

# ID4IDS Methodology: Toward Inclusive Design for Individuals with Down Syndrome

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## ABSTRACT

Over the last couple of years, our research group has partnered with a local NGO aiming at improving expressive language, and reading and writing skills of children with Down Syndrome (DS) from low-income families in Mexico. Thus far, we have struggled to find an adequate design methodology that can incorporate parents, therapists, and children with DS. In this paper, we present the ID4IDS Methodology, an inclusive design methodology, which we expect will help provide adequate, technology-driven prototypes for supporting children with DS, their parents, and therapists.

## CCS CONCEPTS

• **Social and professional topics** → **People with disabilities**; • **Human-centered computing** → *User interface programming*;

## KEYWORDS

Down Syndrome, Participatory Design, Inclusive design

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## 1 INTRODUCTION

Among the different approaches available in the literature to conduct participatory design sessions with children with developmental disorders such as autism and Attention Deficit Hyperactivity Disorder (ADHD), little has been said about involving children with Down Syndrome (DS) during the technology design process. Most participatory design sessions reported in the literature involving children with developmental disorders pertain to autism [3, 7, 17]. For instance, in the work of [12], authors involved children in the design of an Internet-based application aimed at teaching Internet skills to individuals with DS, through design sessions with middle-functioning individuals with DS aged 16-23. The design sessions were aimed at testing different aspects relevant for the application such as user preferences, mouse control, and rate their preferences for sounds or images. The main goal was to obtain knowledge about how they learn and perceive, which were applied to the final design of the Internet-based application. The main contribution of this work was a set of recommendations related to fonts, graphics, images, animations, music and sounds, and buttons to be used when designing applications for children with DS. The design process they followed to involve adolescents and adults with DS consisted of two sessions held four weeks apart, where the first one was conceived to test modules, and the second one was to correct problems found in the first, or further confirm or test additional aspects. During the process, participants were told they were members of a design team helping create better tools and games. No mention of testing was made. Participants' actions were dynamically tracked and video-recorded for posterior analysis.

We draw upon their recommendations to propose a methodology, called ID4IDS (Inclusive Design for Individuals with Down Syndrome), that can serve as a baseline for designing with and for children with DS. Rather than focusing only on Graphical User Interfaces (GUI), the idea is that ID4IDS can

be used for designing technology that can be instrumental to performing activities by children with DS.

### Supporting Individuals with Down Syndrome

Down syndrome, also known as trisomy 21, is a genetic disorder considered to be the main cause of intellectual disability around the world, with a prevalence of 1 in 1000 live births [25]. Some of the physical characteristics of most people with DS are: a flat face, especially by the bridge of the nose; almond-shaped eyes, a short neck, small ears, a tongue that tends to come out of the mouth, small hands and feet, a single line along the palm of their hands, poor muscle tone and weak joints, and they are shorter than neuro-typical children and adults. People with DS are more likely to be born with congenital heart abnormalities, as well as an increased risk of developing hearing and vision problems, Alzheimer's disease, and other conditions. Similarly, they usually have an IQ in the low to moderate range and speak slower than their neuro-typical counterparts. Some people with DS might experience moderate to severe learning difficulties, while others have learning skills close to average. While individuals with DS have relative strengths in aspects of visual processing, receptive language, and non-verbal social functioning, they have relative weaknesses in gross motor skills and expressive language, and typically experience a delay in speech learning [4].

Several of these aspects have been addressed from the computing science perspective using diverse types of technologies, ranging from the use of videos to help people complete or learn to perform a task [18, 19], through the use of interactive educational applications [13], digital boards [8], video games [14, 23], alternative and augmentative communication (AAC) devices [2], tangible objects [10], virtual reality [1, 26], among others. Despite the novelty, innovation, and potential benefits that these technologies can provide, their access and adoption in developing countries such as Mexico are still uncommon.

