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The inclusion and education of pupils with PIMD: What contributions from special institutions?

Mélodie Bourger-Bouveret^{1, 2}, Esther Atlan² & Minna Puustinen²

¹ Paris Nanterre University, France

² Grhapes, INSHEA, France

Abstract

Children with profound intellectual and multiple disabilities (PIMD) are generally considered to have the highest and most complex support needs. Their education is often provided in 'special' classes or schools, but many still do not have such opportunity (Lyons & Arthur-Kelly, 2014). In France, the drive for inclusion has led to new coalitions between institutions administered by the separate Ministries of Education and Social Affairs. A paradigm shift is occurring, with staff from specialised institutions being deployed within mainstream schools to support the education of pupils with PIMD in special classrooms. The implementation of these arrangements requires close coordination between professionals from distinct communities of practice. To better understand this phenomenon, a focus group study was conducted in a specialised institution. Nine professionals working with children with PIMD (i.e., educators, carers, social and educational workers, and a service manager) participated in a semi-structured group interview. Data were collected on the representations of work (e.g., type of activities, duties, norms or values) and on educational practices (e.g., strategies, methods, attitudes or gestures). This interview was audio and video recorded for verbatim accuracy, and a thematic analysis was conducted on the transcripts. Results highlight a representation of the activity as being based on care and education for autonomy and necessarily reflexive, whereas the educational practices are anchored on both high-quality relationships and a deep understanding of the children's needs. Through an overview of their practices, this preliminary study illustrates some of the possible contributions of professionals from specialised institutions to inclusive education.

Extended summary

Introduction

The inclusion and education of students with profound intellectual and multiple disabilities (PIMD) remains a major challenge for most public policies but also for the practices of both schools and disability services (Lyons & Arthur-Kelly, 2014). Children with PIMD face many barriers in learning due to the severity of their cognitive, motor and/or sensory impairments and significant health problems (Bellamy et al., 2010). Nevertheless, considerable research efforts have recently led to the specification of a framework and key indicators for quality education (Maes et al., 2020), and previous

work has shown that inclusive environments lead to better social participation outcomes (Foreman et al., 2004; Nijs & Maes, 2014). In several countries, meanwhile, children with PIMD remain excluded from school education as they fall under separate institutional systems (Slee, 2008). In compliance with UNESCO's guidelines for inclusion in education (2009), many public policies now address this issue. However, their implementation can be challenging, as they may conflict with prevailing measures based on the segregation of general and special education. Unaccustomed to complex disabilities, mainstream schools may struggle to meet high support needs, while specialised services may be reluctant to engage with inclusion if they previously worked in silos (Sailor, 2008). In France, children with PIMD were until recently largely deprived of formal education (Bryon, 2020), leading the government to make this issue one of the main priorities of the last five-year strategy for the improvement of disability services (Secretary of State for Persons with Disabilities, 2017). This resulted in new measures for pupils with PIMD, such as the provision of dedicated classrooms in mainstream schools. These arrangements involve new partnerships, as professionals from specialised institutions are mobilised alongside teachers to provide special care and educational assistance. Previous research has produced a detailed review of French teachers' practices towards pupils with PIMD (Toubert-Duffort et al., 2018), but no data were available regarding the practices of staff working in specialised institutions. Further research is needed to support the implementation of these programmes, particularly with regard to coordination between the professionals involved.

Methodology

A focus group study (Kitzinger, 1995) was conducted in a specialised institution for children with PIMD, with the participation of nine of its professionals (i.e., four educators, three carers, two social and educational workers, and a service manager). The 105-minute interview was audio and video recorded and structured around a list of open-ended questions covering the professionals' representations of work (e.g., type of activities, tasks, norms or values) and educational practices (e.g., strategies, methods, attitudes or gestures). The data were transcribed using the Amberscript software and corrected from the recordings which were then destroyed. Finally, a thematic analysis was conducted to extract salient themes and sub-themes from the verbatim data. Results are presented along two dimensions, namely the characteristics and determinants of staff activity and professional practices related to the learning of children in educational activity.

Results

The staff activity dimension is divided into three themes, namely main orientations and values, reflexivity on practices and organisational determinants. Results suggests that professionals conceive their practices as an interrelated combination of proximal care and education for autonomy. The severity and complexity of children's disabilities often expose them to uncertainty about the outcome of their actions. This difficulty is addressed through a reflective approach to practice, in which three

components are identified: active observation in various contexts, ongoing self-examination through action and reliance on cross-checking. These are related to ethical values and prevention of emotional distress or burnout, and seem to depend on organisational context. The educational practices dimension is divided into four themes, namely individual educational planning, environmental settings, adaptations and supports for learning activities, and identification of optimal learning moments. Results suggest that educational planning is both highly individualised and on-going, with a primary focus on autonomy. Professionals perceive affective continuity as an essential feature of learning environments, along with the reduction of external stimuli or the accessibility of educational contents. Support for exploration and engagement in learning is shaped by warm and proximate gestures and attitudes and linked to a deep understanding of individual needs and preferences. This specific knowledge also enables staff to recognise the optimal moments for learning, perceived as short and fleeting, and related to their students' states of attention and alertness.

