

Pedro Encarnação and Maria Saridaki

1 “LUDI. Play for children with disabilities”

The aim of “LUDI – Play for Children with Disabilities” was to create a novel and autonomous field of research and intervention on play for children with disabilities. The Action integrates the joint efforts of more than 100 researchers, practitioners, and users, from 32 European countries and many different backgrounds (computer science, education, engineering, medicine, occupational therapy, physical therapy, psychology, sociology, speech and language pathology, among others). As set in its Memorandum of Understanding (COST, 2013:3), «the network has three main objectives:

- collecting and systematizing all existing competence and skills: educational researches, clinical initiatives, know-how of resources centers and users’ associations;
- developing new knowledge related to settings, tools and methodologies associated with the play of children with disabilities;
- disseminating the best practices emerging from the joint effort of researchers, practitioners and users».

To accomplish these goals, the Action was organized into four Working Groups (WGs):
Working Group 1 - Children’s play in relation to the types of disabilities

Working Group 2 - Tools and technologies for the play of children with disabilities

Working Group 3 - Contexts for play of children with disabilities

Working Group 4 - Methods, tools and frameworks for the development of the child with disabilities’ play.

In the first two years of the Action, Working Group 1 worked towards defining the framework for LUDI. A definition and a classification of play were adopted, after a thorough review of the many available in the literature. Following a biopsychosocial model of disability, as advocated in the World Health Organization *ICF - International Classification of Functioning, Disability and Health* (World Health Organization, 2001), a working definition of disability and a categorization of childhood disabilities were formulated. Finally, Working Group 1 addressed the characteristics of play in children with different disabilities. All the above was published in the book *Play Development in Children with Disabilities* (Besio, Bulgarelli, & Stancheva-Popkostadinova, 2017).

Meanwhile, Working Group 2 created a database of play systems with records describing the play experience of children with disabilities using toys, assistive technology, or within environments specially designed for play. These examples are meant to inspire users and practitioners, and foster cooperation and discussion between all stakeholders. Since one of the WG2 objectives is to critically review guidelines for the design and assessment of assistive technology and environments to support play for children with disabilities, the database also collects the methods

used in each play experience to assess accessibility, usability, and effectiveness of the assistive technology or environment. This database is publicly available at <http://ludi.utad.pt/>.

It was the goal of WG3, during the first part of the Action, to examine the environmental barriers to play and recreation for children and young persons with disabilities. This was done through a narrative review of existing research and knowledge on play for children with disabilities within four key physical contexts: the home, educational settings, the built environment and the natural environment. Conclusions of this analysis were published in the book *Environmental barriers to play and recreation for children and young persons with disabilities* (Barron, et al., 2017).

Faithful to the motto *Nothing About Us Without Us*, the Action LUDI strives to hear the voices of children with disabilities and their representatives, and involve them in all the work conducted within the network. One of the steps in that direction is the assessment of the children with disabilities play needs *from their perspective*. This was the first goal of WG4 and the result of that work is now published in this book.

1.1 The importance of play for the sake of play

According to Garvey (1990:4) «Play is a range of voluntary, intrinsically motivated activities normally associated with recreational pleasure and enjoyment». Several characterizations of play have been proposed. In the LUDI Action, play is classified along two dimensions: cognitive and social (Table 1).

Table 1.1. LUDI Classification of the types of play (Bulgarelli & Bianquin, 2017)

Dimension	Type of play
Cognitive	Practice
	Symbolic
	Constructive
	Play with rules (including videogames)
Social	Solitary
	Parallel
	Associative
	Cooperative

Practice play, typical in the first two years of life, includes simple body actions or experimentation of body, and visual and tactile experimentation of objects. *Symbolic play* involves giving new significations to objects, persons, actions or events. This type of play typically emerges in the end of the second year of life. *Constructive play* consists of building or assembling something. It also appears by the age of two. *Play with rules* encompasses all those play activities which have rules that are accepted and followed by the players. It usually emerges at the age of three. In *solitary play* children

play alone and independently, even if in presence of other persons. *Parallel play* occurs when more than one children independently engage in the same play activity, without interacting with each other. When children are together, each engaged in his/her own play activity, but sharing, taking turns, or any other form of consideration of the other’s play activity, there’s *associative play*. In *cooperative play* children play together with a common goal or purpose. More details on these definitions can be found in (Besio, Bulgarelli, & Stancheva-Popkostadinova, 2017).

Play is the most prevalent activity in childhood. While playing children develop motor, language, and social skills (Besio, Bulgarelli, & Stancheva-Popkostadinova, 2017) and the references therein). Realizing children’s predisposition to play and the benefits of play activities, several disciplines have devised play-like activities with secondary goals. For example, educators may set up play activities to teach math concepts (many of those activities are easily found these days searching the Internet for “play” and “math”). Or occupational therapists may use play activities to develop a particular functional skill (see for example (Couch, Deitz, & Kanny, 1998)). However, arguably these play-like activities miss some of the characteristics of play. For example, often these activities are chosen and led by an adult, and not by the child; or they are motivated by the product and not by the process. Accordingly, the activity has a goal different from just playing.

