IG on PCT Newsflash 2

Contents:

Dear members, we are happy to present you our second newsflash from the Interest Group on Person Centred Technology (PCT). In this edition we focus on best practices in Person Centred and Assistive Technologies (AT) and their social impact, more specifically we will take a look at how PCT and AT benefit people.
Finally, make sure you read the announcement on the final page of this newsflash, as it reports about an important policy initiative the EASPD fully endorses and invites you to endorse as well.

We hope you enjoy the reading !

The editorial board

Introduction : good practices in PCT/AT

Steve Barnard

This PCT newsflash contains six articles from six different EASPD partners from six different countries. They are different in what they are addressing and in styles of composition. However, they have some very strong similar themes.

Firstly, that perhaps for understandable reasons, we, service providers have encouraged people to be **too dependent on carers**.

Secondly, that the use of Person Centred Technology (PCT) can **increase people's independence and safety** which people want in preference to being reliant on others.

Thirdly, the use of PCT over a period of time is **cheaper** than using carers.

Fourthly, providers and cares are not as aware as they should be as to **the benefits** of and **how to access PCT.**

Fifthly, all articles have values and practices completely consistent with the **United Nations Convention of the Rights of People with Disabilities (UNCRPD)**

Most importantly the articles highlight PCT is applicable to all groups described as vulnerable, which in time will include all of us or people we know.

The first article highlights how giving people knowledge of PCT devices and their benefits can start to inspire organisations to start using PCT

Raising awareness of Assistive Technology

James Crowe

There is still a lack of awareness about what Assistive Technology is and what it can offer people, but it is amazing how a small seed of information can grow into real change.

"In essence, without the course provided by Learning Disability Wales and the Aidis Trust, we would not have been able to secure funding, fundraise and purchase these systems, safe in the knowledge that these technologies would make a huge difference to the everyday lives of our service users."

Learning Disability Wales and the Aidis Trust have teamed up over recent months to provide free awareness sessions about assistive technology to people with a learning disability and service providers in Wales. The quote above is from one of the delegates who attended a session in Bangor.

Through four regional events 100 people came together to learn about what Assistive Technology is and how when used at the right time in the right way it can offer people real benefits of independence and safety.
These events raised awareness of the different hardware and software available for people with learning disabilities and the people who attended were given a better understanding on the different ways that assistive technology can be used. This ranged from using the computer to access the internet or to write emails, playing games, voice recognition software and ways of making communication easier and enabling people to become more independent. The latest communication apps were discussed along with demonstrations on how to use them on tablets and other handheld devices. People were given an opportunity to test the equipment at the end of the session. Clear demonstrations were given for all the equipment along with an idea of what they can cost.

On the day there was a real buzz about what was being shown. Many of the people attending seemed to have no idea of how much was available to them and there was a definite excitement around what they were seeing. The feedback received was very positive from both the people who had some knowledge of assistive technology prior to the event to those who had none at all.

"Very useful and gained a lot of knowledge with regards to assistive technology – will take this into the workplace"

Quote from one of the attendees of the event in Bangor

Since the events a number of organisations who joined us have gone on to run further awareness raising events and to implement what they have learnt and start making a

difference in the lives of the people they work with.

The Aidis Trust is a charity that provides free, impartial technology advice and support to people with disabilities across the UK. www.aidis.org
Learning Disability Wales works to creating a Wales that values and includes every child and adult with a learning disability. www.learningdisabilitywales.org.uk

The second article is a case study showing that people with a learning disability do want to be independent and less reliant on others. Using PCT has not only allowed this to happen but as people gain independence they have increased self-esteem (and saves on staff or carer cost!).

We all stood at the window and waved goodbye to the staff!

Steve Barnard

Anna, Janette, Craig and Pedro all moved into together nearly a year ago. Both Craig and Pedro moved from the family home, Janette moved in from a flat on her own and Anna moved from another Hft service where she received 24 hour support including a sleep in.

When they moved in they had a temporary sleep in for a while.

Telecare was then introduced which included a Connect + (lifeline phone), Bogus Caller and Panic Buttons as well as smoke, temperature and CO detectors. All are linked to a Call Centre for support.

