



CENTERIS - International Conference on ENTERprise Information Systems / ProjMAN - International Conference on Project MANagement / HCist - International Conference on Health and Social Care Information Systems and Technologies 2020

“amik@” Social media platform for people with intellectual disability

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Abstract

Amik@ is an innovative project that connects people with and without intellectual disability (ID), in cherished and safe environments, through a digital platform that strongly follows digital inclusion principles. The Information, Communication and Technology (ICT) solution aims to promote interpersonal relationships and social participation of people with ID, in which life and learning experiences, provided by face-to-face social interaction, brings benefits to participants. A literature review was made on needs of individuals with ID, common attitudes towards people with ID, patterns of use of digital media by people with ID and guidelines that must be followed when developing solutions for improving accessibility of these groups to the digital world. Considering the evidence found, the technical and functional requirements of the solution were defined. Ongoing and future work includes coding the app, piloting and giving massive access to target groups.

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Peer-review under responsibility of the scientific committee of the CENTERIS - International Conference on ENTERprise Information Systems / ProjMAN - International Conference on Project MANagement / HCist - International Conference on Health and Social Care Information Systems and Technologies 2020

Keywords: intellectual disability; attitudes towards intellectual disability; digital media solutions; information, communication and technology solutions

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1. Introduction

People with intellectual disability (ID) are one of the most vulnerable groups in our society. Despite the new paradigms of inclusive education and professional training, there is still a trend to place these people in Occupational Activity Centers, specific residential environments for people with disabilities, or in Learning Support Centers at schools, while continuing to attend some mainstream classes, but always accompanied by a technician, which limits their natural interaction with other people. The evidence also shows the relevance for people with ID to be able to participate and make decisions in modern societies [1], as well as contributing to the creation of conditions to minimize the risk of morbidity, avoidable mortality, difficulty in accessing health services, health promotion and quality of life to which they are subject due to stigma and vulnerability.

The World Health Organization advocates that 15% of the world's population has some type of disability [2], with a rising increase in people with ID. People with disabilities should not be limited to their family or institutional support environment but effectively included in societal dynamics [3].

Digital media such as social networks and online groups promote the development of people with ID [4], helping in their training and supporting their autonomy, being also appropriate channels for establishing positive social relationships [5].

However, digital platforms that specifically encourage interaction between people with ID are scant. Hence, this project deserves attention as we willing to get people with and without ID to be connected through the use of an Information, Communication and Technology (ICT) solution that assures a safe and cherished environment by following the standard principles of digital inclusion. We structured the article as follows: a literature review on needs of people with ID, attitudes towards people with ID and patterns of use of digital media by people with ID; guidelines on developing accessible digital media for this group; amik@ project scope, requirements and features of the ICT solution.

2. Literature Review

2.1. Intellectual disability and Attitudes towards intellectual disability

ID refers to limitations in an individual's functional and adaptive behavior, namely in their learning, reasoning and problem-solving abilities [6]. Despite advances in contemporary society, people with ID continue to encounter difficulties of integration in the community and on performing their social roles with plenitude. These limitations generally lead to situations of poverty and deterioration in the health status of individuals [7].

In society, attitudes are not transmitted through inheritance, but built, acquired and learned through socialization [8]. The set of negative attitudes, beliefs or behaviors reflected in the negative attitude towards ID, can be experienced at all ages, from children to adults, in contexts such as school or work [6][9]. The development of high-quality social interactions with the person with ID and the context inherent to this experience are factors that minimize these negative attitudes [3][9].

However, positive attitudes are influenced by several physical, intellectual, social, emotional, clinical and occupational factors and, as such, are fundamental to education and to society, leading to decisions such as the social and psychological acceptance of the person with ID [8]. Evidence indicates an association between contact and education and the development of positive attitudes and stigma reduction, both in children and in adults [9]. A very positive impact is achieved, when people with and without ID interact socially, with common goals and over a long period, changing the perception of themselves and others [10].

Several instruments can be used to measure the attitude towards the person with ID, but we highlighted the Attitudes Toward Intellectual Disability (ATTID) questionnaire, because it has an excellent internal consistency and test-retest reliability and an adequate construct validity [7][11][12].

Recognizing the quality of attitudes towards ID is essential to: streamline policies and communities; increase the efficiency of programs aimed at people with ID; make attitudes more positive towards ID and educate and inform the general public [8].

Young people and adults with mild to moderate ID are often seen as objects of care and support. This protectionist attitude hinders the development of self-concept as citizens full of rights and duties. They want to be heard, treated

and accepted as other individuals, with the right to participate in decisions related to their own lives and having equal opportunities [13]. Furthermore, the self-concept in people with ID is influenced by a good social support network, namely quality friendships, support from colleagues and teachers, effective communication, parental support and parental education [14].