Although the importance of play-like activities should not be underestimated, the LUDI Action focuses on *play for the sake of play* activities. These are activities whose purpose and objective are the play itself. Benefits of these activities are seen as a side effect of them, and activities are not set to pursue any particular benefit. The apparently incoherent rationale is that play activities will have the greatest outcomes if they have no defined outcomes.

1.2 Barriers to play for children with disabilities

According to the ICF (World Health Organization, 2002), *disability* is an umbrella term for impairments, activity limitations and participation restrictions, including environmental factors that interact with all these components. Children with disabilities may thus have their quality of play compromised as a consequence of a limitation in a body structure or function that prevents engaging in an activity or in a life situation. For an analysis of the factors related to the individual and play, please refer to (Besio, 2008).

From the environment perspective, play by children with disabilities may also be impacted by attitudes of others, lack of supporting technology or environments, or the prevailing policies. In Barron, et al. (2017) examples of these environmental barriers were identified in the literature. For example, ‘risk-aversion’ attitudes towards children may prevent them from playing, with the argument that children should never be put at risk, thus neglecting the benefits of play over potential risks. There is

a lack of information concerning assistive technology to support play. Some countries lack clear policies and legislation in relation to accessible and usable spaces for play (either built or natural environments).

It is well documented in the literature that play deprivation has several detrimental consequences, including anxiety, frustration, passivity (Missiuna & Pollock, 1991), decreased sense of self-efficacy, self-confidence, satisfaction and well-being (Blanche, 2008), and ultimately learned helplessness (Butler, 1986). All these impact the child's future functioning in educational, community and work contexts (Missiuna & Pollock, 1991).

1.3 Case study methodology: an opportunity for disability studies

A case study is a research approach that is used to produce an in-depth, multi-faceted understanding of a phenomenon, which can be an event, group, or social process, in its real-life context. It is an established research design that is used extensively in a wide variety of disciplines, principally in the social sciences (Crowe et al, 2011). Before discussing further the importance of this methodology in disability studies we should highlight some of its different definitions and clarify its overall importance.

Case study methodology, «is both the process of learning about the case and the product of our learning» (Stake, 1995:237) allowing researchers to focus on searching, seeking, and inquiring in order to provide the necessary insight for a deeper understanding of the phenomenon, its origins, development, and recent form.

As a research methodology, a case study can be defined in a variety of ways, the central principle being the need to explore an event or phenomenon in depth and in its natural context. Some of its definitions are rather broad:

«A case study is here defined as an in-depth, multi-faceted investigation using qualitative research methods, of a single social phenomenon. The study is conducted in great detail and often relies on the use of several data sources» (Feagin, Orum & Sjoberg, 1991:2).

Other definitions are much more narrow and specific:

«A case study is an empirical inquiry that, investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident» (Yin, 1994:13).

Case study provides an important methodological option that forms a nice complement to the range of methods available to social scientists for research into society and its components. Obtaining and presenting a holistic depiction of the phenomenon, is a characteristic of the case study method (Suryani, 2008). A case study emphasizes the whole rather than its atomized components.

Case studies permit identification and description of phenomena. Labeling phenomena is the first step to cataloging them, discovering and recording their characteristics. Researchers using the case study method can develop more

comprehensive analytical depictions of the phenomenon, how it works, and the interrelationships between its components. These depictions can be useful in conveying an abstract understanding of the phenomenon. Case studies enable the development of “grounded theory” (Glaser & Strauss, 1967). Case studies can also provide answers to the “why” question and explain the reasons people take certain actions, at least as perceived by them. The researcher’s analysis may suggest whether the reasons offered seem accurate. Findings from a detailed case study research enable the researcher to test existing theories and their validity.

This holistic approach is able to highlight the actual societal issues. According to Tsiolis «the main concern of every researcher is to develop methods that are suitable to illuminate the actual problems of people» (Tsiolis, 2004) and case study methodology seems to be a suitable method towards this goal.

Richness of data is another vital characteristic of this methodology. Detailed data about the phenomenon enables the development of in-depth understanding, allowing the reader to obtain a strong sense of the phenomenon, and derive his or her own conclusion about it (Mazumdar & Geis, 2001).

The case study method provides several benefits that quantitative and experimental approaches do not, though depending on the research question, those methods provide some other benefits that case study does not (Mazumdar & Geis, 2001). Several criticisms have raised questions about the use and popularity of case study as a research method. A frequent criticism of case study research is that it is not possible to draw a generalisation from the analysis of a single case (Ianni, 2003).

However the answer is again in the purpose of the researcher and the type of research he/she decides to carry out (Ianni, 2003). «Case study research is not sampling research. We do not study a case primarily to understand other cases. [...] The real business of case study is particularization, not generalization» (Stake, 1995:8).