## 2 CONTEXTUAL BACKGROUND

### Research Collaboration

Our research group has been working closely with CEART DOWN AC, a non-profit NGO in northwest Mexico, located in a city of about 400k inhabitants. CEART DOWN was established in 2013, with the goal of improving the opportunities of individuals with DS from low-income families through education, art sessions, and motor and cognitive therapies. It offers cognitive therapies focused on reading and writing skills, motor therapies to support eye-hand coordination as well as other activities such as teaching them to perform tasks to support independence (e.g., buying groceries). For these services, parents pay a symbolic fee. Thus, given the target

population, there are a few challenges regarding access to technology for supporting their educational and therapeutic activities (e.g., lack of financial resources).

For over a year, we have developed some research projects for CEART DOWN, including: a) A usability evaluation of commercially available Kinect-based exergames to identify important characteristics of children with DS that should be considered during the design of this type of technology [15]; b) The design and development of a gesture-based video game for supporting eye-hand coordination and literacy skills [24] and; c) the design and development of a tablet-based video game for supporting the control of the facial muscles that intervene in speech, which is still underway.

### Design Thinking Workshop

Two months ago, our research group conducted a design workshop, involving therapists from the CEART DOWN, as well as researchers and students majoring in Software Engineering, Mechatronics, and Multimedia Production Engineering. The main goal of the workshop was to design low-fidelity prototypes of technology-based tools aimed at supporting different developmental skills and addressing various challenges faced by children with DS.

The workshop roadmap was inspired on the design thinking methodology [20]. The specific workshop's activities and their outcomes were:

- First, the therapists from CEART DOWN introduced the therapies and activities that they perform with children, explaining the overall purpose of the therapies and the developmental skills that they would like to support and improve in children.
- Next, the attendees were organized in work groups, balancing off group members from different universities and technical backgrounds.
- Then, each group was asked to define a series of relevant issues that children with DS face with the goal to design technology-based tools to address these issues. For this activity, they had to define two personas, a boy and a girl, based on which each team member had to define particular needs or challenges, the benefit of solving the need for the child, three ideas to address the need, and a definition of the problem that encompasses the previous elements. The last activity was a collaborative activity.
- Each group worked on six design proposals for the issues/needs they had previously defined. Each proposal was then used to construct a low-fidelity prototype based on paper and color markers. Each member was provided with different color stickers to rate each of the proposals, considering three criteria: therapeutically realistic, technologically feasible, and commercial

viability. Attendees went around the room and placed their stickers on design proposals other than their own.

- Next, each group was asked to select the design proposal with the most balanced number of stickers. That is, the proposal that, according to the other participants, was the most balanced in terms of the three aforementioned criteria.
- Finally, each group worked on the feedback received and gave an oral presentation about their final design.

In the end, four design spaces were identified for further exploration: identifying sound levels and help modulate children voice and volume, recognizing money value and quantities, stimulating attention activities, and a communication aid for children who have trouble producing words.

Although these design spaces were proposed based on the needs of individuals with DS and their therapists, we identified the need to involve children with DS in the design of these potential tools. The foundations of human-centered design highlight the importance of including end-users in early design stages to obtain a successful final design that can meet the needs of stakeholders [22]. For that reason, the ultimate goal of our research group is creating or developing an inclusive methodology that can provide our research group general guidelines for our research process in designing technology for and with children with DS, regardless of the specific challenges or developmental skill that would be supported.

As mentioned, different approaches have been documented to serve as a guide to conduct participatory design with children with developmental disorders such as autism [7, 17]. However, not so much has been explored involving individuals with DS in the design process of the technology. We plan to draw on this literature to consolidate the ID4IDS Methodology. Finally, we would like to explore the particular aspects of the methods proposed in the literature that can work out with this population.

Among all projects that we plan to develop with CEART DOWN, we selected one to illustrate the use of the proposed ID4IDS Methodology. The selected project is the aid for communication among parents, therapists, and individuals with DS.

During a contextual study in CEART DOWN, communication was a topic of interest for mothers of children with DS and their therapists. Recently, we carried out semi-structured interviews with 14 mothers of children with DS to study mastery motivation [16]. The main topics included were related to the characteristics of activities developed by children with DS in their daily life, the places where they perform them, and the kinds of behaviors exhibited by children with DS in failure or success when performing these activities. All interviews were recorded and verbatim transcribed. Although

analysis is currently underway, one of the main emerging topics was the difficulty of their children to communicate with the people around them, even with close family members.

