

Pedro Encarnação

2 Methodology: the survey aimed at assessing the children with disabilities play needs from the perspective of parents and children

Taking advantage of the pan-European nature of the Action “LUDI. Play for children with disabilities” network, a survey aimed to collect the perspectives of parents’ associations and individual parents on the children with disabilities play needs was conducted. Given the importance of play for the sake of play in child development and the barriers to play for children with disabilities, it is highly relevant to understand the children with disabilities perspective on their needs regarding play. In their opinion, do they have enough opportunities to play? How about the *quality* of their play? Do they have the chance of playing for the sake of play, or is it only when play has some secondary goals? Which barriers to play do they perceive? What would they need to improve their play experience?

2.1 Surveys development and data collection procedures

Two questionnaires were developed to be applied through the LUDI network in several European countries. One of the questionnaires was directed to representatives of parents’ associations and the other to parents of children with disabilities, both aiming for an indirect assessment of the play needs of children with disabilities.

While the questionnaire for representatives of parents’ associations contained only multiple choice questions, the one for parents contained only open answer questions aiming at collecting the individual play experiences of their children. Assuming it would be easier to get the opinions of representatives of parents’ associations by using a questionnaire that wouldn’t take more than 10-15 minutes to complete, a six multiple choice questions instrument was developed, allowing respondents to include additional comments or explanations if they wanted. In contrast, the questionnaire for parents of children with disabilities included mainly open-ended questions in order to collect some anecdotal evidence. This qualitative information on several singular cases may allow for a general description of the play needs of children with disabilities.

Both questionnaires included a cover letter providing brief information about the LUDI network, the objectives of the survey and ensuring confidentiality of the data. No definition of play was provided thus respondents relied on their own definition. The questionnaires were developed by the members of the LUDI network during the first months of the year 2016. The phrasing and concepts adopted in the questionnaire were thoroughly discussed in particular within the LUDI core group, with the purpose of avoiding bias and increasing the fit to the various international contexts. The questionnaires can be found in Appendix.

2.1.1 Questionnaire for parents' associations

In order to allow for subsequent data segmentation and for requiring any further clarification, if needed, respondents were asked to provide their name, the name of the parents' association, the association's country, the associations' website address and/or alternative contact information, the type of impairment/disability and the age range of the children represented, and the number of associates. To collect the information on the type of impairment/disability, the disabilities categorization utilized within the LUDI network was used (Besio et al., 2017), which includes the categories intellectual impairments (mild, moderate, severe, profound); hearing impairments (partially hearing impaired – deaf); visual impairments (partially sighted – blind); communication disorders (language disorders); physical impairments (mild, moderate, severe); autism spectrum disorders; and multiple disabilities. Respondents could select more than one category or specify a different category under “Other”.

Question 1 “According to you as a representative, do the children with disabilities have sufficient opportunity to play according to their needs?” was aimed to assess the perceived “quantity of play”. Possible answers were “No”, “Yes, a little”, “Yes, a lot”, and “Impossible to say in general”, providing three different “quantity levels” of play and the hypothesis of reporting that the reality of the associates was too heterogeneous, not allowing for a general answer.

To assess the perceived “quality of play”, question 2 was “Do you think that the parents of the children your Association represents are happy with their children's play?” (yes/no). In case of a negative answer, a justification was requested.

Question 3 – “Is play “for play's sake” important for children with disabilities?” - evaluated the importance attributed by respondents to play activities that have no other goals than play for fun, specifically for children with disabilities. Respondents could choose between “Yes, definitely”, “Yes, whenever possible”, “No, play should have a goal”, and “No, play is not important”.

Perceived barriers to play were assessed by question 4 “What would the children with disabilities that you represent need in order to play (more, better)?”. A four points Likert scale (not important, somewhat important, important, very important) was provided to classify the importance of: toys, high tech tools (assistive technologies, robotic tools), peers (friends, other children), time, adapted or special environments, indoor environments, outdoor environments, a knowledgeable adult, policy measures / financial resources, improved skills needed for play, societal attitudes and behaviors. This list of options was informed by the study on the barriers to play that children with disabilities often face (Barron et al., 2017). Respondents could specify an additional item in the list.

