

Mara Westling Allodi and Tamara Zappaterra (Eds.)

Users' Needs Report on Play for Children with Disabilities

Parents' and children's views

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5 Comments on the results of the Associations' and Parents' Surveys

The 75 Associations for persons with disabilities that were selected by the national coordinators in 24 countries and that answered to the survey represented a wide range of disabilities and precisely: intellectual impairments (19%), autism spectrum disorders (17%), communication/language disorders (15%), multiple disabilities (14%), physical impairments (12%), visual impairments (9%), hearing impairments (8%), and other (6%). The Associations have been chosen among the most meaningful ones within each country, however the research sample can not be considered statistically significant because it has been created thanks to the professional network of national coordinators of the research and it is not representative of the totality of existing Associations of persons with disabilities. Nevertheless, a third of the types of disability in the sample of the survey concerning the Associations (36%) and almost the half of the sample concerning the parents' survey (47%) represent the autism spectrum disorders and the intellectual disabilities. As a total, the Associations represented at least 87.000 members. 31% answered that children with disabilities in their organisation do not have the same opportunity to play, and 42% answered that they can play a little. Only 15% answered that they can play a lot. 64% thought that the parents were not happy with their children's play. These results may be considered as highly important, in terms of barriers and facilitators, a construct adopted by the *International Classification of Functioning, Disability and Health* and embraced within the COST Action "LUDI. Play for Children with Disabilities" as a theoretical and methodological model to achieve scientific, social and technological purposes (WHO, 2001; COST, 2013).

According to the comments of the Association's representatives, the facilitators of play for children with disabilities may be: adapted toys, accessible toys to loan, association resources that have appropriate spaces, facilities and trained staff, parents' creativity, purposeful planning. That is, on the one hand, the Associations require accessible and equipped environments and call for improvements of the tools of play and their greater availability and affordability. On the other hand, they emphasize the importance of a more general educational training about play of both parents and professionals. In fact, the barriers reported by the Associations are related to the lack of the same items listed among the facilitators: physical barriers, lack of accessibility and usability of the physical setting that may limit play, lack of accessible and not specifically adapted toys and games, accessible outdoor play environment – both natural and structured. Also the characteristics of the child due to his/her impairments are referred to as barriers. For this reason it would be important a widespread awareness among professionals about the developmental

characteristics of children with the different kinds of impairments, in relation to the play needs and types (Besio, Bulgarelli & Stancheva-Popkostadinova, 2017).

Most of the comments of Association's representatives about happiness/satisfaction with their children's play concerned social barriers, attitudes and behaviors. They may encompass exclusion by peers, attitudes held by teachers, professionals, parents and relatives. Four themes were identified to groups the obtained answers: discrimination, peer relations, parents' skills and human resources.

In several comments the scarce possibilities of having peer relations and the lack of friends is considered the cause of children's limited play opportunities. This assertion is confirmed by the answers to the central question of the questionnaire, related to the play needs: in fact, playmates, peers, friends are the largest reported need in both the questionnaires.

Play for play's sake was considered important for children with disabilities as it is for other children (72%). This question represents the basic assumption on which the whole COST Action "LUDI" engages, even if play for play's sake is not yet an established theoretical construct nor a cultural fact. The largest group of representatives from Associations considered play for play's sake essential for a wide range of reasons which can be related to socio-anthropological, psychological and developmental theories. Anyway, only one comment reported a concern in that some parents may not recognize the importance of play and prioritize the training of motor and communicative skills instead of play. In the perception of Associations, play is related to learning in terms of specific skills (social, relational, emotional skills, basic experiences for daily life), and it is considered as an opportunity to develop abilities (cooperation, creativity, communication, logical reasoning); it is also viewed as a common language with peers, a medium for communication, a tool for preventing difficulties in relation to a certain type of disability. The lack of play is viewed as a symptom of disability itself. Associations reported also that play makes the child feel positive emotions, a statement strongly tuned with the Action "LUDI" assumptions (COST, 2013).

Furthermore, various comments involved the role of the adults in relation to children's play. The role of a knowledgeable adult in children's play has been specifically investigated by the survey through a multiple choice question contained in the questionnaire of the Associations and an open-ended question in parents' questionnaire.

According to the Association's representatives an important improvement to the play of children with disabilities may be obtained thanks to availability of peers, changes in societal attitudes and behaviours and supportive adults. Other measures are mentioned – less numerous than the previous ones – and are related to: more time, adapted or special environments, policy measures and financial resources, outdoors and indoor environments, toys, improved skill of children, high tech tools.

The same contents about the needs of children to play have been found through the answers to the parents' questionnaire, but their respective importance was reported in a slightly different order.