### 3 ID4IDS: OUR PROPOSED METHODOLOGY

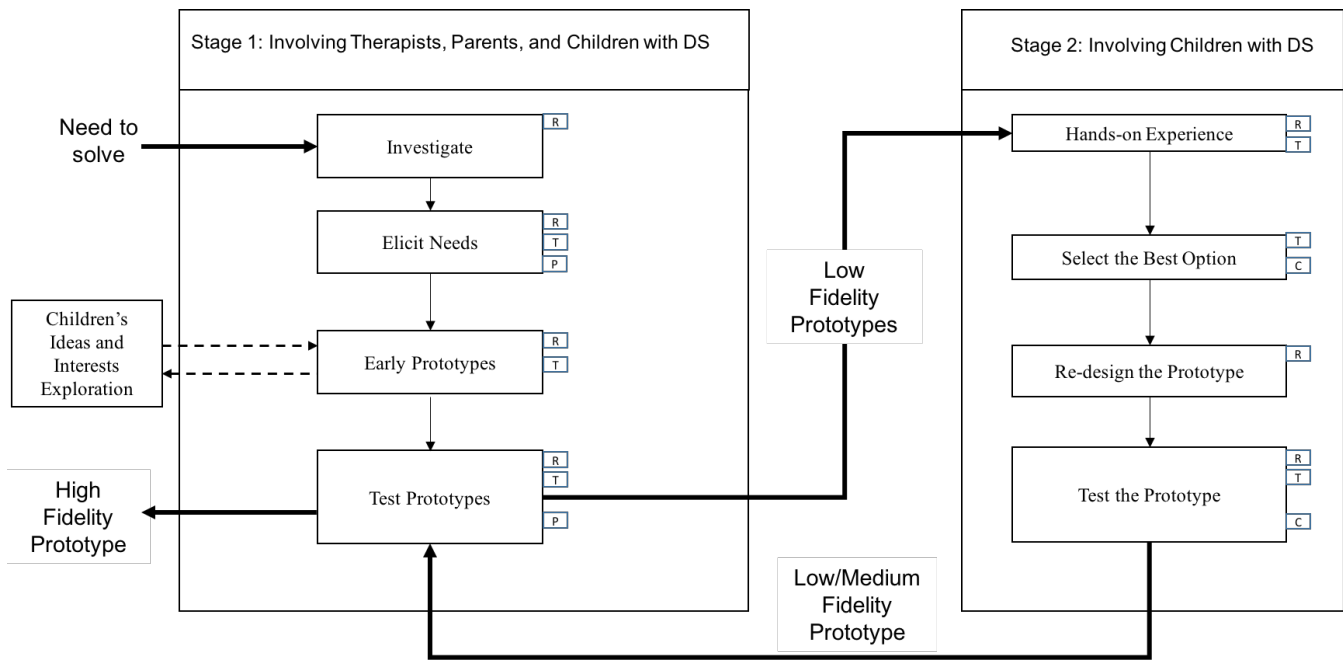
Our proposed methodology, called ID4IDS, consists mainly of two stages (see Figure 1): first, involving therapists, parents, and individuals with DS, is the first step in the design process. Second, after some refinement, it involves exposing children with DS to different design activities taking ideas from the first stage as a departure point, and producing a low/medium fidelity prototypes. The entire process is iterative until a final high fidelity prototype has been created.

It is important to mention that our proposal shares some similarities with other methodologies. For example in [17], the authors implement a participatory design strategy to develop a kinect-based game for autistic children. The methodology includes activities to define the pedagogical goal of the project, sessions for children with autism to propose the design in earlier stages (departing from an initial idea), development of prototypes, and a continual feedback from children. However, one key aspect central to our proposal methodology, is the relative creativity possessed by individuals with DS [11] for enriching the final design.

