

Improving the Quality of Life of Persons with Intellectual Disabilities Through ICTs

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Abstract. Removing barriers to accessing Information and Communication Technologies (ICTs) by Persons with Intellectual Disabilities (IDPs) is crucial. Being excluded from ICTs implies being shut down from the information society, but also from accessing essential public services, as well as from the opportunity of living an independent life. The IdICT project has the general objective of increasing the competences of IDPs, their families and the professionals that work with them to exploit ICTs with a Quality of Life approach. To do that, a training platform and a training program has been developed and tested by IDPs, relatives and professionals in six European Countries.

Keywords. Intellectual Disabilities, Information and Communication Technologies, Training.

Introduction

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour, which covers many daily social and practical skills [1]. It implies limitation on learning skills to carry out their daily activities, to respond in different situations and different places. It is estimated that in the Member States in the European Union there are between 5 and 15 million citizens with intellectual disability [2].

Intellectual disability can be classified in mild, moderate, severe and profound. Mild and moderate represent at least the 90% of people with intellectual disabilities (IDPs) [3] and they usually require low supervision and assistance level that needs to be increased in stressing or unfamiliar situations. Family, caregivers or work supervisors normally provide this assistance.

Social inclusion is highly related with user autonomy to carry out activities of daily living, especially those classified as Instrumental Activities of Daily Living (IADL) because they may be performed as a co-occupation with other persons (e.g. communication management, community mobility, care of others, shopping, financial management, work, etc.) [4]. Family, caregivers or people in the close environment of the persons with intellectual disabilities are responsible in support of IADL and this makes that social inclusion has a strong relation with the presence of someone to accompany the inclusion process. It is here where the Information and Communication Technology (ICT) solutions to support autonomy in these IADLs arise as an opportunity for IDPs to increase their autonomy and self-esteem, thus promoting their social inclusion.

The use of new technologies in supporting IDPs is a resource used in recent years in various studies and by different entities. New technologies, particularly in the field of computer science, have proven to be useful in areas such as cognitive rehabilitation, sensory stimulation, learning literacy, alternative communication, adaptation to environments and situations with the use of virtual reality, etc. [5, 6, 7].

However, the standard software and existing commercial applications are generally not designed for that IDPs can use them easily, as they present complex environments and imply a high knowledge in the use of software. On the other hand, specific apps designed for IDPs are relatively low and are mostly used by specific professionals at therapeutic environments. Moreover, there is a lack of knowledge by users, professionals and relatives about which are the best apps (mainstream or specifically designed for IDPs) that could be used in different environments and situations (e.g.: relax, communication or mobility, among others). Therefore, there is a high risk for IDPs of being excluded from these technologies, which implies being shut down from the information society, but also from accessing essential public services, and from living an independent life. One of the most accepted models to assess the social and economic inclusion of IDPs is the Quality of Life for IDP Model.

Although the concept of Quality of Life (QOL) is not new, the professional or academic approach to its conceptualization and measurement in the field of IDPs is relatively recent [8]. The QOL concept includes the subjective and objective aspects that have a highest influence at the people's perceived quality of life, and that is composed of eight domains: self-determination, rights, emotional well-being, social inclusion, personal development, interpersonal relationships, and material and physical well-being. These domains can be grouped in three core QOL dimensions: Independence/autonomy; Social inclusion and civic participation; and Well-being [9]. Application of ICTs for IDPs must be evaluated based their contribution to Quality of Life dimensions. Nowadays, apps and Software solutions are not linked to QOL dimensions so they cannot be used with a clear purpose when families and professionals work with intellectual disabled people.

It is therefore very important to develop tools that make easier the use of ICTs by IDPs and hence, enhance their personal autonomy and QOL. For IDPs, life-long learning is not only about learning new skills, but also about inclusion and empowerment. Removing barriers to accessing ICTs is thus crucial.

The **IdICT project** seeks to respond to these challenges. IdICT (Development of a Training Programme to Improve the Quality of Life of Persons with Intellectual Disabilities using ICT Solutions) is a European Project, launched in September 2015 that has the general objective of increasing the competences of IDPs, their families and the professionals that work with them for exploiting ICTs with a Quality of Life approach.