In fact, the child's needs according to the parents were most frequently: to have friends and peers to play with, adapted and specialized toys, even technological toys, improved skills necessary to play, accessible outdoor environments; only on a second place they remark the need for knowledgeable adult in order to play more easily and for more time, then societal attitudes and behaviours, policy measures and resources. Thus, one of the most important needs expressed by several parents and children is the need to experience play with other children: many parents in fact express that their children use to play alone, not always as a choice, but because they lack friends and peers to play with. Having access to a variety of adapted toys should also be carefully considered; in fact, they might facilitate or broaden the play activity, or make it more fun. Knowledgeable adults, in addition, may have an important role in facilitating, supporting and sustaining the play activity of the child, his/her interaction with peers or with objects.

From a cross tabulation that connects the data related to the play needs to the type of impairments of the children emerges that the greatest need reported by Associations and parents connected to children with autism spectrum is represented by toys, and the same happens in the case of children with language/communications disorder and with multiple disabilities. In the case of children with intellectual disabilities the playmates are the most important need, but more than for children with hearing impairments, who often play alone. The children with physical disabilities would mostly need toys able to generate improved skills.

Another cross tabulation – concerning the children's age and their play needs – reveals that in the age range 0-5 the most common need is represented by toys; in the age range 6-9 instead different needs emerge with the same number of answers: a competent adult, playmates and time to play; in the age range 10-13 the priority is given to playmates; in the age range 14-18 there is a need of toys, especially technological ones. The 4 age ranges are fairly equally represented, so we assume that this distribution may be representative of the needs related to play at different ages of children with disabilities, regardless of the type of impairment.

Concerning where the child with disabilities plays, the Associations reported homes and other houses as indoor environments, and then schools, rehabilitation centres and leisure centres for children. Cited outdoor environments are: parks and natural environments, playgrounds, gardens/courtyards/streets and outdoor sport centres.

As to the playmates of children with disabilities, who most commonly play with them, these data has been put in combination with where this happens. It seems for example to be little more common that the children play most often alone or “in presence of peers” rather than “with” peers or friends in schools, or than in culture and leisure centres for children.

The Associations' survey also shows that children with disabilities more often do play alone or "in presence of peers" than with peers or friends in outdoor environments such as playgrounds, parks and natural environments and gardens/courtyards/streets. The opposite situation is verified in the case of outdoor sport centres, where children considered in this survey seem to play a little bit more with other children or youth, rather than alone.

Regarding the places of play, the parents involved in the other survey answered that the child plays at home, at school, in outdoor environments, as a park, especially in playground, in other indoor environments as rehabilitation centres or sport centres. About the playmates, several children were reported to play alone. This condition of play the majority of time is reported by parents together to play with partners, but for about a third of children playing alone is the only type of play reported by parents. The reasons that are at the basis of this situation are, according to the parents, related to: a preference of the child, or a condition caused by disability, or a rejection by peers, or also because there was a lack of time and opportunities to have some playmates. Other playmates reported by parents are: parents themselves, siblings, friends or peers in general, professionals, grandparents.

The 129 parents who answered are located in 26 European countries. They represented children of different ages and the various age groups were quite evenly represented. The boys were a majority (63%).

The parents were asked to express their perceptions and opinions related to the play of their children. They used as much positive as negative expressions. Positive words used were, for example: intense, joy, delighted, happy and fun; many positive emotions and fun were stressed about their children's play. Examples of negative expressions adopted to describe the same topic are: rejecting attitudes, childish or monotonous. Restrictions were identified in lack of attention and of peer relations.

Generally speaking, parents think that play is a positive and valuable experience for the child. It means enjoyment, happiness and fun, even if there are also experiences of shortcomings, for instance lack of peers to play with. Play is seen as an activity that fulfill important needs of the child: therefore parents declare to feel frustrated and unhappy when their children experience failure and limitation to their play.

The responses by parents of children with disabilities from many different contexts indicate that play is an essential activity for children with disabilities, as for all children. It is highly enjoyed by their children and makes them happy. At the same time, it may be restricted by environmental and social barriers and limited by developmental delays, and lack of skills related to the impairments. In order to make it possible and to enhance the participation of children with disabilities to play activities, adaptations, positive attitudes in the social contexts, available resources, and adequate policies are needed.

Some additional reflections that are inspired by the parents' answers concern the emerging of other play experiences that could be investigated and possibly included in the existing adopted models of play.

Within the framework of the Classification of the types of play adopted by Action “LUDI” (Bulgarelli & Bianquin, 2017), the parents’ answers regarding their children’s play refer to *practice play* as the most representative type: the children touch handle different materials, and repeat gestures with body movement.

