Multimedia Advocacy

A New Way of Self Expression and Communication for People with Intellectual Disabilities

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Abstract. The paper describes the early stages of one strand of an international project entitled Web 2.0 for People with Intellectual Disabilities (W2ID). The project team reports on a project pilot that involves five countries, 400 learners with Intellectual Disabilities (ID) (13 to adulthood), their teachers and supporters, developing rich media web content using Multimedia Self Advocacy Approach and the specially designed 'Klik in' platform.

The 'Klik in' Web2.0 platform was designed to enable people with ID to express their views and preferences using pictures, videos, sounds and text and to share these with their peers and supporters. Easy-to-use learning materials and a standardised pedagogic approach were also developed to assist learners and supporters throughout the project. The project is being monitored and evaluated using mostly quantitative instruments, although some qualitative data is also being collected and will inform final findings. The early results indicate that learners with ID are motivated to work with rich media content and the web 2.0 'Klik in' platform and are able to express their right to self advocacy.

Keywords: self advocacy, multimedia, digital inclusion, intellectual disability, web 2.0, klik in, website, internet, rich media content.

1 Introduction

The concept of Multimedia Advocacy was developed by researchers at The Rix Centre, based at the University of East London in the UK through their work with people with ID (Intellectual Disabilities).

The Rix Centre is a research and development organisation committed to realising the benefits of new media technologies to transform the lives of people who have ID. It combines expertise in practical development of products and services for this population, with academic evaluative research reflecting on its own activities for both selfimprovement and as a contribution to a wider pedagogical debate on using accessible information technology. The Centre's research involves the interplay between 'development activity' and 'research activity', weaving a path between the two streams of research and development. For example, web developers will take time out to reflect on their learning from the production process and a research project will incorporate practical development work to generate data and evidence. Thus, the research agenda is developed through a dialogue between developers, researchers and communities of existing and potential users, including people with ID themselves.

Multimedia advocacy or more accurately 'multimedia self-advocacy' is an approach employed by the Rix Centre whereby information technology is used with people with ID enabling them to self advocate. It mobilises people around specific topic and methods, which lend themselves to research practice. This is because in the gathering and imparting of the expertise required in multimedia production, the ICT itself – in the form of digital cameras, microphones and recording equipment etc. – facilitate research because they stimulate activity.

2 Self Advocacy

Self-advocacy is facilitated in three key areas: enabling people to express themselves in various situations; helping to promote self satisfaction, pride and confidence; enabling people to better understand information.

The term has been defined as an individual's ability to communicate effectively, convey, negotiate or assert one's own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions (VanReusen et al., 1994). The aims of research promoting self-advocacy include empowerment (e.g. Oliver, 1992), inclusivity (e.g. Walmsley, 2001), and self-reflection (Porter and Lacey, 2005). As Test (2005: p43) points out, 'Literature in both disability and educational research has identified the development of self-advocacy skills as crucial to the successful transition of students with disabilities into adult life'. Of course, self-advocacy skills do not come naturally – people need instruction in acquiring them (Test, 2005; Lehman, et al, 2000).

David Test and colleagues at the University of North Carolina at Charlotte (Test et al, 2005) reviewed the literature on self-advocacy, from which they constructed a 'conceptual framework' of self-advocacy for students with disabilities. The framework includes four components: knowledge of self, knowledge of rights, communication, and leadership. It is worth quoting the framework description at length, as it mirrors the views of the Rix Centre.

'Knowledge of self and knowledge of rights are viewed as the foundations of selfadvocacy, because it is necessary for individuals to understand and know themselves before they can tell others what they want. ... The next component ... is communication of one's knowledge of self and rights. Learning how to communicate information effectively with others through negotiation, assertiveness, and problem solving ... is critical to self-advocacy. The final component, leadership, enables a person to move from individual self-advocacy to advocating for others as a group of individuals with common concerns' (Ibid: p45). All these components of the framework devised by Test et al (2005) fit the work of the Rix Centre, with a central theme of its work encouraging participants to self-reflect, to learn about rights and services, and to communicate that knowledge. The final component, 'leadership' is of particular importance, as the Rix Centre is a strong advocate of peer support and sees this as a key aspect of self-advocacy. As found in Rix's own research (Minnion et al, 2008, 2006; Williams, 2008), people with learning disabilities have difficulty in putting themselves in the position of others, although there is some evidence that technology can help individuals do this (Williams, 2008).

3 The W2ID Project (Web 2.0 for People with Intellectual Disabilities)

In this EU funded project organisations from Portugal, Latvia, Finland, UK and Austria work together for 2 years. The primary aim of the W2ID project is to enhance employability skills and active citizenship of people with ID by developing and adapting an existing prototype Web 2.0 platform called "Klik in".



Fig. 1. Screenshot of the Web 2.0 platform Klik in; Pilotplan (www.klikin.eu/pilotplan)

The platform is designed to give people with ID a virtual space for creating knowledge and sharing their experiences and views of the work and life with others. Content identified as having most impact amongst people with ID is rich media content created by the users themselves via Web 2.0 technologies that share individual experiences. Hence the online platform consists of an accessible, easy-to-use content management system in the back-end, that enables people with ID to upload, organise and finally publish rich-media content within a given framework and a standardised frontend in form of a mind map-looking website for presenting, publishing and 'consuming' rich-media content produced by themselves.

