EASPD PCT Newsflash 3

The Person Centred Technology newsflashes continue to highlight the benefit of PCT to individuals. These benefits are consistent with many service providers' values and, therefore, should be pursued irrespective of the economy. However, again, these newsflash articles show that PCT solutions might make people less dependent on people, and staff, and become more productive as citizens.

The first three articles demonstrate the benefits of PCT to individuals (once they know about the possibilities! – see the submission from Learning Disability Wales). The next two articles look at some of the barriers. It does still appear that PCT is led by technologists, which is certainly part of the problem. However, I would like to draw your attention to the comment by Karen Astegger 'Technology (AT) is not the solution. It contributes, but only when embedded in a holistic approach.' It is the approach that puts people at the centre of any PCT solution that is important and ensuring that any PCT development is accessible and visible, as highlighted by Karel Van Isacker.

However, the opening article in the form of a letter from Marilena and Carlo shows what can be achieved by people who are determined to take responsibility for their lives and where PCT can help. Their attitude is very different from the 'learnt dependency' that was reflected in the last newsflash, and encouraged by some support staff.

Finally, many congratulations to Evert-Jan Hoogerwerf for steering through a successful bid, ENTELIS, continuing the journey in raising awareness of PCT across Europe and beyond!

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A letter from our readers

Casalecchio di Reno (BO), 05/10/2013

Hi all,
We are Marilena and Carlo, a young couple living in the Province of Bologna. We both live with a rather severe motor impairment caused by severe spasticity in all four limbs of the body. We have difficulty performing the most common gestures of everyday life and both use an electric wheelchair for moving around. We also have some difficulty to articulate correctly.
Despite our severe motor disability, eight years ago we decided to start to live together independently. We bought a modest apartment on the ground floor of an apartment block and we made our environment suitable for the wheelchair. We further installed a home automation system called MyHome by bTicino, which allowed us to automate the home. The automation system which we control by smartphone, home phone and remote control, plays an important role in our daily life.
Examples of home automation functions that we use: with the home phone we can open the security door of the home and we can open the door of the our apartments building because the home phone also functions as an intercom;
with the smartphone we can operate: district heating, water the garden, open and close the pedestrian gate of the garden, open and close the shutters of the apartment and the sun shade. We can control these functions both inside and remotely outside of the house.
We also have a surveillance system connected to our smartphone, so when we are away from home we can control whether the pedestrian gate of the garden is open or closed, the apartment shutters are open or closed and whether the sprinkler in the garden is in operation or not. With a remote control we can turn on and turn off the lights of every single room of the apartment. With another special remote control, called Utility System, we are able to lower and raise the kitchen sink. This device is very useful to us because of our limited ability to stand upright and our limited possibilities of action and movement.
The realisation of our apartment with home automation is the result of our ideas and personal counselling received by the technical experts in the field of Ausilioteca AIAS Bologna non-profit organization.

Follow our example! Go independent.

Marilena Benassi e Carlo Cotali

News from Wales

At Learning Disability Wales we are convinced that person centred technology can really assist people with a learning disability to live more independent lives. We continue to highlight its advantages whenever the opportunity occurs and we can report on two good news stories about PCT from Wales.

In September, the Welsh Government launched its 'Framework for Action on Independent Living.' This key policy document marked the culmination of 2 years of consultation with the disability sector, key social and housing agencies and within the Government. In the words of ministers It is designed to be a" genuinely cross –cutting approach to addressing the barriers to inclusion that many disabled people face on a day-to-day basis." The Framework gives prominence to the promotion of person centred technology and quotes extensively from the findings of the Easpd 'ImPACT' project on PCT, citing its recommendations and the barriers to the adoption of PCT that it identified. Particular emphasis is laid in the Framework on the need to train social care staff in its use and its potential.

For more information go to:
wales.gov.uk/newsroom/equalityanddiversity/.../130916-disability-plan/?/lang=eng

In the autumn of 2012 and spring of 2013 we ran some practical awareness raising seminars about PCT devices and gadgets with the AIDIS Trust.
Michael Parsons and colleagues from a team at an n.g.o. who run a care home, Leonard Cheshire Disability, took part in one of the events. Recently Michael wrote to Learning Disability Wales to tell us that:
"as a direct result from that day, I am delighted to say that it was the backbone of our new communication project…. We have established a communication group, made up of management, staff, volunteers and residents, in order to identify each person's communication needs and work towards a common goal of improving communication, to and from those individuals."
Michael concluded that:
"The benefits of (the) seminar will be felt for years to come and will directly affect every person we support, their families, friends, volunteers and staff.
"So PCT really can make a difference for people with a disability and the people who support them.

Jim Crowe
Director
Learning Disability Wales

Ian's Story

About two years ago Ian moved into his own house under a 'shared ownership' scheme. He now has true 'home alone' time, does not have a staff member 'sleeping in' his house at night and travels to his voluntary job on his own. Ian moved from a 'care home' which he shared with seven other people.