The second type of play more represented is *play with rules* which includes videogames or technology tools as tablet, i-Pad, PlayStation, with a wide range of applications useful for children with motor impairments or with autism spectrum disorders.

Symbolic play is the third type of play cited by parents. This includes simple symbolic play such as play with shapes and drawing, but also more sophisticated activities, such as playing with cards or role play.

In the cognitive dimension *construction play* appears only seldom. Sometimes the children are not capable in construction play, but they can disassemble materials (that, of course, is a “practice play” activity and not a constructive one).

As to the *social dimension* of play, it is difficult to distinguish – within the answers to the questionnaire – among the different types (solitary, parallel, associative or cooperative). Some more precise information in this regard may come from the answers to the question dedicated to playmates. When it comes to the open question about play, only few mentioned play activities fall unambiguously under the cooperative play type, such as play with the ball, also with rules as football, or play with cards, or simply dealing with rules. Parents cited also generic activities from a social point of view such as talking, smiling, laughing, and have company.

Furthermore, some parents report an activity of observation of other children’s play, which is called “onlooker play”.³ If the child is not actively playing, the observation of other children while playing, could be considered as an activity in which the child understands and learns, through watching what to do and what happens in play. During onlooker play the child spends most of the time «observing other children playing, sometimes asking questions, commenting, or responding but not overtly engaging in the play activity» (Parten, 1932, quoted in Barton, 2016, p. 268). This activity could be a step that the child experience before joining the play situation, or imitating it.

There is another type of play that some parents report in their answers and was not immediately found in the classical definitions of play: it could possibly receive more attention in future mappings of play activities. It is the play activity with pets, for instance with a dog, which is reported in more than one occasion. It is possible in a way to consider these activities as play activities for the dog and not for the child, but it is also possible to consider these activities as play for both the parts involved in the interaction. The relationship between humans and nature, is something that

³ Within the framework of the LUDI Classification of the types of play, “onlooker play” is part of the “parallel play” (social area).

has been overlooked, since the dominant approach in many theoretical frameworks has been anthropocentric (Wilson, 1984; Kahn, 1997; Keller & Wilson, 2013) but an analysis of the child's interest about and relationship with the nature, particularly with living creatures, could provide further elements to a theoretical model of human development (Lee, 2012), perhaps also of play. This is a general theme that could be possibly explored further and then related to the experience of children with disabilities.

When possible, parents interviewed their children about their concrete experiences of play and their related feelings. The direct voice of users has been thematised as Activities and Events; Partners in play; Emotional states; Agency in play; Evaluation and Places. Play emerges in the children's experiences as a meaningful and pleasant activity that they can engage in, that they can observe, communicate, share; through it, they can experience participation in social relationships. In playing, they feel positive emotions such as joy, happiness, relax, fun, excitement. Children may also experience agency, as they can decide and act as powerful persons, thus showing to be in control of the play situation. With reference to the evaluation theme, several children expressed their wish to play for more time, to have more options and adaptations for play, and that barriers and limitations to play may be overcome.

In conclusion, the children's direct voice reports that the play encourages positive emotions, expands the range of social interactions, and support their agency.

References

- Antia, S. D., & Dittillo, D. A. (1998). A comparison of the peers' social behavior of children who are Deaf/Hard of Hearing and Hearing. *Journal of Children's Communications Development*, 19, 1-10.
- Barron, C., Beckett, A., Coussens, M., Desoete, A., Cannon Jones, N., Lynch, H., & Fenney Salked, D. (2017). *Barriers to Play and Recreation for Children and Young People with Disabilities. Exploring Environmental Factors*. Berlin/Warsaw: De Gruyter.
- Barton, E. E. (2016). Critical Issues and Promising Practices for Teaching Play to Young Children with Disabilities. In B. Reichow et al. (Eds.). *Handbook of Early Childhood Special Education*. New York: Springer International Publishing.
- Besio S. (Ed., 2010). *Gioco e giocattoli per il bambino con disabilità motoria*. Milano: Unicopli.
- Besio, S. (2017). The Need for Play for the Sake of Play. In: S. Besio, D. Bulgarelli, & V. Stancheva-Popkostadinova (Eds.), *Play Development in Children with Disabilities* (pp. 9-52). Berlin/Warsaw: De Gruyter.
- Bianquin, N. & Bulgarelli, D. (2017). Conceptual Review of Disabilities. In: S. Besio, D. Bulgarelli, & V. Stancheva-Popkostadinova (Eds.), *Play Development in Children with Disabilities* (pp. 58-70). Berlin/Warsaw: De Gruyter.
- Bulgarelli, D. & Bianquin, N. (2017). Conceptual Review of Play. In: S. Besio, D. Bulgarelli, & V. Stancheva-Popkostadinova (Eds.), *Play Development in Children with Disabilities* (pp. 9-52). Berlin/Warsaw: De Gruyter.