#### Stage 1: Involving Therapists, Parents, and Children with DS

In this stage, we propose to develop the following activities with therapists and parents of children with DS using a design thinking approach [20]:

- (1) *Investigate*: Once the problem space has been defined, investigate the relevant information about it, including related and commercially available technological tools. This activity is a review of what has been done relating to the topic of interest.
- (2) *Elicit needs*: Conduct a contextual study using data collection methods such as semi-structured interviews, observation, focus groups, and cooperative inquiry [5]. This activity is related to the first stage of the design thinking methodology, where the goal is to empathize with end users. In our case, the goal of this activity is to harmonize the distinct views on what are the most important needs regarding developmental aspects of children (e.g., physical, social, psychological needs).
- (3) *Early Prototypes*: Using the results of the contextual study, conduct design sessions with therapists to propose low-fidelity prototypes to address the problem. This phase is related to the *ideate* and *prototype* stages of design thinking. For our particular case, this activity needs to make sure that the proposed ideas



**Figure 1: proposed Methodology.** Shows activities and participants in each stage. Small box next to activities describe the participating role: (R) researcher, (T) Therapist, (P) Parent and (C) Children.

are addressing the children’s needs from a therapeutic/educational standpoint, and harmonized with the results from the *Children’s Ideas and Interests Exploration* activity. Parents involvement at this stage should be limited, since the therapists’ concerns related to the needs of children with DS greatly differ from those of the parents. To illustrate this, in a situation explained by one of the mothers during our field work, when we asked: *What action do you usually perform when you see your child facing a difficult task?* Almost all mothers answered that the child might try to solve the task by herself, without her direct intervention. However, when the therapist was asked the same question, her response took a different direction, explaining that in her day-to-day interaction, mothers will not see their children face any unusual activity because they are immediately trying to help them to solve it, even when the child does not request it. Parents tend to diminish children’s therapeutic or educational needs, sometimes due to a feeling of denial, but others as a mechanism to cope with stress, favoring a positive perception of the situation [9].

- (4) *Children’s Ideas and Interests Exploration*: This is an desired but not mandatory activity parallel to *Early Prototypes*, aimed at collecting ideas and interests from children to be applied to prototypes. For instance, if

we want to support a reading activity through a story-based didactic strategy, then this activity is responsible for gathering the story characters (e.g., cars, people, animals), the desired scenarios (e.g., beach, city, school), and so forth. We believe this is feasible, given that children with DS could create things using only their imagination [11].

- (5) *Test Prototypes*: Develop a testing/feedback session with parents and therapists with the aim of investigating their perception about the proposed prototypes. If needed, the proposed prototypes will include the parents’ feedback and carry out the testing session again. This will be done until parents do not have any further feedback. The last phase relates to the test stage of design thinking.

### Stage 2: Involving Children with DS

This stage is to select a prototype and carry out a usability testing session, where children with DS provide important feedback, explicit or implicit, about the prototypes to select and design the final version. The activities in this stage are essentially iterative, with testing sessions followed by refining the prototypes taking into account user observations. To do so, we propose the following steps:

- (1) *Hands-on Experience*: Show the prototypes to children with DS and therapists in a group session. Here, it is important to promote the participation of children in a

hands-on experience with the prototypes, so that they can express their opinions later. Due to the age range of individuals who attend to CEART DOWN, we are planning to conduct game-like sessions, considering that in previous works [15, 24] children have been willing and motivated to participate in any game-based activity. It is important that all sessions are video-recorded for posterior data analysis, preferably from multiple angles.