Questions 5 and 6 addressed the perceived play context of the children with disabilities represented by the associations. Question 5 – “Where do the children you represent usually play and with whom?” – aimed for characterizing the environmental

and social context. For a set of indoor environments (home/other houses, school, culture and leisure centers for children, and rehabilitation center) and a set of outdoor environments (garden/courtyard /street/..., playground, parks and natural environments, and outdoor sport center), respondents could indicate if children usually played alone, alone in the presence of peers, with peers (friends, siblings, etc.), with parents or other family members, or with other adults. An additional indoor environment and an additional outdoor environment could be added. To evaluate the cultural and political context, question 6 – “According to you as a representative, has any change occurred within the last five years that has improved the play of children with disabilities? To what extent?” – gave respondents the possibility of, using a four points Likert scale (no, a little, much, and very much), classifying their perceived recent changes in toys, high tech tools (assistive technologies, robotic tools), indoor environments, outdoor environments, and the attitudes and behaviors of educators, rehabilitators, adults, peers and society in general. It was also possible to add an additional item.

All but question 2 included the possibility of inserting additional comments or explanations.

2.1.2 Questionnaire for parents of children with disabilities

Parents were required to fill in the following identification data: country, family relationship (mother, father, guardian), age and gender of the child, and type of impairment/disability. Again, the LUDI disability categorization in was used to collect the information on the type of disability (Bianquin & Bulgarelli, 2017).

To allow some free thinking about their children’s play, the first question requested parents to write down the first three ideas/words that came to their minds when thinking about their children’s play. The second question addressed the environmental and social context of play: “Would you like to tell us where does your child usually play and with whom? [e.g., indoor (home, school, leisure centers, etc.), outdoor (courtyard, playgrounds, parks, sport centers, etc.); alone, with peers (friends, siblings, etc.), with parents and other adults, etc.]”. The perceived barriers to play were assessed through question 3: “What would your child need in order to play (for more time, more easily, more playfully)? [e.g., specialized or adapted toys, technologies, peers, time, improved skills needed to play, etc.]”. Question 4 evaluated the “quantity” of play: “Could you tell us how much time a day does your child spend playing?”. Finally, parents were challenged to interview their children and a small script was proposed: “If it is possible, would you like to interview your child concerning his/her play? [For example: What do you like about playing, where do you like to play, with whom, and how...? How do you choose your toys? How do you feel when you play? How important is play for you? What would you need to make your play better for you (more fun, more frequent, etc.)?]”

2.1.3 Data collection

One member from each country participating in the LUDI Action was identified to coordinate the survey in the respective country. This coordination involved translating the questionnaires from English to the country’s language, using their personal network to contact parents’ associations, collecting the responses and translating them to English. Country survey coordinators were asked to contact at least three parents’ associations, irrespective of the type of disability of their associates. One representative of the parents’ association should complete the parents’ associations’ questionnaire, and one parent from the association should complete the parents’ questionnaire referring to his own particular child. The same person was allowed to complete both questionnaires, assuming the role of a representative of the parents’ association and then of a parent of a particular child with disabilities.

31 members in 31 countries participating in the LUDI Action were contacted. The questionnaires were translated into 23 languages¹ other than English.

The data collection was launched in April 2016 and finished in June 2016. The country coordinators were requested to contact at least three parents’ associations and three parents, and ask them to answer to the questions in the survey. The procedure could imply to contact the respondents in various ways by e-mail, by phone or with a personal encounter, but the information provided about the aim and framework of the study should be the same. The respondents’ answers were collected by the country coordinator, subsequently translated into English, and reported in a web based platform that would allow afterward to export the collected data to Excel or other formats.

The data collection was managed principally by Pedro Encarnação via e-mail and supported by LUDI Working Group 4 members. The data collection was also coordinated by Tamara Prevendar within the framework of a LUDI Short Term Scientific Mission based at the Department of Special Education at Stockholm University.

