

"Young and Enthusiastic": ICT-Based IADL-Training

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Abstract

In the research and development project "Young and enthusiastic", undertaken in Norway in 2009, areas of IADL-skills beneficial to mastering education and work situations were identified. Literature studies, informant interviews and meetings with the external expert group were used for information inquiry. We also investigated available ICT-based learning material. A national survey of available ICT-based programs in the identified areas of IADL was conducted. Finally, a web-based study on IADL-related needs was conducted. The web-based study revealed a set of major challenges for IADL-learning and -training, and pointed to areas in which there is a clear need for more IADL-training. One of the most consistent findings from the informant interviews and a group interview of young persons with intellectual disability is that youths with intellectual disability are highly motivated to use PCs and mobile phones, and that they manage to use ICT-based tools.

Keywords: Down syndrome, IADL, daily living, education, ICT, mobile phone

Introduction

The complex activities of daily living are called IADL (Instrumental Activities of Daily Living). Youths with intellectual disabilities need to be trained in IADL-skills to a much greater extent than other persons of the same age in order to develop mastery of their daily lives and to be independent. Individual learning plans should be made for school-aged pupils receiving special education. According to guidelines from Norwegian educational authorities (Norwegian Directorate for Education and Training, 2004), such plans should be made on the basis of the capabilities and qualifications of the pupil and the content of the curriculum for mainstream education for the relevant school level. It is mentioned that for some pupils the targets in special education could be related to basic skills in areas like self-care, communication, social roles and practical skills.

In the project "Young and enthusiastic" areas of IADL (Instrumental ADL) skills beneficial to mastering education and work situations were identified. Instrumental in this context refers to being complex. Training in specific work situations is not usually included in IADL (Tuntland, 2008), but many IADL-skills are important for mastering a broad range of school and work situations. Early training in such skills is beneficial for the feeling of success and her/his capability to perform work tasks, in supported or open employment work (after school/education).

Youths are in general enthusiastic about ICT, and we wanted to find out to what extent this also applies to youths with intellectual disability. Common ICTs, such as PCs, mobile phones and digital cameras, are widely used in Norway (Ministry of Government Administration, Reform and Church Affairs, 2006). In 2006 an education reform called

Knowledge Promotion introduced digital skills as the fifth basic skill in addition to reading, writing, oral presentation and mathematics (Ministry of Education and Research, 2006).

The first question we wanted to clarify was for which school- and work-related areas there is a need for training in IADL-skills. We also wanted to investigate what can be done on common technology platforms, such as PC or mobile phone, and to specify requirements for IADL-training programs on these platforms. The point of departure for the requirements specifications was how these technology platforms could be utilized to develop IADL-skills in particular, and to create better learning conditions in general. Before specifying the requirements, we also interviewed persons involved in teaching and caring of persons with intellectual disability and a group of young persons with such disability. We asked to what extent and in what ways young people with intellectual disability are interested in using new information and education technologies.

Methods

The important IADL-topics to train in our context were identified through literature (Tuntland, 2006), semi-structured informant interviews and the expert group of the project. The project leader also had experience from her son, a young man with Down syndrome, and his friends. Most topics were identified before the interviews started, but the informants were asked if they had topics to add to our list. A literature study of reports of electronic learning material for persons with intellectual disability was performed.

Interviews

Ten interviews were conducted with informants who had daily experience with persons with intellectual disabilities. The informants included teachers from schools at three levels (6-13, 13-16, 16-18 years), a mother, a folk school (kind of boarding school without any academic degree that many Norwegian youths attend for one year after secondary education), sheltered workshops and flats for people with intellectual disabilities. They provided information about what is trained, where the training is performed, and how the training in IADL is done within specific topics. We also asked which laws and regulations were followed when IADL-training was conducted in different places. The use of ICTs was of special interest in the interviews, particularly how young persons with intellectual disability learned to use it and how ICT-programs were used for education in other topics. Finally we examined to what extent young people with intellectual disability were interested in using ICTs such as PC and/or mobile phone.

Survey of available ICT programs

For our focus areas a survey of available ICT-programs in Norwegian for training children and youths with intellectual disability in IADL was conducted. The sources for this survey were first of all electronic databases for mainstream education and special education. Web-sites for producers and importers of special education software, the web-site for the Norwegian Institute for Adult Learning, the web-site for the Association for Persons with Developmental Disabilities, databases for technical aids, exhibition stands at conferences, and retailers selling electronic games etc. were also screened.