- (2) *Select the Best Option*: Once the Hands-on Experience activity has ended, we propose to conduct a session where children can choose the best prototype from their point of view. The main challenge of this activity is obtaining the children's preferences in their accounts avoiding the assistance of therapists. Techniques like *Sticky Notes*, *The Fun Toolkit* [21], and *This or That* have the potential to be used [6]. However, we propose listening to therapists' assessments and recommendations prior to the application of any technique, considering the valuable feedback obtained from therapists in previous studies.
- (3) *Re-design the Prototype*: Reshape the low/medium fidelity prototype to take into account design insights based on data analysis from the first two phases of this stage, and consider the insights found in the literature regarding applications for children with DS (e.g., fonts related information, color considerations, graphic/image presentation and content, animation, music and sounds reproduction [12]).
- (4) *Test the Prototype*: In this activity, children use the prototype to perform one or more simple tasks. Parents or therapists are also welcome to participate if the scenario requires it. The session must be recorded for further analysis. In addition, all participants should answer a questionnaire to investigate their opinions about the prototype. In the case of children, a scale using emojis such as *The Fun Toolkit* [21] can be used to decrease the participation of the therapist as a proxy. The research group must analyze the videos and questionnaires to obtain the feedback to improve the prototype. After feedback, children may need to test the prototype once more.

#### 4 CLOSING REMARKS

In this paper, we presented ID4IDS, a methodology for Inclusive Design for Individuals with DS. We have implemented the ID4IDS Methodology in designing technology-based prototypes with children with DS who receive cognitive and motor therapies at a NGO in Mexico. We expect to evaluate, refine, and consolidate the ID4IDS methodology during our upcoming projects aimed at supporting communication with

active participation of parents, children with DS, and therapists. Our focus is to establish a well-suited methodology to be used for the design and development of technology for children with DS, particularly taking into account the characteristics of the target population.

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#### REFERENCES

- [1] Catia Afonseca and Sergi Bermudez i Badia. 2013. Supporting collective learning experiences in special education. In *Serious Games and Applications for Health (SeGAH), 2013 IEEE 2nd International Conference on*. IEEE, 1–7.
- [2] Elizabeth E Biggs, Erik W Carter, and Jenny Gustafson. 2017. Efficacy of Peer Support Arrangements to Increase Peer Interaction and AAC Use. *American journal on intellectual and developmental disabilities* 122, 1 (2017), 25–48.
- [3] Peter Börjesson, Wolmet Barendregt, Eva Eriksson, and Olof Torgersson. 2015. Designing technology for and with developmentally diverse children: a systematic literature review. In *Proceedings of the 14th international conference on interaction design and children*. ACM, 79–88.
- [4] Stijn RJM Deckers, Yvonne Van Zaalen, Judith Stoep, Hans Van Balkom, and Ludo Verhoeven. 2016. Communication performance of children with Down Syndrome: An ICF-CY based multiple case study. *Child Language Teaching and Therapy* 32, 3 (2016), 293–311.
- [5] Allison Druin. 1999. Cooperative inquiry: developing new technologies for children with children. In *Proceedings of the SIGCHI conference on Human Factors in Computing Systems*. ACM, 592–599.
- [6] Jerry Alan Fails, Mona Leigh Guha, Allison Druin, et al. 2013. Methods and techniques for involving children in the design of new technology for children. *Foundations and Trends® in Human-Computer Interaction* 6, 2 (2013), 85–166.
- [7] Christopher Frauenberger, Judith Good, and Alyssa Alcorn. 2012. Challenges, opportunities and future perspectives in including children with disabilities in the design of interactive technology. In *Proceedings of the 11th International Conference on Interaction Design and Children*. ACM, 367–370.
- [8] Carina González, Aurelia Noda, Alicia Bruno, Lorenzo Moreno, and Vanesa Muñoz. 2015. Learning subtraction and addition through digital boards: a Down syndrome case. *Universal access in the information society* 14, 1 (2015), 29–44.
- [9] Ashum Gupta and Nidhi Singhal. 2004. Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal* 15, 1 (2004), 22–35.
- [10] Janio Jadan-Guerrero, Javier Jaen, María A Carpio, and Luis A Guerrero. 2015. Kiteracy: a kit of tangible objects to strengthen literacy skills in children with down syndrome. In *Proceedings of the 14th International Conference on Interaction Design and Children*. ACM, 315–318.
- [11] James C Kaufman. 2016. *Creativity 101*. Springer Publishing Company.
- [12] Assadour Kirijian, Matthew Myers, and S Charland. 2007. Web fun central: online learning tools for individuals with Down syndrome. *Universal Usability: Designing Computer Interfaces for Diverse User Populations* (2007), 195–230.