The country coordinators that contributed to the data collection were the following LUDI members: Ms Barbara Prazak-Aram (AT), Karen De Maesschalck (BE), Anna Andreeva (BG), Tamara Prevendar (HR), Panayiotis Zaphiris (CY), Jari Jessen (FI), Sonia Sousa (EE), Elina Viljamaa (FI), Odile Perino (FR), Katina Pavlovska (MK), Ursula Winklhofer (DE), Maria Saridaki (GR), Cecilia Sik Lanyi (HU), Dana Cappel (IL), Tamara Zappaterra (IT), Egle Celiesiene (LT), Veronica Montanaro (MT), Rianne Jansens (NL), Agnieszka Landowska (PL), Pedro Encarnacao (PT), Ana Muntean (RO), Natalia Amelina (RU), Miodrag Stankovic (RS), Noemi Rando (ES), Mara Westling Allodi (SE), Sylvie Ray-Kaeser (CH), Hilary Gardner (GB), and Selda Ozdemir (TR).

¹ Belgian, Bulgarian, Croatian, Danish, Dutch, Estonian, Finish, French, German, Greek, Hebrew, Hungarian, Italian, Lithuanian, Macedonian, Polish, Portuguese, Romanian, Russian, Serbian, Spanish, Swedish, and Turkish.

Table 2 lists the number of questionnaires collected per country. A total of 75 responses to the questionnaire for the parents' associations and 129 responses to the questionnaire for the parents of children with disabilities was obtained.

Note from Table 2 that the number of responses in each country is relatively small which, added to the fact that respondents were chosen from a particular network of contacts, does not allow for generalizations at the country level. Analysis at the European level should also be made with great caution since there are many exogenous variables that were not controlled (for example, cultural, economic and political contexts, type of impairments, to name just a few). Nevertheless, it is interesting to analyze the questions in which there was a big majority of respondents choosing one answer. Additionally, it is worth exploring the obtained anecdotal information considering the current scientific beliefs.

Table 2. Number of collected questionnaires per country

Country	#Parents' Associations Questionnaires	#Parents' Questionnaires
Austria	1	1
Belgium	2	10
Bulgaria	2	4
Croatia	3	3
Cyprus	3	0
Denmark	1	0
Estonia	0	3
Finland	3	3
France	4	5
FYR Macedonia	3	5
Germany	4	4
Greece	2	4
Hungary	3	6
Israel	2	3
Italy	9	19
Lithuania	2	2
Malta	0	2
Netherlands	3	4
Norway	0	1
Poland	4	19
Portugal	1	1
Romania	6	7
Serbia	3	3
Spain	5	7
Sweden	3	3
Switzerland	3	4
United Kingdom	0	3
Turkey	3	3
TOTAL	75	129

References

- 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: De Gruyter.
- Besio, S., Bulgarelli, D., & Stancheva-Popkostadinova, V. (Eds., 2017). *Play development in children with disabilities*. Berlin/Warsaw: De Gruyter.

Appendix



The COST Action TD1309 “LUDI – *Play for children with disabilities*” (2014-2018) is a pan-European network funded by the European Program COST (<https://www.cost.eu/actions/TD1309>) dedicated to the theme of play for children with disabilities, integrating more than 100 researchers and practitioners from 32 countries.

One of the tasks of the Action, managed by its Working Group no. 4, was to gather information about the children’s experiences and needs concerning play. To this purpose, a survey had been organized, conducted through the following questionnaire (developed by Serenella Besio and Pedro Encarnação), addressed to Parents’ Associations of children with disabilities. This questionnaire has been designed to be completed by a representative of the Association and by a parent of a child with disabilities affiliated to this Association.

If you are going to use the current questionnaire, you are kindly asked to cite the COST Action TD1309 “LUDI – *Play for children with disabilities*” as the project that developed this tool. Please, also communicate you are using the questionnaire, by sending an e-mail to the Chair of the Action, professor Serenella Besio: serenella.besio@unibg.it

June 2019

Questionnaire for a representative of a Parents' Association

Name of the respondent _____

Name of the Parents' Association _____

Country _____

Website address and/or alternative contact information

Type of impairment/disability represented

Please try and use the following list even if there isn't the precise category of your Association; or, choose "other" and add the category you wish

- Intellectual impairments (mild, moderate, severe, profound)
- Hearing impairments (partially hearing impaired – deaf)
- Visual impairments (partially sighted – blind)
- Communication disorders (language disorders)
- Physical impairments (mild, moderate, severe)
- Autism spectrum disorders
- Multiple disabilities
- Other _____

Age range of the children represented _____

Number of the Parents' Association members _____

Question 1. According to you as a representative, do the children with disabilities have sufficient opportunity to play according to their needs?