Discussions

Various practices described in this study have an apparent similarity to teaching practices for students with PIMD, but are based on distinct concerns (Sailor, 2008). The care and assistance provided in specialised institutions takes place in close and continuous proximity to children with PIMD, so the professionals of those institutions have an in-depth knowledge of their specificities and needs. The proximal relationship and warm attitude nurtured by these professionals can provide a solid foundation for the quality of the classroom environment, given its impact on learning outcomes (Arthur-Kelly et al., 2007) and the need for children with PIMD to experience high quality and supportive interactions to engage in learning. (De Bortoli et al., 2012; Imray & Bond, 2015). As the identification of optimal learning moments is essential for quality teaching (Petitpierre et al., 2007), these professionals can help teachers by offering useful guidance to encourage their students to be active and alert in their learning (Munde & Vlaskamp, 2015). Finally, their reflexive approach to activity could significantly support the refinement of teaching practices, given the complexity of PIMD situations which require joint analyses based on fine and repeated observations (Atlan et al., 2020), and the considerable benefits of peer-to-peer sharing for professional learning in the teaching of pupils with PIMD (Jones & Riley, 2017). In France, as in other countries, inclusive education now involves the shared commitment of professionals from both mainstream and special contexts. This study suggests that their respective practices and knowledge could complement each other in meeting the challenge of shaping education to meet the most complex needs. Given their different backgrounds, this convergence could be strengthened by opportunities to engage in dialogue on practices, which is a prerequisite for their joint development (Engestrom, 2000).

References

- Arthur-Kelly, M., Bochner, S., Center, Y., & Mok, M. (2007). Socio-communicative perspectives on research and evidence-based practice in the education of students with profound and multiple disabilities. *Journal of Developmental and Physical Disabilities*, 19(3), 161–176.
- Atlan, E., Toubert-Duffort, D., & Puustinen, M. (2020). L'observation et l'évaluation d'élèves en situation de polyhandicap: Une nécessaire réflexion méthodologique. La nouvelle revue – Éducation et société inclusives, 88, 187–203.
- Bellamy, G., Croot, L., Bush, A., Berry, H., & Smith, A. (2010). A study to define: Profound and multiple learning disabilities (PMLD). *Journal of Intellectual Disabilities*, *14*(3), 221–235.
- Bryon, I. (2020). Polyhandicap: État des lieux de la scolarisation. *La nouvelle revue Éducation et société inclusives*, 88, 23–26.
- De Bortoli, T., Balandin, S., Foreman, P. J., Arthur-Kelly, M., & Mathisen, B. A. (2012). Mainstream teachers' experiences of communicating with students with multiple and severe disabilities. *Education and Training in Autism and Developmental Disabilities*, 47, 236–252.
- Engestrom, Y. (2000). Activity theory as a framework for analyzing and redesigning work. *Ergonomics*, 43(7), 960–974.
- Foreman, P., Arthur-Kelly, M., Pascoe, S., & King, B. S. (2004). Evaluating the educational experiences of students with profound and multiple disabilities in inclusive and segregated classroom settings: An Australian perspective. *Research and Practice for Persons with Severe Disabilities*, 29(3), 183–193.
- Imray, P., & Bond, L. (2015). Care as an educational concept. In P. Lacey, R. Ashdown, P. Jones, H. Lawson, & M. Pipe (Eds.), *The Routledge Companion to Severe, Profound and Multiple Learning Difficulties* (pp. 163–171). Routledge.
- Jones, P., & Riley, M. W. (2017). 'Trying, failing, succeeding, and trying again and again':
 Perspectives of teachers of pupils with severe profound multiple learning difficulties.
 European Journal of Teacher Education, 40(2), 271–285.

Kitzinger, J. (1995). Qualitative Research: Introducing focus groups. BMJ, 311(7000), 299-302.

Lyons, G., & Arthur-Kelly, M. (2014). UNESCO Inclusion policy and the education of school students with profound intellectual and multiple disabilities: Where to now? *Creative Education*, 05(07), 445–456.

Maes, B., Penne, A., Vastmans, K., & Arthur-Kelly, M. (2020). Inclusion and Participation of

Students with Profound Intellectual and Multiple Disabilities. In M. Nind & I. Strnadová (Eds.), *Belonging for People with Profound Intellectual and Multiple Disabilities* (pp. 41–58). Routledge.

- Munde, V., & Vlaskamp, C. (2015). Initiation of activities and alertness in individuals with profound intellectual and multiple disabilities: Initiation and alertness. *Journal of Intellectual Disability Research*, 59(3), 284–292.
- Nijs, S. L. P., & Maes, B. (2014). Social Peer Interactions in Persons with Profound Intellectual and Multiple Disabilities: A Literature Review. *Education and Training in Autism and Developmental Disabilities*, 49, 153–165.
- Petitpierre, G., Wolf, D., Dietrich, A., Benz, M., & Adler, J. (2007). Integration of Education and Care Given to Children With Profound Multiple Disabilities in Switzerland. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 141–151.
- Sailor, W. (2008). Access to the General Curriculum: Systems Change or Tinker Some More? Research and Practice for Persons with Severe Disabilities, 34(1), 249–257.
- Secretary of State for Persons with Disabilities. (2017). *Five-year strategy for the development of medico-social services, polyhandicap section*. Ministry of Social Affairs and Health. https://www.gouvernement.fr/sites/default/files/contenu/piecejointe/2016/12/strategie_quinquennale_de_levolution_de_loffre_medicosociale_volet_polyhandicap.pdf
- Slee, R. (2008). Beyond special and regular schooling? An inclusive education reform agenda. International Studies in Sociology of Education, 18(2), 99–116.
- Toubert-Duffort, D., Atlan, E., Benoit, H., Lewi-Dumont, N., Puustinen, M., & Zebdi, R. (2018). *Conditions d'accès aux apprentissages des jeunes polyhandicapés en établissements médicosociaux de l'évaluation des potentiels cognitifs à la mise en œuvre de leur scolarisation*[Research report]. INSHEA. https://hal-inshea.archives-ouvertes.fr/hal-02015513
 UNESCO. (2009). *Policy Guidelines on Inclusion in Education*. Paris.