Focus group interview

A group interview of 6 young persons with mild to moderate intellectual disability was performed. They could all communicate orally and were asked to what extent they used ICTs, such as PCs, mobile phones, digital cameras, MP3-players and TV-games. They explained in detail what they used to do on PCs, such as using the internet (and what they used the internet for), playing games and using learning and other programs.

Web-based survey of key informants

Based on the identified focus areas for IADL-training, a web-based survey was performed. This survey covered both challenges in IADL-training and the need for training in specific activities. Both parents and professionals working with education services, caring and work services for persons with intellectual disability were invited to participate. Brief information about the study was given on web-sites for professionals working with persons with intellectual disability and web-sites for interest organizations whose members were mainly persons with intellectual disability and their parents. From these sites there were links to the survey itself. One of the interest organizations was a Down syndrome association consisting of both parents and professionals supporting persons with Down syndrome. Since e-mail information about the study was sent to parents in the Oslo-region, it is reasonable to assume that a large number of the parents who participated in the survey have a child with Down syndrome.

The respondents were asked about their relationship to persons with intellectual disability in order to know how many respondents were close relatives. Sub analyses were done for respondents who were parents/other relatives as well as respondents who were professionals, but these results are not presented in this paper. All participants were also asked if they worked with people with intellectual disability, and if so, what kind of workplace this was (kind of school, working arrangement, activity centre etc.). They were also asked to indicate whether they had experience from one or more persons with such disability. Further, they were asked to estimate the level of intellectual disability of the persons of whom they had experience (mild, moderate, severe, unknown, mixed). We also asked what the persons with intellectual disability were doing during the daytime (attending what kind of school, working arrangement, activity centre etc.).

Before the interviews, focus areas of IADL-activities were identified and discussed with the expert group of the project. Some topics, for example, socially acceptable behavior and personal hygiene were added. A detailed interview guide with both general and specific questions was developed for the interviews of professionals (teachers, work-leaders etc.) and of a parent. In the interview material, we looked for main trends and information about where IADL-activities were trained. For instance, training in the use of mobile phones was done at the interviewed secondary level school and in adult education, but in no other organization we contacted. Based on the results from the interviews, specific questions about the need for training in specified activities were developed for the web-survey. Some activities, such as using GPS, were not included in the web-survey as they did not seem to be considered as important IADL-activities by the informants.

Results

According to our investigations, the following focus areas within IADL are important for the schooling and work of persons with intellectual disability:

1. Management of time (both being able to know the time, handling time and appointments, and even delays and using a calendar).
2. Money/personal economy (both knowing the value of coins and notes, estimating the value of products and services, reasonable use of money, methods of payment and budget knowledge).
3. Transportation/mobility (using taxi and public transportation, finding the correct walking route, mastering traffic rules when walking, using maps, planning a travel).
4. Advanced communication (ways of contacting other persons, using mobile phones, using e-mail, storing details for contacting others, knowing who to contact for different reasons).
5. Media (other uses of PC and mobile phones in addition to contacting others, use of newspapers and magazines, radio, TV, digital cameras, MP3-players).

6. Household activities (preparing and doing cooking, setting the table, cleaning, washing clothes, tidying up, handling garbage). These activities are included as many persons with intellectual disability are doing such tasks in their work situation.
7. Mastering school and work situations (remembering to bring required items to and from school/home/workplace, communicating with parents and support personnel when needed, especially when problems occur, taking responsibility for work, being able to arrive on time, walking or using public transportation to school/work/activity centre, knowing and complying with regulations for school and work).
8. Social behaviour (including, but not limited to tackling delays, knowing when it is appropriate to contact others, knowing what to talk about in different situations, relationship to others, socially acceptable behaviour, acceptable hygiene).

The results from the interviews can be summarized in the following way:

1. Work leaders in sheltered workshops think many skills could have been trained earlier. Especially important is the development of socially acceptable behaviour and hygiene (including both personal hygiene and for clothing).
2. There is no standard for IADL-training for children and young persons with intellectual disability. There is no curriculum or checklist for what is important to learn if the potential for learning such activities seems to be present.
3. IADL-training (subjects and amount) is not only dependent on pupils and parents, but on experience, views and traditions of schools and individual teachers.
4. At schools and other institutions there is little training of young persons with intellectual disability in ICT apart from basic PC-skills. Only two of the informants said they were offering training in the use of mobile phones (at the lower secondary school and adult education). Furthermore, there was minimal interest in teaching pupils how to use digital cameras.
5. Children and youths with intellectual disability like to use PCs and mobile phones. Typically, the sessions using PC-programs last until the teacher stops them; the pupils themselves like to continue as long as possible. Mobile phones are usually not used in classes, but teachers and work leaders note that youths with intellectual disability use them often when permitted (in breaks etc.).

