for learning	Skillful educator/communication partner	Learning useful skills and concepts
	Being happy	Expressing pleasure when involved in activities	

Educational options for children with PIMD must consider these needs and identify them in the context of daily life activities, to make sure that strategies are implemented and their needs answered. Deciding which activities should be included in the child's program and how can these activities better respond to the needs of children with PIMD is, consequently, an important step in educational planning.

ENGAGEMENT AND PARTICIPATION IN ACTIVITIES

Children´s development largely depends on their ability to explore environments and get involved in activities, as well as on the interactions developed with people in those environments. Limitations shown by children with PIMD´s reduce opportunities to explore environments independently and to interact with communication partners in those environments, requiring supported involvement in activities and adapted means of communication. Although Thompson and Guess (1989) state that teaching functional skills can be quite difficult when working with this population, involving them in everyday life activities has a greater probability of success than trying to teach them isolated skills not embedded in an activity.

The International Classification of Functioning, Disability and Health, of the World Health Organization (ICF-WHO, 2007), states that the classification of a disability should include an analysis of the levels of participation in life contexts shown by an individual. This concept of participation identifies the need, not only to perform isolated tasks but also to get involved in everyday life situations (Grandlund, 2013). Participation in an activity includes, therefore, the ability to perform the activity within a context, as well as the level of involvement that children show in the activity, how they like the activity, and how meaningful it is in the context of their daily lives. Education should, therefore, look at the levels of participation in everyday life situations as an indicator of quality of services.

Active participation of children with PIMD in everyday life activities can be linked to four types of subjects: 1) the quality of environment offerings 2) the levels of attention and engagement in the activity, 3) the opportunities for control over the environment and, 4) the quality of interactions with adults and peers in the environment (Arthur-Kelly, Bochner, Center, Mok., 2007). Although these issues are interrelated, it is worth analyzing it in detail, if we want to identify factors which may contribute to the quality of participation in activities.

Quality of environment offerings

The ability to understand contexts, including the role of objects and people in such contexts increases meaning and facilitates understanding (Oliva & Torralba, 2007). Nevertheless, the cognitive challenges, motor disabilities and limited communication abilities of students with PIMD severely reduce opportunities for incidental learning and context understanding. Children with PIMD, when left alone, do not actively explore environments, leaving to families and educators the task of providing them with opportunities to learn about the world around them.

Positioning is a major issue when working with children with severe motor disabilities. Not all positioning promotes the best behavior states or the best opportunities for attention and engagement in an activity. Although there is still not enough information on the relationship between the quality of learning and positioning, a study points out (Arthur, 2003) to the fact that children with PIMD spend a lot of time sitting in their wheelchairs. The sitting position seems to be associated with alertness states (Guess et al.,1993), requiring that a good sitting position is guaranteed before starting and activity.

The need to use the sitting position, as well as the limitations in active movement of children with PIMD, carries along reduced opportunities for movement, which can limit environment awareness, particularly in children with visual impairments. Although research in this area is still virtually inexistent with this population, normal development indicates that children need to move and to explore the world. Grasping the full content of an activity requires children to actively move around and search for necessary materials, as well as to plan their movements in order to perform actions during the activity (Amaral & Lolli, 2011) Assisted movement, as a way to explore the environment with children with PIMD, facilitates access to the whole activity and helps taking the child through all the steps or tasks in an activity. In this process, the teacher is a mediator between the complex world that surrounds a child and the child's level of understanding, thus making environments a more meaningful place.

Levels of attention and engagement

The participation construct identified in ICF should include, as we said before, not just the ability to attend to an activity, but also the ability to get involved while attending (Grandlund, 2013). Maxwell (2012) suggests that "frequency of attending and doing an activity are strongly related to the availability and accessibility of the environment, while the degree of involvement while being there is strongly related to how well adapted and acceptable the activity is for the child and others in the close environment."

In order to reach an optimal level of involvement, *states of alertness* need to be taken into consideration. Alertness is described as the level of an individual's interaction and engagement with the environment (Munde, Vlaskamp, Maes & Ruijssenaars, 2014). In children with PIMD alertness levels vary throughout day and are influenced by various internal and external factors. Alertness can be assessed through eight different stages: inactive sleep, active sleep, drowse, daze, awake inactive-alert, awake active-alert, awake active-alert with stereotypy and crying/agitation (Simeonsson, 1988). Previous studies have revealed that stimulation might have a greater impact on levels of alertness than the internal conditions of the individual, and emphasized the importance of interaction in order to influence the level of alertness (Green, Gardner, Canipe & Reid, 1994). By carefully observing alerting levels teachers identify the right moment to offer an activity. Alertness can be observed in relation to different conditions of environment like: opportunities for interaction with people in environment, the level of class activity, materials availability and positioning of a child. Alertness level can be regulated through these aspects of environment (Munde, Vlaskamp, Ruijssenaars & Nakken, 2009).