Ian's move was made possible by an inspiring and committed care home manager who realised how technology delivered within a person-centred approach, could help people achieve greater independence and safety. The technology solutions that have been developed in this person-centred context is called personalised technology (PT) and includes ICT, telecare, mobile and prompting devices, mainstream and specialised technology.

The care home where Ian previously lived was one of the locations Hft, as part of an ESF project, looked at new technological solutions and how they could help the people we support.

Ian was one of the first to benefit from PT in the form of a 'disco shower'. This installation encouraged Ian to take control of his personal hygiene so he could maintain his employment.

However, once the care manager saw the opportunities, she wanted people to become more independent, move into the community and become tenants or owners of their own homes. To do this they would need a range of technology including telecare. A visit had been made to a 'state of the art' home for elderly residents.

However, it was clear that the telecare in the form of movement and door sensors were used to support the staff and not to support the residents.

This approach was unacceptable to both Hft and the Mental Capacity Act, which requires either consent from the individuals, or to know that the technological solution is in the person's best interest.

Hft developed a new ethical code that led to people taking ownership, as far as was possible, of their own technology. There is a video clip of Ian describing how his telecare works and this approach has led to Ian gaining a great deal of responsibility and independence.

Ian now has his home to himself for the first time, using a simple mobile phone enables him to go to work independently and not require any staff to sleep in his house.

Better all round for Ian and cheaper!!

ATLEC boosts uptake in Assistive Technology by People with Disabilities, their trainers and family

Recent studies throughout Europe [e.g. ACCESSIBLE, AEGIS (FP7 projects), and KA3 project ImPaCT in Europe] with over 1000 end-users and Assistive Technologies (AT) specialists, have revealed a number of barriers that block people with impairment to fully embrace AT. The core findings indicated that:

- about 80% of AT application software is available only in English, thus hardly usable in most EU countries;

- end users are largely unaware of the available AT solutions;

- in many cases even the supporting service providers are unaware of what is on the market;

- the distribution of AT still mainly goes through traditional rehabilitation centres, and also depends on its occurrence on reference lists (list of AT approved for funding by local or national social security funds);

- the organisation of national and local agencies assisting and supporting people with disabilities and the expected experience of staff varies greatly between countries;

- the possibilities for trying out AT before purchase varies greatly between countries, and in many cases is not even possible;

- the lack of training by people with disabilities in being aware of relevant AT and how to use them is omnipresent throughout Europe.

The above findings are obviously main barriers for people with impairments in being confident in using AT, and hamper their struggle in gaining employment in the regular labour market.

ATLEC (Assistive Technology Learning Through A Unified Curriculum) project, coordinated by PhoenixKM (Belgium), and also involving EASPD member AIAS Bologna onlus (Italy), aims to counter these barriers. It does so by offering people with impairments, trainers and teachers, and family members a free training on AT knowledge, and related background information (legislation, AT database usage, etc.). This training is particularly tailored to their individual and employability needs. Equally, ATLEC created the job profile of ICT AT trainer, relevant for VET (Vocational Education and Training) Centres, to offer a framework through which service providers can enhance the competences of their own staff.
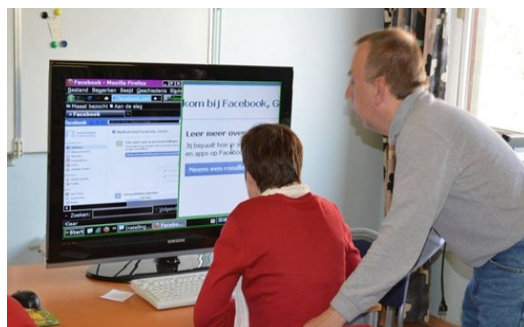
Picture by PhoenixKM

Core outcomes achieved by now are the creation of an extensive curriculum and supporting training content and material, available in multiple languages (Dutch, English, Greek and Italian) and customised to local user needs. In addition, the project also developed a freely available mobile application (Android) that provides guidance for the user on what AT is most relevant for him or her. This application is built in such manner that the content can be dynamically updated and maintained, through a web-based backend. Content updates are thus not limited to the project duration itself. Plans go also beyond, since PhoenixKM in collaboration with University of Athens will further enhance and extend this mobile app through the new project M-Care (to start in 2014), whereby personal assistance (or care) training will be incorporated. After all, also personal assistants/carers tend to have a painful lack of knowledge regarding AT applicability and usage.

The pilots in 4 countries (Belgium, Greece, Italy and the UK), are now coming to an end and have yielded satisfying results as can also be witnessed in below statement.