Results from the ICT-Survey

Programs developed for pupils with intellectual disability

In the survey, we found very few programs focusing on IADL and developed particularly for pupils with intellectual disabilities. Most of these programs were at a beginner's level. An example of this is time training just in hours,

half hours, quarters and 5- minutes, but not minutes and seconds. Often, such programs had rather childish graphics.

These programs were often only available on CDs, and had a much higher cost per pupil than online programs.

The fact that we only found a few programs in ADL-topics is consistent with the findings from a report published in 2008 (Directorate of Education and Training) about the need for specially adapted learning resources in Norway. This report was commissioned by the Directorate for Education and Training. It was based on informant interviews of persons involved in special education. It stated that most young persons with intellectual disability need specially adapted learning material. Many of them will have a need for training in basic skills and knowledge in secondary school in order to master daily life and society. They need wide multifunctional learning resources that could be adapted individually to the needs of each pupil. There is a need for digital learning aids that combine text, sound, picture and video.

Programs for mainstream pupils

Some of the identified IADL-activities were included in programs for mainstream subjects such as mathematics. There were many programs for children aged 6 to 10 years that included IADL-subjects such as time, date, money and basic PC-skills. Typically there was not very much focus on each IADL-activity, like telling the time, knowledge of money and shopping.

Interestingly, programs for mainstream schooling were in general not as childish as programs for special education. This seems to be due to a deliberate development from the national education authority after the introduction of the education reform in autumn 2006. Programs for special education were often older than this. Online programs were most often used for mainstream students together with text books. At the time that the survey was conducted, these programs were typically available free of charge.

Very often programs developed for mainstream education were not suitable for persons with intellectual disability. Most often literacy was assumed. Moreover, the older the target students, the more complex language and less motivating factors were used.

Web-based survey

There were 75 respondents in total. More than half of them were parents. Many parents were also professionals within relevant areas. 95 % of the respondents thought there were challenges with IADL-training and pointed out what kind of challenges they had experienced. 87 % of the respondents thought there was a need for more IADL-training than they had experienced so far.

Figure 1 shows the number of respondents who had experienced the different challenges. The figure shows the total number of persons who have ticked this issue, not percent of respondents (N=70).

Figure 1. Number of Respondents Experiencing Specific Challenges with IADL.