Similar to what happens with the general population, social interactions in our times are promoted by social media and can also result with people with ID.

The use of digital media, especially the use of social network, listen to music or watch videos, boosts autonomy and social skills, contributing to the increase in the quality of leisure time and enhancing new social and friendship relationships.

2.2. Digital media solutions

Digital media comprehend a broad spectrum of concepts, among which include social networks and social media, that provide an opportunity for people with ID to establish or increase the frequency and quality of their social interactions [15]. In addition to help fighting the feeling of loneliness, it may also contribute to their training and autonomy, as it constitutes an alternative and appropriate means of support, for the establishment of social relations [5] outside their family or institutional environment.

For this article, social media defined as “a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content” [16], and social networking (sites) is defined as “applications that enable users to connect by creating personal information profiles, inviting friends and colleagues to have access to those profiles, and sending e-mails and instant messages between each other. These personal profiles can include any type of information, including photos, video, audio files, and blogs” [16].

Several studies suggest that people with ID also obtain positive results when using social networks to create friendships, contributing to the development of social identity and self-esteem [17][18]. Scientific evidence has also shown that in addition to positive experiences, barriers exist for people with ID to successfully access social networks: concerns about security and privacy, accessibility and availability of support, difficulties with language and cyber etiquette, communication and literacy skills [19]. However, despite the strong motivation to learn how to interact in digital environments, and the enormous positive potential of using digital technology in the daily lives of people with ID, its use remains very low and much lower in participation in social networks [20].

People with ID are just like other people, they may have more difficulty in perceiving or learning new things, but if they receive clear and easy to understand information, they can learn and interact with other people, it is a right that is enshrined in the United Nations Convention on the rights of persons with disabilities [21].

The “Internet Accessibility Initiative” is an international association, which has developed important rules for the accessibility of digital information that considers challenges faced by people with disabilities. They suggest that all sites on the internet should be easy to read, and when this is not possible, there should be a link to another accessible reading page, as well as audio and video tools (sound and image). Additionally, the following rules were particularly designed for addressing the needs of users with ID (Table 1).

Table 1. Rules for an accessible digital media [22].

Domain	Rule
All	Get to know the population that is going to receive information or use social media Always involve people with ID in the process of creating information and digital media
Digital information	Use screen reading programs or synthesized voice messages or short films with narrators Use “meta-tag” on the home page or homepage, with “easy-to-read” words Avoid “Pop up”, can confuse some people Avoid using special programs that are too heavy, so as not to slow down the page or digital application display Bear in mind that users may have old or poor-quality technological devices Use search button on pages to facilitate the search for content

Connections	Underlining words can make reading more difficult for people with reading difficulties When the call is too long you should hide behind a word Make sure people know what information they'll find on new pages Indicate when a connection has already been visited, e.g.: Blue, if we haven't clicked on a link yet. Purple, if we already clicked Avoid putting a link to another page behind an image because it's not easy to find
Screen appearance	Putting little information on the screen is visible without having to scroll down Place text menu at the beginning of pages It is not necessary to walk to the right and left to read the text Leave space between paragraphs in the text of the screen as if it were a written document Don't put things in motion on the screen
Written information	Always use simple language appropriate to the age group Use words that people know well and always use the same word to describe the same thing Explain the subject clearly and explain the difficult words whenever you need to use them Do not use words from other languages unless they are well known Avoid using initials or abbreviations, if you need to use initials, explain Avoid information with very large percentages and numbers You should use words like too much and too little to explain what you mean Phrases should be short and positive, e.g.: "Stay until the end of the meeting" instead of "You should not leave before the end of the meeting"

3. Amik@: A solution to enhance the use of social networks in intellectual disabilities

Amik@ is a digital media that converges aspects of both social media and the social network, connecting youth and adults with ID with certified volunteers, allowing them to identify common interests and promote face-to-face social interaction through participation in activities, such as, trips to the cinema, library, tours, and snacks, previously agreed between users, and distance videocalls.

Although there are already several ICT applications on the market, amik@ aims to stand out from the others, allowing social interactions in populations often stigmatized by society, considering their particular limitations, difficulties, needs, and interests. Those interactions will support the development of social skills in real-life contexts.