Regarding that criticism, Cohen and Manion explain that case studies involve the «observation of the characteristics of an individual unit – a child, a clique, a class, a school or a community» (1994:124). Therefore, after such observations and investigation of the subject, case studies aim to establish generalisations that can be applied to a wider audience.

«The purpose of such observation is to probe deeply and to analyse intensively the multifarious phenomena that constitute the life cycle of the unit with a view to establishing generalizations about the wider population to which that unit belongs» (Cohen & Manion, 1994:106).

Geis (1991:217) has claimed that «case study material will rarely be published today by any of the leading journals» which might be a reason for its decline in popularity. However since generalization seems to be the main problematic of using case studies as a methodology, it has to be reminded that in a case study we are in the field of ‘naturalistic enquiry’, whose “meaning in use now, in educational research

and evaluation, emphasizes the idiosyncrasy and intentionality of human action, the importance of biography, history and particular circumstance» (Davis, 1994:21).

Especially regarding disability studies, case study methodology can offer great potential in raising the voice of the person with disabilities, especially if it focuses on special in-depth understanding. Apprehending and depicting the complexity of the phenomenon is a main feature of the case study method that fits with the demanding nature of disability studies.

According to Yin (2003) there are some limitations of a case study approach. First, people may think that case study researchers do not follow systematic procedures and may have biased views that probably influence the findings and the conclusions. However, according to Suryani, similarly to all other researchers, case study researchers should «stay in a neutral position in reporting the facts or at least triangulating the data to ensure that the claims are supported» (2008:121).

As a qualitative research approach, a disability study case might be an individual or a group/collective; it might also be simple or complex. Some examples of individual cases might be a child, an adult, a student, with one or multiple disabilities, a person's experience or phase in life, a teacher, parent or caretaker. On the other hand, a collective or complex case might be in the form of home environment, educational or working environment, neighbourhood, or region (Suryani, 2008; Myriad Consultants, 2005; New Zealand Ministry of Health, 2000).

According to Mazumdar & Geis, in disability studies, statistical reports can reduce emotions to «dry and dreary numerical formulations that fail to convey the most significant elements of the world of persons with disabilities and provide little advanced understanding of that world» (2001:256). For persons with disabilities, being the subject of impersonal study rather than of sincere attempts at empathetic understanding, can at times be exasperating, a demonstration of distancing by others that hides many ethical implications for the study subjects. From observation to analysis, case study methodology offers a particularly valuable tool for conveying beliefs and feelings in a clear manner, allowing the person with disabilities or hers/his caretakers to present their situation, experience and needs (Mazumdar & Geis, 2001).

Case studies can give a better sense of the effects of disability. In their encounters and dealings with the natural, human-made, and social world, persons with particular disabilities have specific experiences. Describing these in detail and providing a rich understanding is important for researchers who desire to obtain a more complete sense of the experience of a variety of disabilities.

Oliver and Hasler (1987) provide examples of different effects of various disabilities and how the services offered by the Spinal Injuries Association assisted these persons with disabilities. They also describe how professionals charged with assisting persons with disabilities exercise their power and how sharing of power with persons with disabilities would conceptualize solutions differently needs (Mazumdar & Geis, 2001).

A case study enables the researcher to offer to the reader an in-depth sense of the context, social and physical, of the life of a person with a particular disability or multiple disabilities. Two persons with the same apparent disability may experience different contextual situations (Imrie, 1996:147) depending on societal, psychological or environmental reasons. For example, Matthews (1983) describes her situation and that of some others who had different experiences. She describes how the institution, including doctors and staff, were unwilling to make adjustments and failed to understand how persons with disabilities felt.

Case studies have been also used in the educational experience of students with disabilities, allowing an in-depth view and analysis of their everyday struggles, strengths and needs. Especially regarding the introduction of educational and technological innovations in special or inclusive education settings there have been many researches that were based on the case study methodology (Bates et al, 2015; Brown et al, 2011).

Finally, and perhaps most importantly, case studies afford the depiction of the emotions of persons with disabilities. In a case study a researcher can express the feelings associated with being disabled and their feelings towards current policies and social situations (Mazumdar & Geis, 2001). In data collection stage, the researchers in a qualitative case study tend to spend more time on research locations, have personal interest and contact with the case or participants, as well as make reflection and certain meanings about the natural phenomenon (Suryani, 2008).

Like most other methods, case study method has strengths, weaknesses, and potentials. However, case study approach provides important qualitative insights into the experiences of an individual or a group of persons with disabilities. Case studies, when done properly, can produce lasting and crucially important contributions. Disability studies can gain from case studies in the manner that fields of education, anthropology, sociology, medicine, information systems, and many other realms of intellectual inquiry have.

The second section of this report provides three case studies at the country level (Finland, Lithuania and Sweden) based on literature reviews of empirical studies, reports and evaluations. These case studies at the country level provide information about the policies, and examples of the needs of children, parents and other users on the topic of play for children with disabilities, needs that are observed and identified in these societal contexts.

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