Another aspect which is guiding the design of interventions for children with PIMD is the *level of attention* during activities. Attention episodes can be evaluated on the continuum from no attention toward shared attention (Hostyn, Daelman, Janseen & Maes, 2010). Individuals can direct their attention toward another partner, toward an object, or they can share attention between the object, action or event, and the person involved in it, that is, joint attention. Joint attention is considered as one of the most significant developmental achievements, but many students with profound and multiple disabilities experience difficulties in coordinating attention to people and objects, actions or events in environment. This ability is co-created and represents an outcome of interpersonal relationships (Ine, Heleen & Bea, 2011). Neerinckx, Van Den Noortgate, and Maes, 2014), again calling attention to the quality of interactions developed.

Finally, *engagement* can be taken as an important indicator of the relationship between the individual and his environment and subsequently as a measure of quality of participation in activities within an environment. Engagement is defined as "the amount of time children spend interacting with the environment (with adults, peers, or materials) in a developmentally and contextually appropriate manner" (McWilliam & Bailey, 1995; Ridley, McWilliam & Oates, 2000). Engagement behaviors can vary from simple to more complex and need to be constantly monitored. The goal of educational programs for children with PIMD must include an increase in the child's total amount of engagement as well as the level of engagement shown. This can be done by an analysis of the environment in which the activity is performed, defining the type and appropriate level of support, providing the structure for learning and meaningful outcomes, adapting complexity to level of understanding and ensuring effective communications system.

Opportunities for environment control

The ability to understand and have control over the environment is considered as a key point in the education of students with profound disabilities (Schweigert, 1989; O'Brien, Glenn & Cunningham, 1994) as it helps develop expectations and increase activity and self-esteem. Although many children with PIMD do not have an opportunity to initiate movements and activities independently, they can show awareness of contingencies (Saunders et al., 2003) which may lead to having control over their lives in adapted environments, therefore being able to choose preferred objects, people or activities, as well as initiate actions related to activities.

The quality of interactions

The role of teachers of children with PIMD is changing from a traditional view of a provider of decontextualized and fragmented skills in isolated settings to an interactive approach based on meaningful activities (Bricker & Cripe, 1992). Along with that, the need to look at participation as a qualifier of people's abilities (WHO, 2007.) identifies the need not only to select activities in children's programs, but to also to consider how students pay attention and get involved in such activities.

The results of interactions between adults and children relate to the quality of the feedback and instruction provided (Mc William, Scarborough & Kim, 2003; Almqvist ,2006). Research has shown that levels of happiness increase, not just with the quality of offerings but also with the social interactions which go along with such offerings (Davis, Young, Cherry, Dahman & Rehfeldt, 2004).The quality of interactions between teacher and child, as well as factors contributing to such quality, should therefore be discussed.

Effective communication can be ensured by taking into account :1) the student's level of interaction, 2) different communication modalities, (body movement, gestures, objects or pictures, used to represent people, places, activities), 3) various functions (requesting, refusing, greeting, making choices, commenting, etc.), and 4) the selection of motivating topics to help build meaningful relationships.

Person to person interaction (Lock, 1999) features many interactions with children with PIMD and it is considered as a good starting point for intervention (Neerinckx, Vos, Van Den

Noortgate & Maes, 2014). It can be facilitated through interactive approaches like Intensive Interaction which is becoming widely used in interaction with children with PIMD (Nind & Hewett, 2012) or resonance (van Dijk, 1986.) which means that the teacher provides resonance to children's behaviors by imitating his/her behaviors. In both cases, the teacher follows the child's lead and exchanges are not focused on a specific topic or outcome. Although social interaction (person to person) is an important basis for the development of further interactive skills, content turn-taking (Amaral, 2003) needs to be explored and extended whenever teachers want to introduce and explore meaningful topics derived from real life activities.

Encouraging children to initiate interactions helps them develop a sense of control over the world. Initiation is encouraged by contingent responding to a child's behavior, and allowing enough time to respond or to initiate a turn (Amaral, 2003). Activities can be planned to include opportunities for the use of various communication functions, while pacing interactions so that children have an opportunity to understand the meaning of the activity. Teachers need to encourage interactions to include more turns by responding and expanding on 'learners' turns and by including in such interactions meaningful topics that provide content and support further learning (Amaral, 2003). By joining into the child's activity the teacher can sensitively expand topics and include more turns while referring to the features or use of objects, necessary movements, and people in the environment to the added conversation. In such interactions, shared meanings are co-created within an activity which supports the development of meaningful language (Nafstaad & Rodbroe, 1999). A careful selection of activities helps establish meaningful relationships, through choosing people in specific environments who can become communication partners.