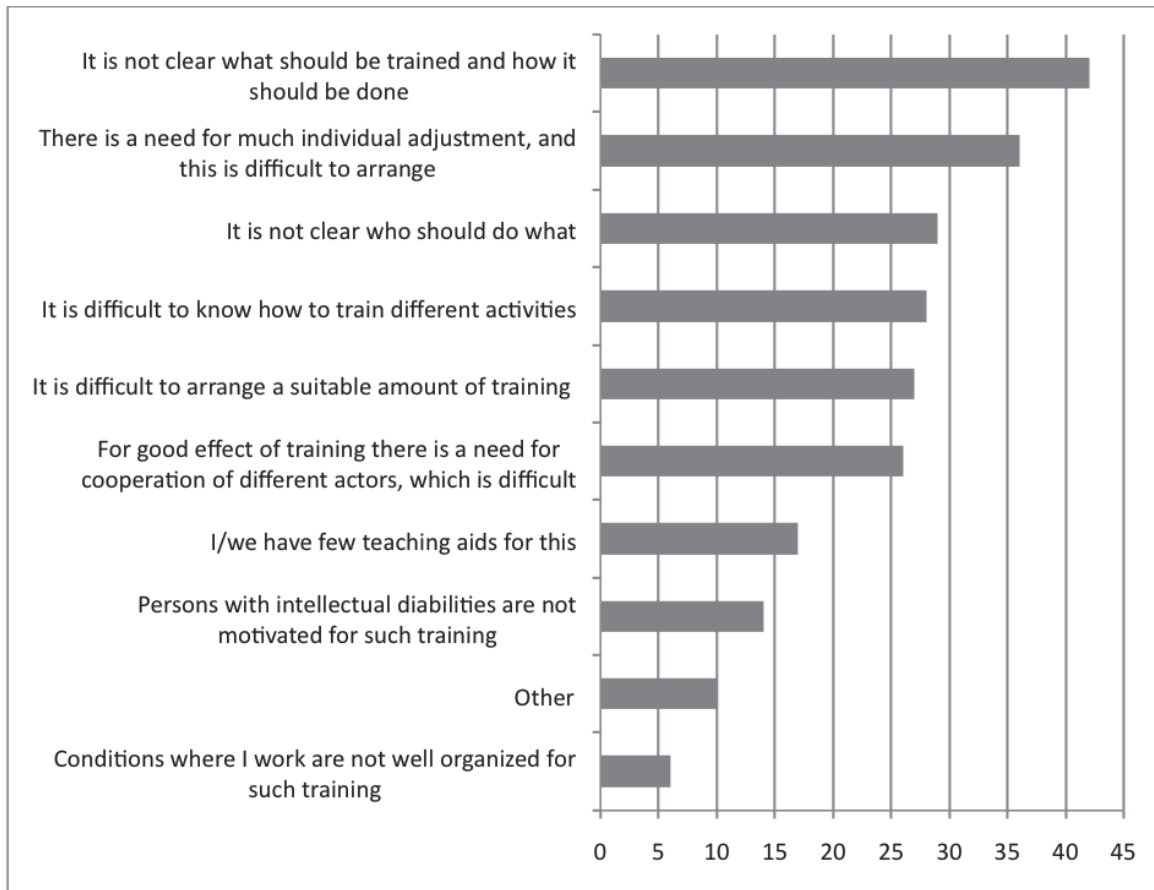


Figure 2. Number of Respondents Identifying Need for further Training in Specific IADL Activities.



The main issue seems to be that it is not clear what should be trained and how it should be done. This was experienced by 42 persons, or more than half of the respondents. Another important issue seems to be that many individual adjustments are needed in IADL-training (as pupils in special classes often are at different levels and have quite different needs), and this is difficult to arrange. Unclear responsibilities for who should do what kind of training also gets a high score, followed by "It is difficult to know in detail how to train different activities". Many of the respondents had not experienced a suitable amount of training. Typically there are some favorite activities such as baking Norwegian waffles. This is not very difficult, and it is often performed repetitively. Other training which is important for future life is often done very briefly.

With regard to the need for more training in IADL-activities related to education and work, 50 persons or 67 % thought socially acceptable behavior was important. Almost the same number of persons indicated the need for more training in handling money. Third in importance was household activities like cooking, cleaning and laundry. The same number of respondents thought there was a need for more training in managing changes in plans without being frustrated or otherwise unable to cope with it. Shopping and the use of money with care and personal hygiene, including changing clothes, were rated equally. This is followed by telling the time, taking responsibility for personal belongings and calculating available time.

The activities in figure 3 seem to be even more related to self-reliance and the basic use of mobile phones and PCs.

Figure 3. Number of Respondents indicating needs for IADL and related Training in Self-reliance and use of Hardware.

