

2 Seas Magazine

SPECIAL FOCUS

INTERREG IV A 2 MERS SEAS ZEEËN

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A cluster initiative:

Empowering Disabled users and carers through the Ethical development and Care provision of assistive Technology (EDECT)

2 Mers Seas Zeeën

INTERREG IV A

FRANCE - ENGLAND - VLAANDEREN - NEDERLAND



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3 FOREWORD

4 INTRODUCTION

- 4 Demographic changes
- 4 Assistive technology
- 5 Ethical reflection

6 CHAPTER 1: Why EDECT?

- 6 Results of the SYSIASS project
- 8 Results of the DIC project
- 9 Lessons learnt from SYSIASS and DIC
- 10 The EDECT cluster

12 CHAPTER 2: Developing user-centred Assistive Technology

- 12 Questions to be addressed by EDECT
- 13 State of play in the 2Seas area

16 CHAPTER 3: Integrating provision of Assistive Technologies with good care practice

- 16 The Challenge
- 16 Support and training

19 CONCLUSION

- 19 Benefits of cross-border working
- 20 Holistic provision of Assistive Technology

21 Annex 1 EDECT's Framework

- 21 • Workshops
- 21 • The cross-border network
- 22 • The International Expert Group



Anneliese Dodds
Member of the
European Parliament

Cross-border research collaborations provide a great opportunity to work with partners from other cultures and countries. At the same time as helping to solve some of the major problems of our age, they facilitate learning about different cultural attitudes and the building of strong relationships across country borders, languages and cultures. In the case of EDECT (Empowering Disabled users and carers through the Ethical development and Care provision of assistive Technology),,, partners from two previous Interreg 2 Seas projects have come together, pooling their experiences and lessons learned to investigate the problems surrounding the ethical implementation of Assistive Technologies needed to improve the support and care given to users.

The issue of the ethical use of Assistive Technologies could not be more important, but so far it has not received the attention it deserves. Since the beginning of the twentieth century, average life expectancy has risen significantly in the industrialised world. Despite significant improvements in curative technologies, this welcome increase in life expectancy has led to many more individuals having an increased chance of being faced with a long period of enduring debilitating conditions.

People living with chronic illness and long term disabilities may be limited in their ability to perform important functions independently. They often suffer from pain on a long-term basis, and can be dependent on the help of others. This help may come from professional carers or informal caregivers like family members, partners, neighbours or friends. Although people subject to a chronic illness or long term disability often participate in society, many may feel isolated and marginalised, and more often than not become economically vulnerable. This has often been exacerbated, sadly, by prejudice and a lack of awareness and willingness to adapt to disabled peoples' needs. The providers of Assistive Technologies, health care professionals and carers thus need to work with those with disabilities and chronic long-term health conditions to ensure that Assistive Technologies can genuinely empower their users and suit their requirements.

As a result, I fully support the EDECT cluster in its efforts to ensure an ethical approach to the involvement of users and carers in the development of Assistive Technologies. The EDECT cluster's interactive conference will allow participants to provide invaluable feedback to engineers, researchers, politicians, and the wider general public about the needs of disabled people and the elderly in relation to an increasingly technically complex society.

Anneliese Dodds MEP

Introduction

Demographic changes

One billion people around the world live with some form of disability. In the European Union, according to the European Disability Forum, there are 80 million disabled people, which is more than 15% of the population. For example, in the Netherlands there are 1.8 million disabled people, while in France there are 9.6 million and in the UK 10.7 million. The numbers using Assistive Technology are much lower but still significant, with 800,000 in the Netherlands and 5.4 million in France, for example.

The ageing or greying of Europe has also been a subject of much concern. The International Monetary Fund (IMF) in 2006 projected that by 2050 the number of retirees would increase from 75 million (16% of EU population 2004) to 133 million. Furthermore the number of pensioners over the age of 80 years is set to rise from 18 million to 49 million and according to Age UK most people who need care services are aged over 85.

As the EU population ages, the IMF predicts the number of people of working age will fall from 306 million to 257 million meaning that there will only be 2 workers for every retiree by 2050. The 2011 UK census showed that the number of retirees rose by 10% from 13.2% to 14.6% of the UK population over the ten year period since the last census in 2001.