1. Objectives and expected results

The IdICT project seeks to develop and test a training platform for users (IDPs), relatives and professionals that will allow them to search apps based on QOL criteria. To do that, a consortium formed by entities supporting the IDPs and technical/research institutions from 6 countries (Spain, Slovenia, Croatia, Italy, Portugal and Germany) will implement the following specific objectives:

- To identify main competences related to use of ICT by IDP with a Quality of Life approach.
- To identify, assess, prioritize and link to QOL dimensions the best “free of charge” existing ICTs following Universal Design Criteria (accessibility and usability).
- To motivate IDPs, their families and professionals, about the importance of the use of ICTs for improving their quality of life.
- To develop a Training Methodology, focused in the transference to accessible and usable guidelines addressed to IDPs, their families and professionals working with them about the appropriated use of ICTs.
- To develop an accessible and usable online Training Platform, supporting the Training Methodology, serving as a node or centralized connection point, linking to selected and grouped ICT tools.

To meet these goals, IdICT follows an innovative approach, based on the following milestones:

- Searching, linking and grouping existing ICT tools (Apps and Software) with each of the dimensions of QOL Model.
- Developing guidelines for proper use of those ICT tools (Apps and Software) with a Quality of Life approach.
- Involving IDPs and their families in this selection, linking, grouping and guidelines development.
- Developing accessible and usable training materials adapted to IDPs but also to the support environment (families and professionals).
- Developing an accessible and usable online Training Platform, where trainees and trainers can directly access to the training materials, guidelines and linked selected ICT tools (Apps and Software)

2. Methods

The implementation of the project is organised into the following phases:

1. **Identification, selection, prioritization, linking and grouping ICT solutions in each of the dimensions of the QOL Model.** To do this, the following activities have been carried out:
 - a. Selection of the criteria that should have the ICT solutions that are going to be included (open access, free/ow cost, international availability, multiplatform, usability, etc.).
 - b. Documental revision and compilation of existing materials that comply with the above criteria.
 - c. Selection of the most representative solutions.
 - d. Classification of the selected resources depending on: users’ profiles and needs, type of support needed, applications, QOL dimensions, etc.

2. **Development of Training Program and online Training Platform Specifications.** This has included:
 - a. the development of the methodological, educational and technological requirements for the idICT Training Program,
 - b. the usability and accessibility requirements for the platform,
 - c. the architecture and structure (mock-ups and conceptual design) of the platform.
3. **Development of Training Materials.** With the information of the previous phases, the training materials have been developed, including:
 - a. General materials about how to ease ICT access for IDPs.
 - b. Specific materials for each ICT solution, including description, guideline, good practices, examples and practical activities.
 - c. Training materials translations.
4. **Development of an e-Training platform.** Taking into account both the requirements (phase 2) and the materials (phase 3), the e-training platform has been designed to include help and tutorials, searcher and results (apps) grouped in categories, and an area of collaborative work.
5. **Validation.** In order to ensure the quality and applicability of the Training Materials, a Validation Action will be done at each country with 30-40 persons with Intellectual Disabilities, their families and professionals.

3. Results

The first result obtained (phase 1) has been the identification and selection of ICT solutions, related to the needs of users, professionals and relatives. To identify the requirements and needs, an initial questionnaire has been developed and carried out by 31 professionals from different centres. The following aspects have been covered with this questionnaire:

- ICT devices used at the centres with IDPs: Desktop computers are the most used devices. These are owned mostly by the centre and used both individually and in-group activities. Android smartphones are also frequently used (mostly individually and with the own users' smartphones). Android tablets and laptops have a medium use, while Apple devices are barely used.
- How these ICT devices are being used? Centres use ICTs mainly for the following purposes (ordered by frequency):
 - Specific activities on ICT (computer learning, learning to use software, etc.)
 - Support for other activities / workshops held in the centre (search for information, tutorials, learning, cooking workshop ...)
 - Leisure (both supervised and free)
 - Communication (mainly internal)
- Types of apps and software used at the centres. Internet and internet-based apps are the most used tools at the centres (google, youtube, email, etc). Traditional computer apps (word processing, presentations) are also frequently used. Lastly, specific IDPs apps have a medium (and decreasing) frequency of

use: cognitive training apps and adapted games are the most used at this category.