Anna said she enjoys writing stories on her laptop and as Anna is the main person who is sometimes home on her own, feels happy that she has the personal alarm she can take up to her room with her to feel safe, and the bogus caller system.

The sleep in has since been removed and everyone is getting on really well.
It has not only made people feel safer and reassured them but it has given them greater independence. It has also encouraged them to take more responsibility for their own safety. Everyone is involved in testing the sensors on a regular basis and this has benefitted their awareness greatly.

Craig said he feels safe in the house as they have the bogus caller system and the personal alarm and a chain on the door.

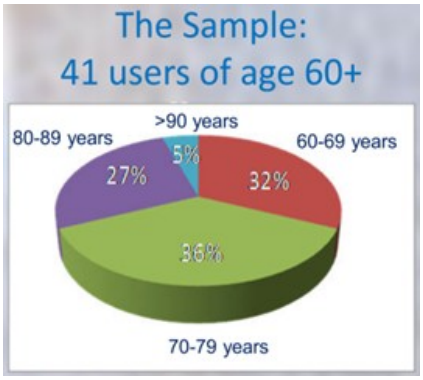
The individuals can now spend long periods of time at home on their own during the day, which they would not have been able to do before.
Anna now spends up to 3 hours on her own, especially on weekends. She makes sure she carries her panic button with her and this not only reassures her but makes her feel safe too.

The third article highlights that, over a period of time, the use of PCT will save costs. However, the article does also highlight that people (seniors) gain greater autonomy from the use of PCT. We know that the recession is the main driver for using telecare and PCT, but should we not be doing this anyway!!

Home Adaptation and Assistive Technology for senior citizens: opportunities for supporting independence while saving on social costs

Claudio Bitelli, Nicolò Bensi, Viviana Brandan, Evert-Jan Hoogerwerf

The making of cost assessments seems crucial in this phase of drastic reductions in public and private spending. Today, more than ever, it is worth verifying what others in the field have found and what common sense tells us to be true: that despite their initial costs in terms of equipment and procedures, solutions making for greater autonomy of seniors can lead to significant savings in terms of social costs.



Emilia Romagna's Regional Centre for Assistive Technology and the Centre for Adaptation of the Home Environment in Bologna (Italy) are engaged in a process that sees the introduction of evaluation and outcomes assessment tools in their ordinary practice. These Consultancy Centres operate without commercial interests and independent from the providers, guaranteeing an appropriate and personalised intervention, in response both to the needs of citizens, as well as to the needs to reduce and qualify public spending.

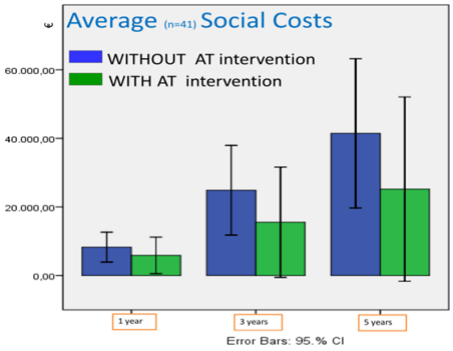
Using the SCAI tool (Siva Cost Analysis Instrument) the social costs of intervention are compared with the costs of non-intervention in a 1, 3 and 5 years scenario, where social cost is understood as the sum of the costs incurred by all the actors in a given situation, in the sense of how much is spent (cash disbursement) or in the sense of the economic value of resources committed with reference to:

- aids (purchasing, leasing, renting etc.);
- maintenance/use;
- services related to the use of the aid by the user;
- human assistance (assessed according to the expertise of the caregiver);
- cost of the processes involved (the evaluation of aids, training etc.).

Further, tools are being used to measure the satisfaction of the clients, the effectiveness of the solutions and their impact on "activity and participation" and personal factors (QUEST and an ad hoc form based on specific health domains from the International Classification of Functioning) .

Suggested solutions	
Mobility	6
Uplift and transfer	9
ADL (Activity for Daily Living)	6
Ergonomics and posture	5
Communication	2
ICT access	1
Environment control and domotics	1
Out-door accessibility	10
In-door accessibility	20
Forniture and fitting	2
Plants	5

Preliminary results based on a sample of 41 cases of senior citizens (60+), indicate that adapting the living environment to better cope with disability leads to important savings both in the resources deployed by the family and those committed by governments. It further increases the perceived level of wellbeing.