These demographic changes will inevitably lead to a substantial increase in the need for care support services whilst the declining number of workers, and the median age rise of the worker, will no doubt mean a significant labour cost increase. Therefore a significant and growing problem exists, of how to empower less able individuals to a level which permits them to remain in their own homes, work,

socialise and undertake their daily needs with reduced dependence on carer assistance, whilst simultaneously encompassing both the rights and needs of those individuals and, importantly, changing society's attitudes.

Assistive technology

One of the answers to all these needs could be Assistive Technology. Assistive Technology can be defined as any service or device which has been designed for the purpose of aiding the disabled and the elderly to maintain their independence. The level of that technology can range from walking sticks to sophisticated electronic Brain-Computer interfaces. Two important applications of Assistive Technology are devices to enable users who can no longer speak or access a computer to communicate, and powered wheelchairs to provide independent mobility.

In a very practical way, the use of Assistive Technology is also one of the possible answers to allow people to stay at home as long as possible and as a consequence improve their quality of life. Indeed, older people do not want to go into hospital unless it is unavoidable. Additionally there is an increasing recognition by health professionals and politicians that hospital is not the best place to care for older and frail individuals.

More generally, the use of technology should also be a way to empower people. For people without disabilities, technology can make empowerment easier. For people with disabilities, technology makes empowerment possible.

For most people, technology will only be successful if it is easy to use and understand and this mainly depends on the way it has been constructed. It is therefore important to listen and take into account the user's needs from the beginning of the technology

development process, to be sure that both the function and the operation are acceptable to the users.

Ethical reflection

Given this, we increasingly need to develop an ethical reflection as well as a practical one, a reflection that helps us to see technology as fundamentally mediating the way we live in the world today. The main ethical question is how we should work with dependent and disabled people. How should we listen and take into account their point of view, especially in such a technologically driven care context?

Ethical reflection must take into account the practical abilities of stakeholders and must be collaborative, articulating care, the wider needs of the user and empowerment. Such ethics are not only relational but also organizational and social, in that sense less a question of principles and more a matter of actions that articulate human relationships, professions, organizations and politics.

Finally, ethics is also about creating an inclusive society that enables stakeholders to set up accessible places to live (and technologies to help) which are adapted to individual requirements, socially connected and that people can use with maximum benefit. EDECT, therefore, has to show a pathway where dependence and disability, technology and care are developed in a more integrated way. EDECT (Empowering Disabled users and carers through the Ethical development and Care provision of assistive Technology), is conceived as a way to integrate better normal care and Assistive Technology by the involvement of all the stakeholders. The stakeholders include and are focussed on the users of care and Assistive Technologies. This includes the dependent or disabled people, as well as their families and caregivers who may also be users of that technology.



Bi-modal (EMG and Facial) human-machine interface for hands-free control of a wheelchair

CHAPTER 1

WHY EDECT?



Human Machine Interface for wheelchair driving – Alternative to a Joystick

EDECT brings together two previous Interreg IVa 2Seas projects, SYSIASS (SYStème Intelligent et Autonome d'aide aux Soins de Santé/ Autonomous and Intelligent Healthcare System) and Dignity in Care. The outcomes of these inspired partners to explore the complementarities between the two. This chapter will summarise the results of both projects and demonstrate the need for EDECT.

Results of the SYSIASS project

Reconciling Disability and Independence is the major question to which the project SYSIASS (SYStème Intelligent et Autonome d'aide aux Soins de Santé/ Autonomous and Intelligent Healthcare System) sought an answer by developing new technologies and trialling them with patients and health professionals from our regions.

The advances in technology proposed by SYSIASS have been realised in practice through an intelligent wheelchair that can provide better mobility to the patient. It also allows health care professionals to easily transport patients to desired locations within a clinic or home environment. The goal of the project was the design and implementation of a robotic powered wheelchair, which would have new assisted navigation devices for driving assistance

and hands free human-machine interfaces. These would be adaptable enough to take a user's specific needs into account and also interface with any commercially available powered wheelchair. The devices were evaluated by powered chair users through clinical trials.

One underlying theme was to consider what users might require from such assistance. For example if a person with no assistive needs finds the robotic wheelchair

unsuitable, why would anyone expect disabled users to accept it? Therefore the underlying research of the project focused on developing a wheelchair which provided driving assistance to the user, helping them to avoid collisions and maintain their control over the machine without taking over control.