- Problems detected in the use of ICTs and apps with IDPs. The difficulties in finding apps suitable for users with different disabilities is the most common problem that hinders the use of ICTs. Other important problems are:
 - Lack of knowledge on which ICTs and apps can be used with IDPs and how.
 - Lack of time to find and test apps
 - Limited financial resources to purchase specific apps.

Using the information obtained above, a second questionnaire was prepared to identify and assess the specific apps that are being used at the centres. A total number of 41 apps were initially identified, described and classified. The following aspects have been the most relevant:

- Some apps (e.g.: Facebook, WhatsApp or YouTube) were mentioned by most of the centres.
- Mostly multi-language (60%). Some apps, although not multi-language, have a low language dependency (e.g.: are mostly visual).
- Mostly free (92%)
- Mostly multi-platform (Android + smartphone is the most frequent combination)
- Mostly mainstream/general apps (66%) instead of specific apps for IDPs
- Apps were described accordingly to their functionality and use with IDPs. The most common uses are communication (including alternative communication), multimedia, simplified environment, information, leisure and productivity. Six groups were created to gather all the apps covering the most frequent functions performed and demanded at the centres:
 - Cognitive stimulation
 - Communication and information (including AAC)
 - Entertainment and leisure
 - Health, active life, sport
 - Personal autonomy
 - Productivity
- Each country valued the apps with regard to their impact in the QOL domains. To do that, the professionals had to assess if the app could be identified at each of the dimensions of the domain and prioritize the 3 most important dimensions. A map with the weight of QOL domain per app was obtained using this technique (see figure 1).

After the analysis of the previous information, a focus group with professionals of the participant countries was held to decide the common apps that are going to be part of the platform and available for all the partners in all languages. 14 apps have been selected, matching the following criteria:

- Mainly mainstream apps (e.g.: Facebook), although there are some apps that are specific for IDPs.
- Multilanguage and multiplatform.

- Free (or having free open source alternatives).
- Covering the QOL dimensions (independence, social participation and wellbeing) and the main areas of interest (communication, cognitive stimulation, entertainment, active life, personal autonomy and productivity).