The designation “amik@” was conceived and inspired by the word amiko (friend) in Esperanto, with the symbol “@” at the end of the word to include the female and male gender. Just as Esperanto is a language created to facilitate communication between people from all over the world, with the aim of making friends, participating in international events and discovering other cultures [23], amik@ intends to facilitate communication and promote cherished relationships between people with and without intellectual disabilities. Therefore, the intention is to develop an innovative tool in the field of interpersonal relationships and social participation of people with ID, in which life experiences and learning, provided by face-to-face social interaction, bring benefits to all participants.

Youth and adults with ID candidates as users of amik@ will be subjected to interviews by technicians from the social and psychopedagogy areas before being admitted and start using the application. Data such as interests, location or proximity, will allow amik@ to select the closest people geographically, filtering interests loaded in the youth and adults with ID user profile, to later present possible volunteer candidates in the application. Social factors such as race, ethnicity, income and religion will not be taken into account. The assessment of the functionality of youth and adults with ID, through applying WHO Disability Assessment Schedule 2.0 (WHODAS) will be also settled. Then, the dissemination of recruitment of amik@ among formal, informal and interest groups will take place.

The main focus to disclosure of volunteer recruitment will be volunteer associations and the general public, so they would be selected by an interview and ATTID questionnaire.

The project also includes training modules for volunteers, on communication and relationships with people with ID, before they start using the platform.

Through the consultation of volunteer profiles by youth and adults with ID and vice versa, the digital platform will allow participants to arrange joint participation in activities, such as: outdoor walks, snacks, concerts, cinema, football, among others. By accompanying youth and adults with ID in socio-cultural activities, the volunteers promote social participation of people with ID, thus contributing to their development and positive self-determination. On the other hand, volunteers will develop a positive and supportive attitude towards ID and collaborate in innovative volunteer programs, outside the traditional volunteer circuits, performing functions that will not be mistaken by the functions of other professionals in the field.

The specifications of the ICT solution that we intend to make available (table 2), will take into account the characteristics highlighted in rules for an accessible digital media (table 1), so that it becomes a truly inclusive platform for people with ID, counting on these people for the development of its features, going to meet their needs.

Table 2. amik@ specifications.

Technical requirements	Functional requirements
Android User	Periodic scheduled videocalls
iPhone User	Extra videocalls in case of need
Compatible with smartwatches	Appointments for scheduled activities
Compatible with desktop, laptop and tablet	Appointment alarms for scheduled activities
Access to Camera, Microphone, Location and Contacts	Agenda for scheduled activities
Live Streaming	FAQ's including visual and audio guide
	Advice on emergency situation
	Recommended and established exercises (with videos and photos)
	Exercises - log
	Exercises - scheduled
	Exercises alarms and reminders
	Blog
	Chat
	Podcasts
	Videocasts
	Integration with social media
	Points of interest
	Local weather

Due to the specific characteristics of the person with ID, the ethical component as well as privacy and data protection policy are ensured and considered as a priority.

3. Conclusion

The “amik@” project intends to impact on the health and well-being of a highly underprivileged population, due to their health / disability, social stigma and social isolation. Social interactions and community participation, involving significant and reciprocal relationships are essential for the quality of life of people with disabilities and critical for their social inclusion [24] [10]. Digital media can be used to facilitate social interactions and promote active participation in the community by people with ID, however, there are still some barriers on its use, like privacy settings, words with multiple meanings and cyber-etiquette and cyber-language [17][18]. Considering review of literature discussed above, the technical and functional requirements of an innovative ICT solution were defined. Ongoing and future work includes coding the app, piloting and giving massive access to the target groups.

Acknowledgements

We would like to thank Professor Vitor Duarte dos Santos from NOVA-IMS for the availability and interest in coding and piloting the solution.