In each country the project will culminate in the publication of a set of self-made multimedia websites that provide personal stories, information and guidance produced by people with intellectual disabilities. This peer support and learning resource will be accessed from a single national portal.

The W2ID Project focuses on three different target groups: school aged learners 13-18, adults aged 24+ who have an ID and 18-24 year olds with ID not in formal education, employment or training (NEET).

At the core of the project is to pilot the web 2.0 platform and its accompanying pedagogic approach within 5 European countries, evaluate and report on personal level outcomes and impacts among the pilot group of end users with ID.

4 End-User Pilot and Its Curriculum

This chapter briefly describes an extract of the standardised session plans, as it is an essential part of the accompanying pedagogy and evaluation design.

4.1 Session 1: Getting Started

Working with 'Klik in' starts with a brief introductory session for learners on the project itself and its goals. This is followed by the baseline analysis process, designed to find out about the pilot learners' present knowledge, confidence and skills in each of the four areas that the pilot intends to cover: Active Citizenship, Employability, Web & ICT and Communication.

Learners are introduced to the 'About Us' website in this first session and get an opportunity to experience how the 'Klik in' easy-build system works and how easy it is to use. The 'About Us' website is password protected, so it cannot be seen publicly on the Web.

4.2 Session 2: About Us

This session focuses on the class as a group as well as aiming to give website building experience to each individual, introducing and developing the activity of making multimedia by using photos, videos, audio and text to present yourself and talk about your life. There is a lot to learn in this session e.g. communicating in pictures, using cameras, recording video and sound. Adding titles and captions to pictures and how this can shape and change what they mean. Planning together using pen & paper or a white-board. Team-working skills etc. – plus of course 'How to make a 'Klik in' website!'

4.3 Session 3: Thinking Pictures

The primary aim of this session is a focus and practical examination of how to take effective pictures. What is a good picture? How can I express something with an image/picture? How do I want to present myself in public? What experiences do I have of publishing pictures on the Internet (e.g. on a social network like Facebook). These are some examples of questions that should be raised in this session. The aim is that learners learn to plan and take pictures in a more conscious and thoughtful way and then review them to make selections of the best images to use.

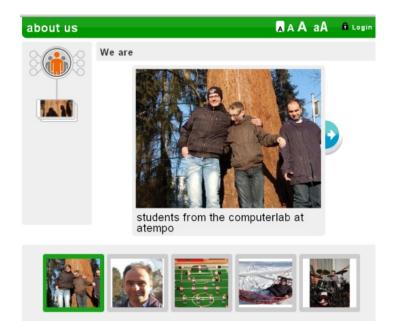


Fig. 2. Screenshot of the Web 2.0 platform Klik in; About us (www.klikin.eu/aboutus)

4.4 Session 4: Going Out

This session is about active participation in society. Out of many possibilities, we have elected to start with the general activity of "Going out" as a true-to-life example of how to actively participate in society. We talk about going out with friends or family, going to the movies, etc. It could be any "going-out activity" that learners suggest. In this session learners go out to public places of their choice and take pictures, record video and audio clips to represent places that are significant to them and share them with others. Their work is structured and guided by questions like: Why is it worth-while to go there? What do you like about that place/activity? Etc.

4.5 Session 5: Jobs and Activities

The focus of this session is the learners' personal experiences of work, jobs or everyday activities (e.g. supported employment, activities within a day center). School-aged participants or people without any job experiences can alternatively talk about their dream job or their ideas and wishes about work, volunteering or other activities that contribute to the community. The aim of the session is to share some of these experiences and wishes with others and find out more about learners' skills and abilities.

4.6 Session 6: Sharing

The last pilot session aims to give users the opportunity to visit the national portals to see what websites others have created. Viewing and experiencing the different multimedia outputs of other people with ID is a crucial part of Klik in. It enables pilot users to have additional learning experience, as they see what others have done and draw on their experience to evaluate the usefulness and quality of the material. They are taking a significant further step as they share their multimedia online via the national portal. This also provides opportunity for learning about risks and responsibilities as you publish content online. They review what they have learned and experienced during the pilot. At the end the learners finalise this reflective process by evaluating the pilot by completing questionnaires and feeding back their points of view.

5 Evaluation Design and Methodology

The evaluation is still in its early stages. It follows an explorative research design and therefore makes use of a multi-perspective approach to capture different points of view. It puts the main emphasis on the user's perspective, but also asks for the supporter's perception of the pilot and its impacts on people with ID as well as an analysis of the generated content output in form of created multimedia websites.

The methodology employed for the data collection and analysis is quantitative as it will provide good standardised, comparable data and results. We will also collect some qualitative data by asking open ended questions to address more difficult topics, such as changes in personality, self-perception or satisfaction.