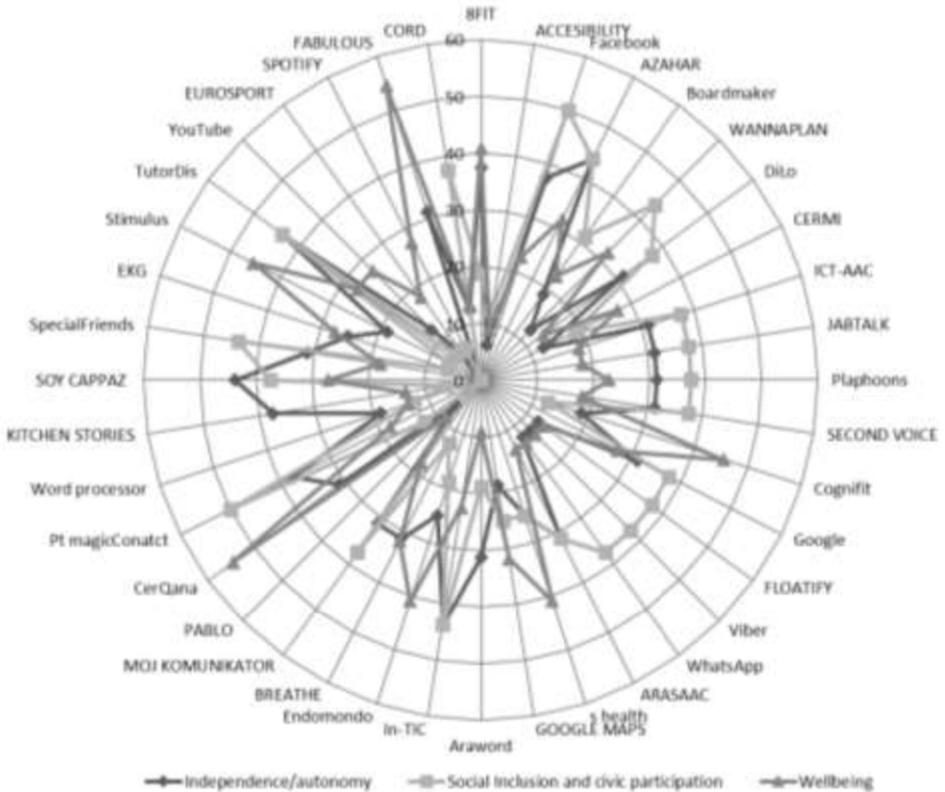


Figure 1. Apps classified according to their impact in the QOL domains.

At last, the partners have prepared the **training materials** about these apps, covering description, guidelines, tutorials, practical activities and reference resources. The materials use online and downloadable documentation, images and demonstrative videos. The direct access to the app is included whenever possible. Two versions have been developed for each app: materials for users (IDPs) and for professionals/relatives.

All these materials have been implemented into an **online interactive platform** that allows users, professionals and relatives to search apps and obtain detailed information and practical activities. The disabled users can, through an easy-to-use interface, search apps that can be useful for them to do daily activities (see figure 2). Similarly, professionals and relatives can search apps by the QOL dimensions or the main use. The platform also allows obtaining general information about how to use ICTs with disabled individuals.

I WANT TO / I WOULD LIKE TO...:



Figure 2. Screenshot of the online app searcher for IDPs (excerpt).

The online platform includes a **collaborative working space** (see figure 3) in order that all the stakeholders (users, professionals and relatives) can be in contact and prepare and follow activities and training sessions.

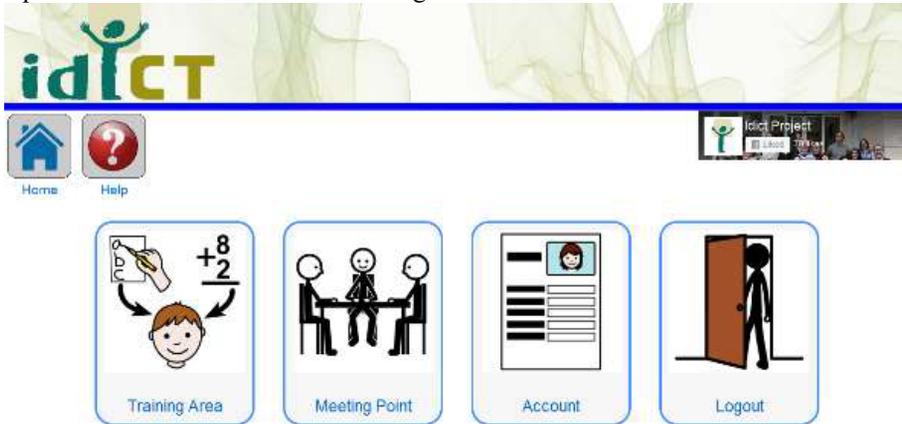


Figure 3. Screenshot of the collaborative working space.

The last stage of the project comprises a practical **validation process** that has started in February 2017 and will end in July 2017. Each country has arranged training sessions and activities involving 30-40 persons with disabilities, their relatives and professionals. The goals are:

- Testing the accessibility and usability of the platform,
- Assess the quality and usefulness of the developed training contents,
- Validate the training methodology and the tools used,
- Propose practical activities and also new apps and ICTs to be included at the platform.

4. Discussion

IdICT project has the goal of increasing the competences of IDPs, their families and the professionals that work with them to exploit ICTs with a Quality of Life approach. To do that, an online training platform and a working space have been developed.

The online platform includes an initial selection of apps that have been identified as useful for enhancing the QOL of IDPs. The selection of apps is the results of a process of identification of needs and demands by the relatives and the professionals working with IDPs. Each app contains information, tutorials, guidelines, examples and practical activities.

All these materials have been arranged in customized training sessions that are being validated and completed by users, professionals and relatives during 2017. After the validation, the complete platform will be available for use to all the interested.

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