In order to understand users' needs better, a questionnaire was sent out to wheelchair users, their caregivers, relatives and friends, as well as medical and social care professionals working with powered wheelchair users. It asked people to evaluate their satisfaction with their current powered wheelchair, how interested they were in having an assisted navigation device that would, for example, help them avoid obstacles and whether new users would benefit from a device that would help them learn to drive the wheelchair.

251 people responded and their feedback clearly showed that whilst nearly all participants were very interested in the general principle of driving assistance or collision avoidance, interest became more divided when the issue of taking away control from the user was suggested. Professional caregivers often had

the opposite point of view to that of the users and their family.

This was particularly so when an assisted navigation device was suggested as a tool for learning to drive the wheelchair. The caregivers thought that this application of Assistive Technology would be very useful, while the users themselves were less enthusiastic.

After technical development and the first evaluation by able-bodied volunteers, the assisted navigation system was evaluated by 32 disabled people through clinical trials in Garches and Lille in France. These identified two significant challenges. The first was that the users did not like the chair taking control from them. They would prefer to retain control and accept the increased risk of collision.

The second was that correct alignment of the chair with a doorway was critical if a collision was to be avoided, so the research team developed a second system which prevented collisions yet allowed the user to still feel that they were in control of the powered chair. It was also concluded that any assistive system must warn the user when corrective measures are required,

whilst remaining unobtrusive, making only minor changes that are directly proportional to the apparent risk, such that small risks are not noticed and large risks are corrected in a naturally intuitive fashion.

Q General principle of an Assisted navigation device

High interest 92%

Average interest 3%

Modest interest 4%

Q Specifically obstacle avoidance

High interest 85%

Average interest 10%

Modest interest 4%

Q Assistance for manoeuvring wheelchair into the best position for transferring to bed

High interest 80%

Average interest 14%

Modest interest 7%

Q System navigation assistance when tired or fatigued

High interest 86%

Average interest -

Modest interest 14%

Q System with fully autonomous navigation

High interest 65%

Average interest 18%

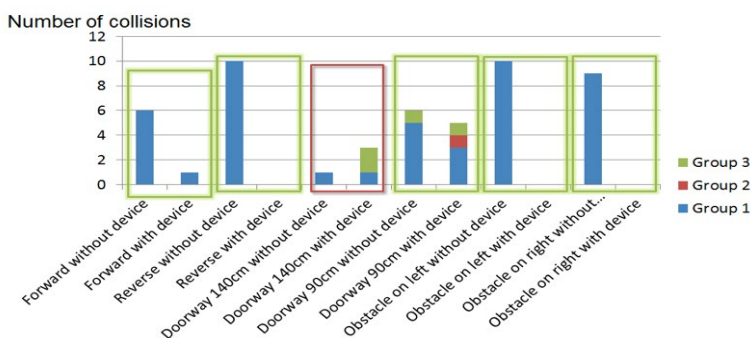
Modest interest 18%

Q Assistance for learning to operate powered wheelchair

High interest 55%

Average interest 23%

Modest interest 21%



The SYSIASS (SYStème Intelligent et Autonome d'aide aux Soins de Santé) project also highlighted the need for training and support of both users and their care network and the paramount need to understand the user's perspective. The Dignity in Care (DIC) project provides insights and expertise on precisely this issue.

Results of the Dignity in Care project

Over a three year period (1/7/2011 to 30/6/2014) partners from Lille, Dorset, Zealand and Flanders worked together on the INTERREG IVA 2 Seas Dignity in Care (DIC) project to improve the impact of ethical reflection and practice by students and professionals in health and social care organisations in the cross-border region by experience-based learning in the sTimul: Care-Ethics Lab. There were three main project activities:

The sTimul experience

In this activity the cross-border partners and their stakeholders

sent 387 participants (health care students, trainers, professionals and management staff) from the four partner regions to undertake the sTimul experience; they were coached by a regional facilitator and a student trainer under the supervision of a sTimul coach.

The sTimul experience provided a fully equipped care environment, where, for two days and a night care professionals and students could experience through simulation the impact of care at first hand. The focus was the way in which care is provided and concentrates on attitude rather than core technical and clinical skills. After the simulation, participants reflected upon their experience in groups coached by an ethicist.