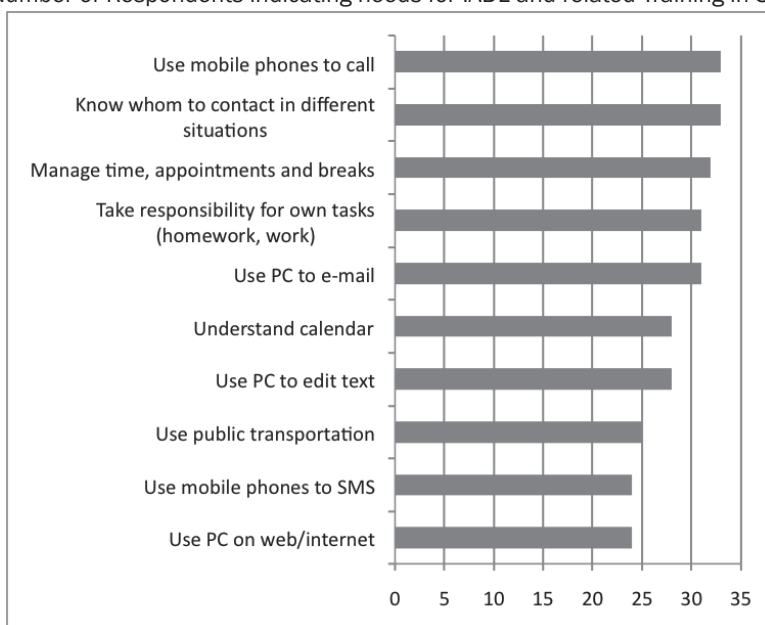
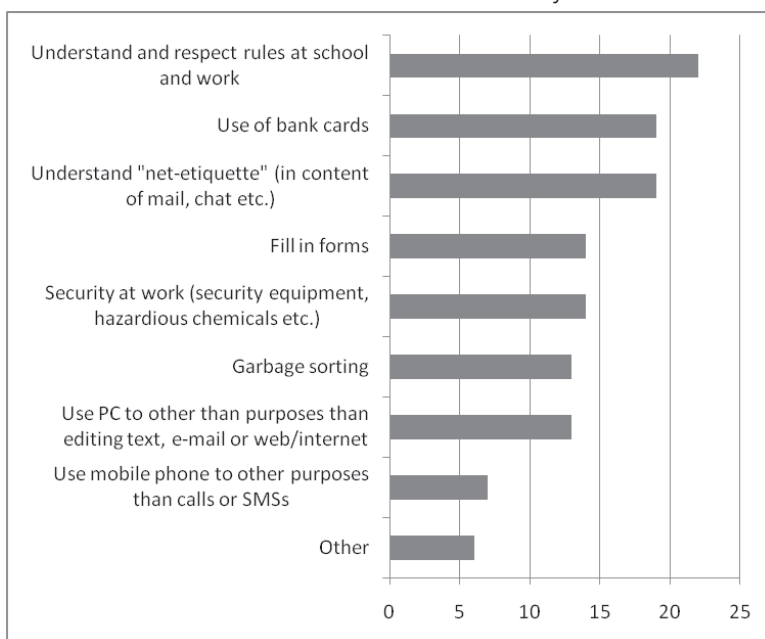


Figure 4. Advanced Activities believed to be Unrealistic for Many Persons with Moderate and Severe Intellectual Disabilities.



More than half of the respondents indicated that they had experience with persons with moderate intellectual disability, 12 % had experience with mild, 8 % severe and 23 % mixed groups. For many persons with intellectual disability of moderate degree the activities in Figure 4 are so advanced that mastery seems unrealistic.

Conclusions

IADL-training in Norway is not particularly well-structured, and there are many challenges related to such training. There is a clear need for more IADL-training in very many topics. The web-survey revealed alarming results with regard to IADL-training with three major challenges: 1) it is not clear what should be trained and how it should be done, 2) many individual adjustments are needed in IADL-training and this is difficult to arrange, and 3) it is not clear who should teach the youth what.

Youths with intellectual disability are highly motivated to use PCs and mobile phones and are often mastering the use of such information technology surprisingly well. There are few ICT-based programs within IADL that are suitable for youths with intellectual disability. Not any programs using mobile phone technology was found even if our target group is very enthusiastic about using such devices. The researchers believe that for youths with mild to moderate intellectual disability almost all IADL-activities mentioned in this paper can be trained by using such technology, supported by real life training. More research is needed to establish the learning effect of using communication technology to scaffold learning and independent living.

Recommendations

We recommend a more structured IADL-training for reaching the individuals potential for independent/self-dependent living. To obtain this the development of age- and capability-adjusted PC and mobile phone programs for IADL-training would be desirable. The training should be both theoretical and connected to real situations with real objects. The incorporation of self-produced material (such as photos, videos taken by teachers, pupils themselves and/or parents) seems very useful. This could easily make the youth understand how to do tasks in usual situations in his/her daily life. For example, photos of the different objects to be placed in the school bag or rucksack could help the youth to take responsibility for doing the packing himself/herself. Another example is a video describing how to buy a bus ticket at the local bus stop. The pupil could bring the bus ticket to school, register on the PC or mobile phone each time this is done, and a specific number of such registrations could lead to a diploma. For most people mastering activities of daily living and reducing dependency on others help to increase the quality of life. Many of the activities mentioned in the context of the web-survey may increase social inclusion.

Future work

As a result of the study presented in this paper, we have produced rather detailed requirement specifications for ICT-based programs for IADL-training, and are currently proceeding to the development of such software for PCs

and mobile phones. The project team is currently developing prototypes of mobile phone software to support IADL training. In connection with this software development it is important to develop guidelines for using the software, both for the pupils themselves, as well as their teachers, parents (and other family members), carers and work leaders. This is in line with the findings in the report by Directorate of Education and Training (2008), concluding that more information on using software in teaching is necessary.

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