Building further on the results obtained the Regional Government of Emilia Romagna has decided to extent to the regional level the investigation concerning the impact on the social costs of interventions in this domain. This activity further fits the commitment undertaken in the European Innovation Partnership for Healthy and Active Aging.

***Contact**: Emilia Romagna's Regional Centre for Assistive Technology. E-mail* info@ausilioteca.org.

The fourth article is another case study showing how an empathetic approach to an individual with severe restrictions can give him the option to take more control of his life by the use of PCT, which also appears to be having a positive effect on his condition. Why are we not more aware of these opportunities?

Next Generation of Person Centered Technology (PCT): flexible, adaptable, low cost and: Service providers can put it in place

Klaus Miesenberger

Franz is 45 years old and lives in a permanent-care institution in Austria. When he was 42 a ruptured aneurysm caused a brain bleeding. He ended up with locked-in syndrome. The only controlled activity remaining was eye-blinking.

As there was no perspective to come back to the job or to live independently, Assistive or Person Centered Technology to support him, which would have cost at least several thousand Euros at that time, was not even considered.

But technology matures, gets more flexible and affordable. In the AsTeRICS project (www.asterics.eu) an open, extendible and flexible framework has been developed, which allows to set up and adapt assistive solutions for a broad variety of users with motor impairments at low cost in a fast more and more "non-techy" manner and therefore manageable by therapists, friends and relatives with interest in ICT. AsTeRICS allows employing a large number of sensors to measure controlled activities of a user and mapping them to Human-Computer Interaction (HCI) and/or Smart Environment Functionalities.

Franz was one of the first users benefiting from AsTeRICS. A group of volunteers managed to set up an eye-blinking system for Franz using a cheap off-the-shelf web cam. The web cam delivers a video signal which is analyzed by AsTeRICS and matches the user-

controlled eye-blinking activity with a scanning interface.

After a couple of weeks Franz started interacting with devices in the environment. It is expected that he will gain a new way of expressing himself and communicating: he writes with eye-blinking and scanning and people can read on a screen.

Another good thing about AsTeRICS: Franz's condition began to improve – perhaps AsTeRICS helped – and AsTeRICS easily adapts to these improvements and allows considering new activities (e.g. in particular he loves to play card games) and exploiting new or regained skills (e.g. controlled body movements, sip/puff).

AsTeRICS is free and open source and invites engaged people interested in ICT to join and help to build a crowded sourcing and exchange community for flexible, adaptable and cheap PCT solutions. Interested? Learn more about this approach to PCT and other user stories at http://www.asterics.eu and get involved at asterics-info@ki-i.at.

The fifth article highlights the growing possibilities that software applications can have in, again, giving people more opportunities to control their lives. Once more, the article highlights that people like to be more independent and less dependent. The solutions mentioned are straight forward and simple for the user, which should not mask the complexities that lay behind the solution.

More autonomy and social inclusion by using Cloudina and BlueAssist.

Ann Decorte, Geert Vandewalle, Lien Debie, Kamran Vahedi

The motive to develop BlueAssist and Cloudina

Over the years Ithaka (a daycare center for adults with intellectual disabilities in Ostend, Belgium), had experienced that heartfelt care led too much towards learned helplessness. Ithaka created a range of innovative practices to maximize the autonomy and social inclusion of its clients. As a consequence Ithaka became a coaching center. The clients had all kind of

assistive tools such as a picto-agenda, alarm clocks, a special telephone, a communication book to support their autonomy. Ithaka developed Cloudina to integrate all this tools in one device. A new function BlueAssist was added to being able to ask co-citizens for help.

The social innovation BlueAssist

BlueAssist is an icon combined with a message to ask other citizens for help. It is a new international icon for asking for help. The user of BlueAssist may have difficulties in understanding a situation and in asking an understandable question.