- Bulgarelli, D. & Stancheva-Popkostadinova, V. (2017), Characteristics of play in children with intellectual disabilities. In: S. Besio, D. Bulgarelli, & V. Stancheva-Popkostadinova (Eds.), *Play Development in Children with Disabilities* (pp. 88-93). Berlin/Warsaw: De Gruyter.
- Brambring, M. (2005). *Assessing developmental differences in Blind versus Sighted children*, key-note speech, ICEVI European conference, Chemnitz, Germany, 14-18 August 2005, Conference proceedings/report, 2005, 18–23.
- COST (2013). *Memorandum of Understanding for the implementation of a European Concerted Research Action designated as COST Action TD1309: Play for Children with Disabilities (LUDI)*, https://e-services.cost.eu/files/domain_files/TDP/Action_TD1309/mou/TD1309-e.pdf
- Guralnick, M. J., Connor, R. T., Neville, B., & Hammond, M. A. (2006). Promoting the peer-related social development of young children with mild developmental delays: Effectiveness of a comprehensive intervention. *Journal Information*, 111(5).
- Haight, W. (1998). Adult Direct and Indirect Influences on Play. In: D. P. Fromberg, & D. Bergen (Eds.), *Play from Birth to Twelve and Beyond: Contexts, Perspectives, and Meanings* (pp. 259-265). New York & London: Garland Publishing.
- Kahn, P. H. (1997). Developmental Psychology and the Biophilia Hypothesis: Children's Affiliation with Nature. *Developmental Review*, 17(1), 1-61.
- Kellert S. R., & Wilson E. O. (2013). *The Biophilia Hypothesis*. Island Press.
- Lee, P. C. (2012). The Human Child's Nature Orientation. *Child Development Perspectives*, 6(2), 193-198.
- Lender, W. L., Goodman, J. F., & Linn, M. I. (1998). Repetitive activity in the play of children with mental retardation. *Journal of Early Intervention*, 21(4), 308–322.
- Luttrupp, A., & Granlund, M. (2010). Interaction—it depends—a comparative study of interaction in preschools between children with intellectual disability and children with typical development. *Scandinavian Journal of Disability Research*, 12(3), 151–164.
- Nader-Grosbois, N., & Vieillevoys, S. (2012). Variability of self-regulatory strategies in children with intellectual disability and typically developing children in pretend play situations. *Journal of Intellectual Disability Research*, 56(2), 140–156.
- Organisation for Economic Co-operation and Development (OECD) (2007). *Students with Disabilities, Learning Difficulties and Disadvantages: Policies, Statistics and Indicators* <http://www.oecd.org/education/innovation-education/studentswithdisabilitieslearningdifficultiesanddisadvantagespoliciesstatisticsandindicators-2007edition.htm>
- Reid, D. (2004). The influence of virtual reality on playfulness in children with cerebral palsy: A pilot study. *Occupational Therapy International*, 11(3), 131-144.
- Schneekloth, L. (1989). Play environments for visually impaired children. *Journal of Visual Impairment and Blindness*, 83, 196–201.
- Slade, A. (1994). *Children at Play: Clinical and Developmental Approaches to Meaning and Representation*. Oxford University Press.
- Sylva, K., Taggart, B., Melhuish, E., Sammons, P., & Siraj-Blatchford, I. (2007). Changing Models of Research to Inform educational Policy. *Research Papers in Education*, 22(2), 155–168.
- Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M. (1989). Role relations between children who are mentally retarded and their older siblings: Observations in three in-home contexts. *Research in Developmental Disabilities*, 10, 61-76.
- Weiss, P. L., Bialik, P., Kizony R. (2003). Virtual reality provides leisure time opportunities for young adults with physical and intellectual disabilities. *Cyber Psychology and behaviour*, 6(3), 335-342.
- Wilson, E. (1984). *Biophilia: The human bond with other species*. Cambridge: Harvard University Press.
- Wood, E. (2009). Developing a Pedagogy of Play. In: A. Anning, J. Cullen, & M. Fleer (Eds.), *Early Childhood Education: Society and Culture* (pp. 27-38). London: Sage Publications,

- World Health Organization (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO.
- Zapatera, T. (2018). The Role of Knowledgeable Adults in Children with Disabilities' Play. An Exploratory Research in Europe. *Today Children Tomorrow Parents*, 47-48, 74-85.