In this activity sTimul participants had the opportunity to share and put into practice what they learnt during the sTimul experience. Sharing experiences and exchanging good practice took place during regional networking events, cross-border study visits and a virtual communication platform. 115 people were involved in the cross-border

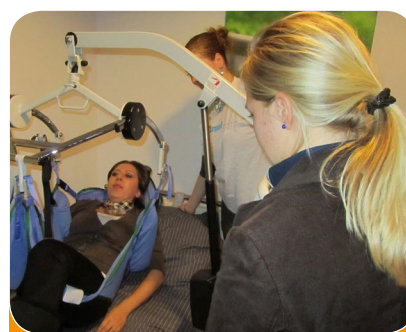
study visit and over 2000 people were reached by the networking and decision-makers events, the international conference presentations and press releases.

An International Evaluation Expert Group (IEEG) with a member from each partner was created to evaluate the data, processes, and learning. The goal of this group was to set up and execute an evaluation programme for activity one (the sTimul experience) and activity two (learning into practice). Several methods were adopted to collect data for evaluation purposes, including written questionnaires, interviews and group discussions. sTimul participants also conducted a process of reflection and completed questionnaires at three stages of the process. Also, additional evidence was obtained through interviews and formal discussions. In addition, in each region a resonance group of care receivers has been established. In this way, the needs of the final target group remained the primary focus of the project.



Tanesh Bhugobaun Management Consultant (UK)

As chair of Kent Brain Injury Forum I believe Assistive technology could help to enhance, promote or sustain the functional abilities of someone who is either physically or cognitively impaired. Devices should be user friendly and should have the potential to promote independence, empowerment and social integration.



**Students and professional
during simulation session**

User groups in each region provided feedback to the project partners and participants. The groups were very diverse and comprised a range of people who use health and social

care services. Cross-border value was added through the participation of members of local user groups in study visits and conferences during the project duration. More than 122 users of services were actively involved in contributing to this project. Their opinions and viewpoints were heard by over 14 stakeholder organisations. The involvement of service users at cross-border study visit discussions and conference presentations gave the opportunity for local politicians, educational centres and care organisations to listen and understand better the meaning of dignity for those who use health and social care services. The feedback from the participants of these different events shows the work done by the user groups had an additional value in this Dignity in Care project. The final cross-border study visit in Ghent brought the main target groups of the project (students, caregivers and end-beneficiaries) together to consider and reflect on a common understanding of the term 'dignity in care'. Undoubtedly involving users of services in the project has enhanced the understanding of those who deliver care thus ensuring the long term sustainability of the Dignity in Care project methods.

The experimental learning method was based on transformative learning by putting participants in an unexpected situation. The sTimul concept enabled health and social caregivers and students to experience first-hand what being cared for in a day-to-day setting means. Adopting the role and characteristics of

Questionnaire 1A
Time of data collection
at lunch day 2

Questionnaire 2A
Time of data collection
after reflection day 2

Questionnaire 3A
Time of data collection
at end of the
follow-up session

Questionnaire 1B
Time of data collection
at lunch day 2

Questionnaire 2B
Time of data collection
after reflection day 2

Questionnaire 3B
Time of data collection
at end of the
follow-up session

Overview data collection

a person who needs care and support, professionals moved into a residential eight-bedded care home, the sTimul: Care-Ethics Lab, for a period of 24 hours and became totally dependent upon the care they received from students in health and social care. Much of the value of the experience showed in reflective thinking, group discussions and ethical reviews of individuals' own practice. Overall, the key learning outcomes of the Dignity in Care project were:

- 1 Structured and comprehensive preparation of the sTimul experience is important
- 2 Maintaining the participant's character role had an impact on the value of the experience

3 Multiple and different stages of reflection throughout the experience are crucial

4 Sharing experiences and exchanging good practice via cross-border and regional networking has enhanced the dissemination and implementation of dignity in care

5 Despite the differences in cultural and national settings, dignity is boundary-less and is all about paying attention to the person and the relationships

The Dignity in Care project mainly focused on the attitudinal and ethical aspects of care and learning, and professional reflection. Whilst in most care settings and in the delivery of care services the use of technology is on the rise, until now technology and dignity have not been directly linked.