References

- [1] McDonald, Katherine E., Conroy, Nicole E. and Olick Robert S. (2018) “A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree?” *Disability antfrd Health Journal* **11**: 345–350.
- [2] World Health Organization, 2011. World Report on Disability. [online] Malta: WHO Press, p.29. Available at: <https://www.who.int/disabilities/world_report/2011/report/en/> [Accessed 19 July 2020].
- [3] Boo, Lena Song Hui and Nie, Youyan. (2018) “Attitude Towards Persons with Intellectual Disability Scale: Further Development.” Springer Science, *Curr Psychol* **37**:760–768.
- [4] Andrew, Bayor & Sitbon, Laurianne & Ploderer, Bernd & Bircanin, Filip & Koplick, Stewart & Brereton, Margot. (2019). Leveraging Participation: Supporting Skills Development of Young Adults with Intellectual Disability Using Social Media. 143-155.
- [5] Suria, R. (2017). “Redes virtuales y apoyo social percibido en usuarios con discapacidad: análisis según la tipología, grado y etapa en la que se adquiere la discapacidad.” *Escritos de Psicología / Psychological Writings*, **10 (1)**: 31–40.
- [6] Harrison, Ashley J., Bisson, Jennifer B., and Laws, Carol B. (2019) “Laws Impact of an Inclusive Postsecondary Education Program on Implicit and Explicit Attitudes Toward Intellectual Disability.” *AAIDD* **57 (4)**: 323–336.
- [7] Palad, Yves Y., Barquia, Rensyl B., Domingo, Harvey C., Flores, Clinton K., Padilla, Levin I., and Ramel, Jonas Mikko D. (2016) “Scoping review of instruments measuring attitudes toward disability.” *Disability and Health Journal* **9**: 354–374.
- [8] Benomir, Aisha M., Nicolson, Roderick I. and Beail, Nigel. (2016). “Attitudes towards people with intellectual disability in the UK and Libya: A cross-cultural comparison”. *Research in Developmental Disabilities* **51-52**: 1–9.
- [9] Blundell, R., Das, R., Potts, H. and Scior, K. (2016) “The association between contact and intellectual disability literacy, causal attributions and stigma.” *Journal of Intellectual Disability Research* **60 (3)**: 218–227.
- [10] Kropp, Jerri J. and Wolfe, Brent D. (2018) “College Students Perceptions on Effects of Volunteering With Adults With Developmental Disabilities.” *Journal of Higher Education Outreach and Engagement* **22 (3)**: 93-118.
- [11] Morin, D., Rivard, M., Boursier, C. P., Crocker, A. G. and Caron, J. (2015) “Norms of the Attitudes Toward Intellectual Disability Questionnaire.” *Journal of Intellectual Disability Research* **59 (5)**: 462–467.
- [12] Chadwick, D., Quinn, S. & Fullwood, C. (2016). “Perceptions of the risks and benefits of Internet access and use by people with intellectual disabilities.” *British Journal of Learning Disabilities*. **45 (1)**: 21-31.
- [13] Byhlin, Sofie and Pia, Käckner (2018) “I Want to Participate! Young Adults with Mild to Moderate Intellectual Disabilities: How to Increase Participation and Improve Attitudes.” *Scandinavian Journal of Disability Research* **20 (1)**: 172–181.
- [14] Fonseca, I., Almeida, B., Roldão, S., Jesus, R., Lopes, J. and Santos, S. (2019) “O autoconceito na população com Dificuldade Intelectual e Desenvolvemental (DID) em Portugal: Revisão sistemática.” *Análise Psicológica*, **37**: 53-70.
- [15] Catona, S. e Chapmanb, M. (2016). “The use of social media and people with intellectual disability: A systematic review and thematic analysis.” *Journal of intellectual & developmental disability*. **41**:125-139.
- [16] Kaplan, Andreas M., and Michael Haenlein. 2010. “Users of the world, unite! The challenges and opportunities of social media.” *53(Generic)*: 59–68. DOI: <https://doi.org/10.1016/j.bushor.2009.09.003>
- [17] Kydland, Frederik, Molka-Danielsen, Judith and Balandin, Susan 2012, Examining the use of social media tool “Flickr” for impact on loneliness for people with intellectual disability, in NOKOBIT 2012 : Proceedings of the 2012 Norsk konferanse for organisasjoners bruk av informasjonsteknologi, Akademika forlag, Trondheim, Norway, pp. 253-264.
- [18] Caton, Sue & Chapman, Melanie. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability*. 1-15.
- [19] Rocha, Tânia (2014). “Tese de Doutoramento em Informática - Metáfora de Interação para o Acesso à Informação Digital de uma Forma Autônoma por Pessoas com Deficiência Intelectual.” *Universidade de Trás-os-Montes e Alto Douro*, Vila Real.
- [20] Patrick, P. A., Obermeyer, I., Xenakis, J., Crocitto, D. e O'Hara, D. M. (2017). “Technology and social media use by adult patients with intellectual and/or developmental disabilities.” *Disability and Health Journal*. **13 (1)**:1-5.
- [21] Inclusion Europe. (2015). “Não escreva para nós sem nós.” *Brussels. Belgium*. 1-12.
- [22] Inclusion Europe. (2015). “Informação para todos.” *Brussels. Belgium*. 1-44.
- [23] Gomes, S. (2016). “O Esperanto em Portugal.” Tese de doutoramento - Língua Internacional e Movimentos Sociais. *ISCTE-IUL, Lisboa*.
- [24] Simplican, S. C., Leader, G., Kosciulek, J. and Leahy, M. (2015). “Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation.” *Research in Developmental Disabilities*. **38**:18–29.