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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Introduction

This book is the result of a specific part of the European research project "LUDI. Play for Children with Disabilities" (http://ludi-network.eu), a COST funded Action (www.cost.eu/TD1309, 2014-2018) that collected a multidisciplinary international network of professionals, researchers and practitioners, devoted to the study and enhancement of play for children with disabilities.

The Action is aimed at the creation of a general awareness on the quality of life of children with disabilities, starting from a crucial aspect, i.e. play activities, and initiating a process of cultural and social change that will break down the barriers that hinder the full exercise of their right to play and will pave the way to the realization of a true social inclusion.[1]

Participants to the research project were organized into 4 Working Groups, as will be explained in more detail in the section on theoretical framework of the Action. The book collects the results of the Working Group 4, *Methods, tools and frameworks for the development of the child with disabilities play*, which has the final goal to provide guidelines for the play of children with disabilities.

The research field and the Working Group 4 aims are to collect and develop previous studies on play for children with disabilities in order to produce an overview on this theme, to develop intervention models and training and policies addresses. The book represents the first outcome of this line of research: a *Users' Needs Report on children with disabilities play*. Who are the users? They are representatives of family associations, families of children with disabilities, and children themselves, but also practitioners and researchers of different field, such as healthcare, education, industry, technological, policy makers.

The book is divided into two Sections that are the result of two different research phases and covers different but complementary aspects of the research line of Working Group 4. The aim of the report is to investigate the users' needs on the matter of play for children with different disabilities and in various contexts. The users' needs were collected by means of surveys addressed to disability associations and to parents of children with disabilities (Section 1) and by means of case studies at a country level, based on reviews of research and reports from three national contexts (Section 2).

The report is compiled by members of the LUDI Working Group 4. The members of the LUDI Core Group and Management Committee contributed to the development of the questionnaires, under the supervision of Serenella Besio, Chair of the Action. Pedro Encarnação and Mara Westling Allodi supported the management and Tamara

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[1] www.cost.eu/TD1309; www.ludi-network.eu.

Prevendar coordinated the data collection.[2] Several colleagues from the other countries represented by LUDI participated to the mapping of users' needs in the case studies.

In Section 1 the users are representatives of associations for disabilities, parents of children with disabilities and, to a lesser extent, the children themselves. Through an empirical research conducted by two semi-structured questionnaires we investigated the needs of children with disabilities in the play. The two questionnaires were developed by members of the LUDI network in January-February 2016 and distributed to 31 LUDI national coordinators. The structure and issues of the questionnaires are similar, but the version for the parents contained more open questions. The identification of questions to ask the representatives and parents has been driven by the knowledge that the Action LUDI aims at reaching a large and triple impact:

1. scientific, on the recognition of the right to play for children with disabilities, and on the adoption of measures to allow the exercise of this right;
2. societal, by training parents and professionals to become proficient at interacting with children with disabilities in order to give them the chance to learn and grow through play;
3. technological, by planning and designing technology products and tools for play as well as by expanding the number of people able to use them and also improving their competence.

The coordinators translated the questionnaires into 23 languages. The questionnaires were distributed to at least 3 associations and 3 parents in the respective countries. The coordinators translated back the collected answers into English and reported them into a web-survey tool. The survey was performed from April to June 2016. 75 answers were collected from associations in 24 countries and 129 from parents in 26 countries. The answers were analyzed with content and thematic analysis.

Hearing the direct voice of users as players – in our case the perception of parents and children themselves – is a line of action planned by LUDI. It is a methodology of research already accredited in different fields, i.e. it is a research methodology widely used in the construction of models of quality systems and in the quality review processes.

In order to develop suitable and relevant policies, practices and professional training on the topic of play for children with disabilities, it is vital to sensibly take into account the users' needs in their daily lives, and in particular, in this case, the needs of children with disabilities, their parents and families. The views of persons that are target for products, educational and social services are essential in order to develop facilities and products that truly and responsively match their needs. Listening to people's needs and eliciting their evaluations make it possible for them

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[2] Respectively from: Italy, Portugal, Sweden and Croatia.

to participate in and influence the future development of products and practices. In doing so, it is recommended for the developers also to consider a whole range of experiences, and from a variety of contexts, in which there might be different policies, attitudes, resources and barriers, which may affect accordingly the users' experiences and needs. Based on this rationale, the task at hand was to investigate the available knowledge and to collect empirical accounts on the topic of users' needs for children with disabilities.

In section 2 the users' needs have been investigated indirectly and with reference to specific national contexts as "case studies" in three European countries, Lithuania, Finland and Sweden. To ensure a common structure to the study, the reviews at country level were based on a shared protocol. Previous literature searches in scientific research databases revealed that very limited research was available, if any, on the topic of parents' and children's views on play, and even less on users' needs on play for children with disabilities. The reviews at a country level were consequently chosen with the aim of collecting empirical evidence that might be available in the local context, as grey literature, research, official reports and evaluations that were not reported in scientific articles.

Shortly, as we shall detail at the end of the report, the results shows that:

- Children with disabilities needs to play and to have all the positive experiences that children experience when they play in various environments and with peers, friends, relatives.
- Play is a vital and fundamental need that is not always fulfilled for children with disabilities.
- There is needs for adaptations in toys and environments.
- Children with disabilities and their parents should be involved in planning so that they can influence policies and practices.
- Training for teachers and other professionals should be improved so that they can be more sensitive and skilled in supporting play in inclusive settings.
- Policies and indicators should be developed and implemented in field of play and disability and evaluations carried out.