5.1 Users Perspective

The users view will be captured at two different points in time: prior to the pilot workshops and at the end of the pilot delivery. The first survey will measure the pilot users existing knowledge, confidence, self advocacy and skills in areas such as employment, active citizenship and communication/ICT, providing a baseline for impact evaluation. The designed questionnaire is written in easy-to-read language and mostly easy answer categories are used (e.g. 4-point frequency scales).

This survey will also be used for setting individual goals. People are asked to say what they want to learn. The possible aims are partly predefined and orientated on the content of the standardised sessions – they reflect possible learning impacts and help users to focus on their goals for the pilot.

Within the impact survey in the last pilot session supporters repeat the set goals and ask the learners to assess if they have achieved the aims or not.

5.2 Supporters' Perspective

Supporters and teachers will trial the pedagogic approaches and the learning materials. Their experiences and perceptions during the pilot are essential components of the further development of 'Klik in' and the learning materials. Their perspective is a key resource for getting a richer picture of users' learning impacts and developments. The supporters' point of view will also be captured by a specially designed questionnaire that will cover the following: Learning impact of users (concerning the core themes, confidence, and motivation); Training of supporters (scope, contents); Learning materials; Conduct of pilot sessions; Challenges & lessons learned; Recommendations and improvements.

5.3 Analysis of Website Output

Another source of information on the pilot is the final output of the websites produced by participants.

According to the aims of the end-user pilot delivery a minimum of 8 websites per country should be produced (involving 80 learners). Partly the thematic orientation of these Websites is determined by the standardisation of the pilot (due to the general session plans), but there is still a lot of space for personal interests and individual priorities. Furthermore, the final focus and realisation of the content-output depends on the learners themselves and how the supporters lead the workshops.

5.4 Sample and Data Collection

The aim of the End-User Pilot is to implement and evaluate 'Klik in' with 400 Users with ID from the 3 target groups. This means that every partner organization is expected to involve 80 users. Because of different levels of learning disabilities and capacities it is improbable, that all participating users can also participate in the evaluation. Nevertheless, we aim for a total population survey, expecting as many users as possible to participate in the survey. The expected participation rate should be at least 50%, which means 40 users per country.

The expected distribution of participating learners is at least 30% school aged and 30% adults.

6 Outlook and Early Findings

The pilot was still continuing at the submission date of this paper in April 2012. Therefore it is not possible to present any empirical evaluation results. At the ICCHP statistical results as well as some case studies will be presented focusing on personal level impacts of users and possible fields of application of multimedia advocacy.

Within the Austrian Pilot an interim meeting took place, where the participating organisations reported their first experiences. In Austria, over 11 different organisations participate in the pilot. Most of them have a focus on digital inclusion and education. Some of these reflections conclude this paper.

In General learners were motivated to work with rich-media and the web 2.0 platform. They showed willingness and enthusiasm to actively participate in the sessions, take pictures of themselves and their colleagues and finally build their own websites.

All organizations unanimously assessed 'Klik in' as very user-friendly and reported that learners very fast found themselves able to use it independently and also felt confident in using it. Some of them experienced challenges in using the tool due to a lack of ICT knowledge and confidence in working with computers and multimedia.

Difficulties were reported concerning independent work and the responsibility to take one's own decisions (e.g. in selecting pictures or movies). Different pedagogic approaches were used. Some supporters provided more guidance and structure, but others preferred to hand over the projects lead to learners themselves and let them manage the pilot sessions with a lot of room to maneuver. One supporter reported an interesting development which leaves us with a lot of questions for the analysis of the evaluation data: "For our clients it was a totally new experience to be in control of a project, to realise, that it's their project and that they can decide what to do. At the beginning they were confused and overtaxed. But very fast the whole process gained momentum and they started to take the wheel".

References

- 1. Lehman, J.P., Davies, T.G., Laurin, K.M.: Listening to student voices about postsecondary education. Teaching Exceptional Children 32(5), 60–65 (2000)
- Minnion, A., Staples, P., Singh, R., Williams, P.: Beyond the Road Ahead London: University of East London Report submitted to the Social Care Institute of Excellence (2008)
- Minnion, A., Williams, P., Kennedy, H., Bunning, K.: Project @pple: e-learning and the World Wide Web Report submitted to the ESRC PACCIT Programme. University of East London, London (2006)
- Oliver, M.: Changing the Social Relations of Research Production. Disability Handicap & Society 7(2), 101–115 (1992)
- 5. Porter, J.M., Lacey, P.J.: Researching Learning Difficulties. Paul Chapman, London (2005)
- Test, D.W., Fowler, C.H., Wood, W.M., Brewer, D.M., Eddy, S.: A conceptual framework of self-advocacy for students with disabilities. Remedial and Special Education 26(1), 43– 54 (2005)
- 7. VanReusen, A.K., Bos, C.S., Schumaker, J.B., Deshler, D.D.: The self-advocacy strategy for education and transition planning. Edge Enterprises, Lawrence (1994)
- 8. Walmsley, J.: Normalisation, Emancipatory Research and Learning Disability. Disability and Society 16(2), 187–205 (2001)
- 9. Williams, P.: Transition and people with learning disabilities: reflections on the quality of content that emerges from the process of involving service-users in information provision Aslib Proceedings 60(5), 474–492 (2008)