With BlueAssist-messages on a BlueAssist-card, on a BlueAssist application for smartphones or the BlueAssist-function on Cloudina, they can ask co-citizens for assistance. The co-citizens understand better what the BlueAssist-user needs and feel more comfortable to help.

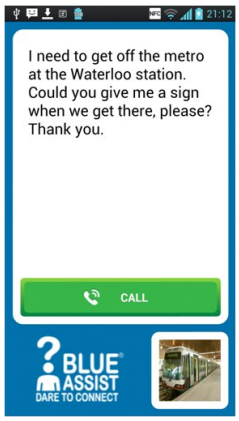
In using BlueAssist, many things, that seemed unthinkable and inaccessible before, become possible for the user: going into town on their own; going to the supermarket; buying a compact disc; or taking the bus alone. BlueAssist completely changes the lives of the users and of the caregivers who become coaches. Before, we saw people with intellectual disabilities only going out with assistance and in groups. Now they can take part in society in an individual way.

The coach together with the user adds messages and pictures/symbols (to recognize the right message) in the app with regards to the possible problems that the user may encounter when he/she goes out on his/her own.

On each page there is a call button next to the message. If the passer-by cannot help, he/she can push the call button and get in touch with the coach of the user. They can then consult the coach and find a solution for the situation.

Cloudina : apps that provide more quality of life

Cloudina is a series of apps that support people with reduced independency in their daily activities. These apps have been developed following the demands coming from coaches and users in Ithaka. They have been tested in the practice and in Belgium and The Netherlands and have proven their efficiency for different users. Working together with a carer or professional coach, Cloudina can be set up according to the needs of the individual user. Because of its universal design a whole range of users successfully use Cloudina and BlueAssist: individuals with intellectual disabilities, with Autism Spectrum Disorders, with acquired brain injuries, with speech disorders, with mild dementia, ...



Cloudina is cloud-based. All the information is transferred wirelessly, through the cloud, back and forth

between the management website and the apps. This makes using and programming of Cloudina easier for both the user and the coach. Cloudina can be programmed even if the user is abroad. The carer or professional coach needs no special computer experience or training to be able to use the management website. You only need a PC with internet connection.

Each app is linear, meaning there is only one level and so the user does not get lost or confused in any tree structure. The information cannot be erased or altered on the smartphone itself making the app easier to use. More importantly, pushing the "wrong" button has no negative consequences for the user.

Cloudina can be tailored. The user composes his/her own Cloudina from the apps that are useful to him/her. Cloudina evolves with its owner. According to the needs of the user apps can be added or removed. Through the available settings on the management website and on each individual app the use of Cloudina can be fine-tuned. For example: free choice of pictures, font size, alternative time indication, speech support … The user can choose between 5 simplified apps: an agenda, telephone, BlueAssist, making pictures, photo-album. Other apps will be added in the future. At the moment Viamigo is being developed. Viamigo is supportive to learn new routes making use of GPS-location. It gives the responsible carers signals when there is a difference in time and location.

More information: Ann Decorte, Geert Vandewalle, Lien Debie, Kamran Vahedi
www.blueassist.eu
www.cloudina.eu

The final article highlights the work of the ETNA network, whose goal is to establish a European web portal on assistive information technologies, stemming from the already-existing website of the European Assistive Technology Information Network (EASTIN).

European Thematic Network on Assistive information technology

Katrijn Dekoninck

EASPD participates in the ETNA project. The ETNA network involves 23 organisations in 13 countries, each with acknowledged commitment in ICT and Assistive technology (AT). It is coordinated by the Centre for Innovation and Technology Transfer of the Don Carlo Gnocchi Foundation in Italy.
Over a period of three years, ETNA will have implemented **a European Web Portal which provides information on ICT-based assistive products and e-accessibility solutions which are available in Europe**, as well as on related organisations and services. The ETNA and the ATIS4All networks have jointly been working on the creation of a European Web Portal. The Portal will be released at the end of 2013 and will evolve from the current EASTIN system. After the end of the ETNA Project, the ETNA information system – which is currently accessible in test phase: www.etna-project.eu – will disappear as such and will be taken up by the EASTIN system: www.eastin.eu. The Portal has been designed to **meet the information needs of 5 categories of stakeholders**: end-users (persons with disabilities, their families, primary caregivers), professionals (in social & health care and education), manufacturers & suppliers, researchers & developers and policy makers.