MANAGING ACTIVITIES

Quality of life requires a balance between different life domains such as activities of daily living, domestic, educational, cultural, leisure, and occupation. Each of these domains should be part of the child's life as activities can happen in different environments like home, school and community.

There are many activities going on in a child's life, some of them happening on daily basis and some others not as frequent. More frequent activities in child's life can include *learning purposes* whereas others may be just *participation* activities that seek to involve the child in naturally occurring situations in the contexts where they live. Participation activities contribute to making the life of students more meaningful (Amaral et al., 2006) and to enlarge knowledge about the world in which they live (Barber, 1998).

Special consideration should therefore be given to the selection of appropriate activities which contribute to supporting students become active and engaged in meaningful contexts, while looking at the efficacy of interventions as "enhancing, supporting, improving and optimizing participation outcomes" (Grandlund, 2013). In cooperation with parents, environments are analyzed and activities that can be included in those environments are identified.

Activity-based intervention (Bricker & Cripe, 1992), as an identified approach to implement activities under curriculum options, is defined as a "child-directed, transactional approach that embeds intervention on children's individual goals and objectives in routine, planned, or child-initiated activities, and uses logically occurring antecedents and consequences to develop functional and generative skills." According to Pretti-Frontczak and Bricker (2004) the common points of such approach are: 1) Choosing activities according to the child's interests, 2) Teaching individual goals embedded in routines and planned activities, 3) Teaching functional and generalizable skills, 4) using before and after behavior stimuli which have natural and meaningful relations with behaviors and environment.

The use of an activity-based intervention in educational planning for children with PIMD allows meaningful participation in everyday life situations including meaningful interactions with people in the environments where activities take place. In activity-based approaches, everyday life situations become the context for learning (Tellevik & Elmerskog, 2009). Within this approach, developmental, learning and functional goals can be embedded in naturally occurring activities helping children build a framework for their understanding of the surrounding world.

Understanding the result of an activity makes activities meaningful and increases participation. Activities with clear and likable result are more motivating (example: exploring ingredients in the context of preparing a favorite cake in the kitchen is more meaningful than exploring it separately in the classroom), suggesting that education should be guided by outcomes or achievements and not just by skill abilities. Products of an activity (example: baking a cake) are tangible and could be used in another activity (having dessert, for example) or be compared with cakes in different environments (home, bakery), in different occasions (birthday cake) or with different flavors (sweet vs. salty flavor). Teaching the process of baking a cake can start with experiencing the product (eating the cake) so the child knows the result of the activity, which helps keeping him motivated and engaged.

A note should be made on activities related to the educational domain. Although limited information exists on academic goals while working with children with severe disabilities, Bobzien (2014) suggests that involving children with PIMD in academic activities increases their levels of happiness. This may lead education to include more academic tasks embedded in naturally occurring activities, as Collins reinforces while referring to the need to incorporate core curriculum contents in naturally occurring activities. (Collins, 2012, p. 122)

Choosing activities in children's life should focus on those activities that are happening frequently, possibly on daily basis and in different contexts, thus providing more opportunities for repetition and application of functional skills (Tellevik & Elmerskog 2009). Setting a schedule of frequent activities where balance between different domains is achieved provides a safe and predictable framework that can be planned and skillfully expanded. Such frequency helps skills´ generalization and concept development, which are some of the main challenges when teaching a child with complex combinations of disabilities.

Janeslätt, Grandlund and Korttorp (2009) identified time processing abilities as a possible conditioning factor in daily time management. That suggests the need for a limited number of activities per day as an educational measure to support students' needs of additional time to process information. Activities developed must ensure that children have both a way to

understand what is going on, and an opportunity to participate and have control (directly or indirectly) over the environment.

Teacher of children with PIMD should be able to reflect and critically evaluate what, how and why the child does what he does, and how education can contribute to enhancing their abilities. By sharing his work with other professionals and parents, besides empowerment, teachers contribute to building supportive learning environment for all participants in the educational process

Implications for practice

The ability to translate theory into practice is necessary when looking for a sound evidenced-based approach to education of students with PIMD. Although there is not much information concerning the results of teaching and the strategies to teach such a population, it is necessary to analyze intervention and education in order to be able to produce information on the kind of educational needs of these children, and how well this responds to the needs of the children.

The identification of quality indicators for school activities as a way to help professionals decide not just on the activities they provide, but also on the quality of interactions among students, activities and the people involved in the activities, can promote inclusion, happiness and, indeed, better quality of life for students with PIMD.

Based on the discussions above, Appendix I proposes a set of quality indicators which support assessment of education, particularly assessment of quality activities for children with PIMD. It should be noted that such a set of quality indicators is not designed to assess the child but to document to which extent the needs of the child are provided for during an activity.

Future studies regarding education of children with PIMD can help validate content and structure of this checklist and draw conclusions regarding its usefulness.

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