- [13] Hannah Kirk, Kylie Gray, Kirsten Ellis, John Taffe, and Kim Cornish. 2017. Impact of Attention Training on Academic Achievement, Executive Functioning, and Behavior: A Randomized Controlled Trial. *American journal on intellectual and developmental disabilities* 122, 2 (2017), 97–117.
- [14] A Lopez-Basterretxea, A Mendez-Zorrilla, B Garcia-Zapirain, A Madariaga-Ortuzar, and I Lazcano-Quintana. 2014. Serious games to promote independent living for intellectually disabled people: Starting with shopping. In *Computer Games: AI, Animation, Mobile, Multimedia, Educational and Serious Games (CGAMES), 2014*. IEEE, 1–4.
- [15] Adrian Macias, Karina Caro, Luis A Castro, Veronica Sierra, Edgar A Ahumada, and Iván A Encinas. 2017. Exergames in Individuals with Down Syndrome: A Performance Comparison Between Children and Adolescents. In *International Conference on Smart Objects and Technologies for Social Good*. Springer, 92–101.
- [16] Adrian Macias and Luis A Castro. 2017. Mastery Motivation of Children with Down's syndrome in Naturalistic Environments. In *Proceedings of the 8th Latin American Conference on Human-Computer Interaction*. ACM, 20.
- [17] Laura Malinverni, Joan Mora-Guiard, Vanesa Padillo, MariaAngeles Mairena, Amaia Hervás, and Narcis Pares. 2014. Participatory design strategies to enhance the creative contribution of children with special needs. In *Proceedings of the 2014 conference on Interaction design and children*. ACM, 85–94.
- [18] Linda C Mechling and Beth Cronin. 2006. Computer-based video instruction to teach the use of augmentative and alternative communication devices for ordering at fast-food restaurants. *The Journal of Special Education* 39, 4 (2006), 234–245.
- [19] Linda C Mechling, Leslie S Pridgen, and Beth A Cronin. 2005. Computer-based video instruction to teach students with intellectual disabilities to verbally respond to questions and make purchases in fast food restaurants. *Education and Training in Developmental Disabilities* (2005), 47–59.
- [20] H Plattner. 2010. An Introduction to Design Thinking Process Guide. The Institute of Design at Stanford. (2010).
- [21] Janet C Read and Stuart MacFarlane. 2006. Using the fun toolkit and other survey methods to gather opinions in child computer interaction. In *Proceedings of the 2006 conference on Interaction design and children*. ACM, 81–88.
- [22] Yvonne Rogers, Helen Sharp, and Jenny Preece. 2011. *Interaction design: beyond human-computer interaction*. John Wiley & Sons.
- [23] Silvia Rus and Andreas Braun. 2016. Money Handling Training-Applications for Persons with Down Syndrome. In *Intelligent Environments (IE), 2016 12th International Conference on*. IEEE, 214–217.
- [24] Veronica Lizeth Amado Sanchez, Oscar Iván Islas Cruz, Edgar Armando Ahumada Solorza, Iván Alejandro Encinas Monroy, Karina Caro, and Luis A Castro. 2017. BeeSmart: A Gesture-Based Videogame to Support Literacy and Eye-Hand Coordination of Children with Down Syndrome. In *International Conference on Games and Learning Alliance*. Springer, 43–53.
- [25] Francine A van den Driessen Mareeuw, Mirjam I Hollegien, Antonia MW Coppus, Diana MJ Delnoij, and Esther de Vries. 2017. In search of quality indicators for Down syndrome healthcare: A scoping review. *BMC health services research* 17, 1 (2017), 284.
- [26] Yee-Pay Wuang, Ching-Sui Chiang, Chwen-Yng Su, and Chih-Chung Wang. 2011. Effectiveness of virtual reality using Wii gaming technology in children with Down syndrome. *Research in developmental disabilities* 32, 1 (2011), 312–321.