The project will soon end and have achieved the following objectives:

Make information on AT products and e-accessibility solutions more transparent and easily available to all to contribute to 1) the empowerment of citizens with a disability in relation to the knowledge and choice of AT, and 2) the advancement of the AT market,

Funded by EU's ICT Policy Support Programme — Competitiveness and Innovation Framework Programme

ket, which will have to respond to a wider audience of informed, demanding and responsible consumers across the EU;

Connect developers, providers and suppliers of AT solutions from all over Europe, by improving exchange of knowledge, ideas and open source tools, overall contributing to the advancement of R&D and help companies benefit from a wider market potential;

Connect researchers, developers, professionals, and end users of AT. The network will help include the user's viewpoint and improve public service delivery systems, by making transparent across Europe the variety of regulations, standards & procedures, and bringing to light best practices that can be adopted and localised;

Support mainstream developers in the development of ICT products intended for the general public, enabling them to find information and resources instrumental for creating more accessible products, or products that are compatible with current and future AT products.

How to join the ETNA network?

Participation as a partner in the EASTIN Association is open to organisations able to serve as:

National Contact for their country;

maintaining the EASTIN language layer related to a given country;
answering questions posted by citizens of that language through the EASTIN website;
answering questions posted by manufacturers who want to make publicity for their product in a given country.

National or Thematic Information Provider to the EASTIN search engine;

Serving as an information provider means being responsible for providing data to the EASTIN system, according to the agreed information quality standard. Information providers may be national, in case the data provided encompass the whole spectrum of AT products, cover the whole national market and are localised in a given culture of that country. They are thematic in case they are specialised in a specific subset of AT, e.g. open source e-accessibility solutions, with international perspective.

For more information, send an e-mail to info@etna-project.eu or to EASPD's Project & Liaison Officer: Katrijn.Dekoninck@easpd.eu.

Conclusive remarks

So, PCT if delivered in the right way, is totally consistent with the UNCRPD, then why is it not used more? It is increasingly apparent that PCT is not added value; it is about basic needs that increase independence, communication, health and mobility. There are a variety of reasons and barriers to the widespread use of PCT including awareness, access, funding, social policy and manufacturers.

I would like to pose the question that if PCT is consistent with both service providers' values and with the UNCRPD, then denying people access to PCT might, in the future, be liable to claims of abuse??

Steve Barnard

ANNOUNCEMENT

Assistive Technology and Development : an open letter to the United Nations

Five umbrella organisations in the field of Assistive Technology have published an open letter to the participants of the High level Meeting of the General Assembly of the United Nations that will be held in New York of the 23rd of September. This meeting will be dedicated to "Disability and Development".

In their letter AAATE, RESNA, ARATA, RESJA and AITADIS express appreciation for the intention to mainstream Disability into the post-2015 UN Development Agenda. They further express their commitment to the UN Convention on the Rights of Persons with Disabilities and their support to the recommendations of the Secretary General, in particular the one on the centrality of "Accessibility" and "Universal Design". They highlight the role of enabling technologies in enhancing human potential and citizenship and how these technologies may allow people with disabilities to contribute to the development of their communities. To make this happen appropriate policies and programmes should be in place and the letter lists the main areas of interest, such as awareness raising, the development of competence, research into socio-economic and cultural factors that impact on the advancement of Assistive Technologies worldwide, access to products and services, collaboration and knowledge sharing. Finally in their letter the organisations express their availability to collaborate with initiatives supporting these causes.

The letter is published on the following web site:
http://www.aaate.net/open_letter_to_un
Members and non members can endorse the letter using the same web link.

AAATE = Association for the Advancement of Assistive Technology in Europe
RESNA = Rehabilitation Engineering and Assistive Technology Society of North America
AITADIS = Asociación Iberoamericana de Tecnologías de Apoyo a la Discapacidad
ARATA = Australian Rehabilitation & Assistive Technology Association
RESJA = Rehabilitation Engineering Society of Japan

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@easpd.eu.

With support from the European Union Progress Programme.
The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.