*"We achieved something unique with our Belgian participants: our people became **knowledgeable about their own capabilities**, and what they could achieve with help from assistive technology solutions. This awareness is crucial in supporting them in becoming **full members of society**, in feeling **respected**, and in being able to prove to others that **they can stand up for their own rights**. ATLEC has given us these possibilities and we are thankful for this opportunity. We look forward to a continued cooperation."*
(Wim Moeyaert, main pilot coordinator in Belgium)

For more Information, please contact:
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Follow ATLEC project via Twitter: (at)ATLEC_project or find us on Facebook: www.facebook.com/ATLECproject

The ATLEC (Assistive Technol-
Picture by University of Athens

ogy Learning Through A Unified Curriculum – 518229-LLP-1-2011-1-UK-LEONARDO-LMP) project has been partially funded under the Lifelong Learning program. This press release reflects the views only of the author (s), and the Commission cannot be held responsible for any use which may be made of the information contained therein.

AAATE conference review – EASPD and AAATE coming closer

The AAATE conference 2013 was a next important step in intensifying the cooperation between service provision and the technology/research sector. Karin Astegger's (EASPD, Lebenshilfe Salzburg, Austria) Opening Keynote on Person Centred Technology and Assistive Technology & Quality of Life was presented as the EASPD keynote outlining the vivid cooperation between both organisations. Her message was well received by more than 400 participants, mostly coming from the R&D field. This summary should also reach those who were not able to attend!

Karin outlined and underlined how important ICT and AT become in everyday life and how the gap between mainstream and the disability field is growing in particular for people with cognitive disabilities. Seeing that in mainstream almost anybody uses ICT on a daily basis and that ICT is indispensable and a prerequisite not only but in particular for education and the job, the situation for people with disabilities is crucial: statistics and studies show that ICT and AT reaches only a small percentage of people with disabilities. Following a small study in Austria people with cognitive disabilities are almost excluded from this technical and societal shift. The following analysis that even personal AT is often not very much used underlined that the potential is huge, but the practical implementation is lacking far behind the fast and faster developments in society. Karin showed "there is something wrong here" and outlined what service provision expects from R&D approaches:

1)   User centred design is of highest priority in the sector but often not implemented accordingly. Users and their environment, based on a human rights and disability & self-advocacy movements, have to take the ownership of R&D in terms of defining the prioritised topics and organising all phases of the engineering process. The AT and R&D sector seems to be very reluctant towards such an approach.

2)   User groups involved are often "pre-selected" and not representative (e.g. cognitive disabilities). This leads to a low understanding of the actual needs, preferences and potential positive or negative impacts on quality of life. Only in this way topics of central interest and impact will get priority.

3)   Technology (AT) is not the solution. It contributes, but only when embedded in a holistic approach.

But it is important to see that also in the service sector there often negative attitudes towards ICT/AT, a lack of experience and knowledge. Independent information and advice following proper user centred assessment and addressing ICT/AT into education and training are still an exception. This gap between the demand and actual practice leads to frustration. Involvement of service provision in the mainstream accessibility movement – beyond an often framed and closed activity spectrum – have to become part of daily routine. Only based on a shared understanding and cooperation between the service sector and R&D we are able to tackle the challenges of the ICT/AT revolution which tends to leave certain groups behind – Karin's keynote underlined this with significant data. Let's hope, the message gets heard – the PCT group has it on its agenda.

The AAATE conference provided a broad spectrum of presentations and discussions on ICT/AT research, development and application for

- personalized assistive solutions for the diverse user groups

- accessibility design for all of mainstream environments

- supporting and improving the service delivery process from assessment towards evaluation

- new challenges of developments like non-classic Human-Computer Interaction, cloud based services and accessibility beyond the desktop computer (mobile computing)

- socio-economic aspects of ICT/AT and Inclusion

- policy and standardization

- ageing and addressing the needs of ageing people with disabilities

- new approaches to user needs analysis and user involvement

The program made evident that all the bits and pieces needed for advancing service provision in terms of including ICT and AT are there, but, as the EASPD keynote of Karin Astegger underlined, a coherent and comprehensive process as well as an intensive cross-sector cooperation which would allow exploiting the potential and avoiding new barriers are still missing.

This defines the agenda of the PCT group – Come and get involved!

Klaus Miesenberger,
Member of the Board of AAATE, Member of the PCT Group; University of Linz, Austria

Good news from the European Commission!

ENTELIS project selected for funding.

By Evert-Jan Hoogerwerf

The good news comes from Brussels this time in the form of an acceptance letter of the ENTELIS proposal that was submitted under the Lifelong Learning Programme. The proposal aims at creating a sustainable network of organisations working for the systematic development of PCT competence of persons with disability. The project sees, among others, the involvement as partners of EASPD, AAATE -the Association for the Advancement of Assistive technology in Europe- and EVBB - a European network of Vocational Training providers-.

Although there is a core consortium, the project is focussed on the involvement of many stakeholding organisations, that will mainly be recruited via the three European networks, in research and seminars. Methodologies and strategies for end user empowerment will be identified and analysed, leading to the design of future scenario's and a roadmap. Partners and associate partners in the US and other continents will give the project a global flavour. The project will start in 2014 and we will keep you regularly updated via this newsletter.

If you want to be part of this interest group on Person Centred Technology (PCT) or would like to be kept informed, please contact Sonia.Staskowiak(at)easpd.eu.