- No
- Yes, a little
- Yes, a lot
- Impossible to say in general

Please, use this space for any additional comments or explanation for answers provided

Question 2. Do you think that the parents of the children your Association represents are happy with their children's play?

- Yes
- No. *Could you write why, please?* _____

Question 3. Is play “for play sake” important for children with disabilities?

- Yes, definitely
- Yes, whenever possible
- No, play should have a goal
- No, play is not important

Please, use this space for any additional comments or explanation for answers provided

Question 4. What would the children with disabilities that you represent need in order to play (more, better)?

Please tick the column you prefer per each line

Needs	Not important	Somewhat important	Important	Very important
toys				
high tech tools (assistive technologies, robotic tools)				
peers (friends, other children)				
time				
adapted or special environments				
indoor environments				
outdoor environments				
a knowledgeable adult				
policy measures, financial resources				
improved skills needed for play				
societal attitudes and behaviours				
other; <i>specify below, please</i>				

Please, use this space for any additional comments or explanation for answers provided

Question 5. Where do the children you represent usually play and with whom?
Please tick the column appropriate for you

Where		With Whom				
		alone	alone, in presence of peers	peers (friends, siblings, ...)	parents, family members	other adults
indoor environments	home, other houses					
	school					
	culture and leisure centres for children					
	rehabilitation centre					
	other _____ _____					
outdoor environments	garden, courtyard, street, ...					
	playground					
	parks and natural environments					
	outdoor sport centre					
	other _____ _____					

Please, use this space for any additional comments or explanation for answers provided

Question 6. [optional] According to you as a representative, has any change occurred within the last five years that has improved the play of children with disabilities? To what extent?

Change in...		no	a little	much	very much
toys					
high tech tools (assistive technologies, robotic tools)					
indoor environments					
outdoor environments					
attitudes and behaviors of:	educators, rehabilitators				
	adults				
	peers				
	society in general				
other; <i>specify below, please</i> _____					

Please, use this space for any additional comments or explanation for answers provided

Thank you very much for your contribution!
The LUDI Network

Questionnaire for a parent of a particular child

Country _____

Family relationship (mother, father, guardian) _____

Age of the child _____

Gender of the child _____

Type of impairment/disability

Whilst we are aware that asking parents about the impairment type of their child may be a sensitive issue, we would be most grateful if you were willing share with us the nature of your child's impairment. Please consider which of these options best describes the impairment of your child. If none of these options is a perfect fit for your child please choose "other" and let us know of the particular needs of your child

- Intellectual impairments (mild, moderate, severe, profound)
- Hearing impairments (partially hearing impaired – deaf)
- Visual impairments (partially sighted – blind)
- Communication disorders (language disorders)
- Physical impairments (mild, moderate, severe)
- Autism spectrum disorders
- Multiple disabilities
- Other _____

As a parent of a child with disabilities, please write down the first three ideas/words that come to your mind when you think about your child's play

1. _____

2. _____

3. _____

If you have time to say why these words are important, then please do – this would be valuable information for us

Would you like to tell us where does your child usually play and with whom? [e.g., indoor (home, school, leisure centers, etc.), outdoor (courtyard, playgrounds, parks, sport centers, etc.); alone, with peers (friends, siblings, etc.), with parents and other adults, etc.]

What would your child need in order to play (for more time, more easily, more playfully)? [e.g., specialized or adapted toys, technologies, peers, time, improved skills needed to play, etc.]

Could you tell us how much time a day does your child spend playing?

If it is possible, would you like to interview your child concerning his/her play?

[For example: What do you like about playing, where do you like to play, with whom, and how...?

How do you choose your toys?

How do you feel when you play? How important is play for you?

What would you need to make your play better for you (more fun, more frequent, etc.)?]

Thank you very much for your contribution!
The LUDI Network