Students and professionals during a simulation session in the sTimul: care-ethics lab

Lessons learnt from SYSIASS and DIC

Dignity in Care enhanced ethical practice and introduced critical reflection to professionals and students in health and social care organisations by improving their



Students and professionals during a simulation session in the sTimul: care-ethics lab

experience-based learning in the sTimul: Care-Ethics Lab. It focused on enhancing knowledge about the ethics of providing and receiving care. 'Good care' is not only about moral or ethical theories, but also about the empowerment of both care-receivers and the professional caregiver.

The SYSIASS experience in developing technology and the outcomes from questionnaires, trials and clinical experience have shown that it is vital to involve users and other stakeholders in the design and development process. This not only includes the perceived requirements of the user and carers but also an understanding of the demands that a technological solution will place upon them once the device has been delivered into their lives. Whether or not that delivery will improve the quality of life of the user and their carers will not only depend on the technical ability of the user but also critically on the support that the care network can provide.

The role reversal experience methodology employed during the cross-border Dignity in Care project has shown that the problem of successfully

adopting Assistive Technologies in the health care arena can only be fully understood when all relevant parties are involved in the solution. Support and training requirements of users and carers need to be properly identified before technological solutions can be integrated into the wider area of general practitioner, carer, and user training.

The EDECT cluster

Cluster partners recognise the risk of developing ever more sophisticated technology without sufficient thought being given to the needs or wishes of the end user and their care network. This is likely to lead to the new technology becoming unwanted, devalued and viewed with deep suspicion.

EDECT (Empowering Disabled users and carers through the Ethical development and Care provision of assistive Technology) is creating a bridge across this potential gap, benefitting both ends of the spectrum – engineers and care providers – and, most importantly, the users of the technology. The goal of EDECT is the empowerment of disabled people and their care network through responsive care, Assistive Technology and ethical reflection.

The cluster brings together all the stakeholders (users and their families, care-givers, health care professionals, companies, associations for the disabled etc) in the development and use of Assistive Technologies to discuss, debate and then understand the



Demonstration of technology at "La vie devant Soi", Lomme, France

issues and problems. Cluster partners have identified that the central question that people who develop Assistive Technology need to keep in mind is how, through responsive care and ethical reflection, technology can be implemented, maintained and improved through continual feedback.

EDECT brings together experts working in Assistive Technology research, manufacturers and clinicians as well as experts working and having expertise and experience in the field of training, and especially in training with empathy.

Coming from different countries with cultural differences, they soon discovered much common ground.

This combination of cross-border expertise provided a strong team, the foundation for a future collaborative network, to build upon the methodologies developed.

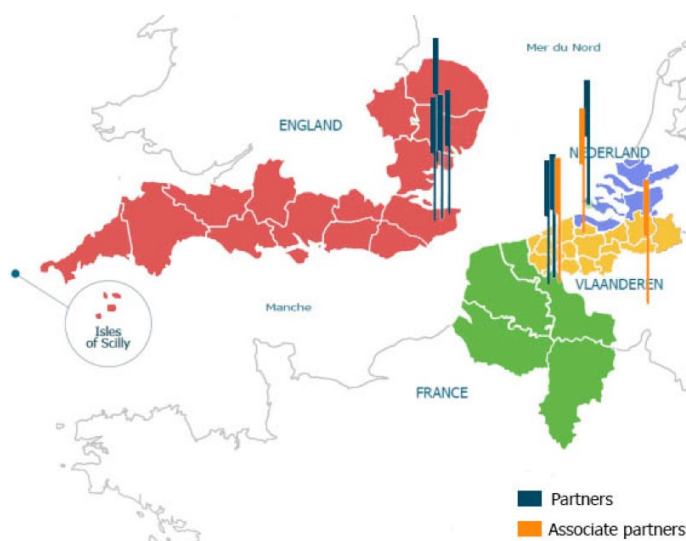
Acronym	SYSIASS	DIC	EDECT
Title	SYStème Intelligent et Autonome d'aide aux Soins de Santé (Autonomous and Intelligent Healthcare System)	Dignity in Care: Enhancing Ethical Practice and Critical Reflection by the sTimul experience in a care-ethics lab	Empowering Disabled users and carers through the Ethical development and Care provision of assistive Technology
Total Budget	€ 2.46M	€ 2.66M	€ 276 486
ERDF	50%	50%	100%
Time Frame	2010/12/01-2014/06/30	2011/07/01- 2014/09/30	2014/02/01 - 2014/10/31
Lead Partner	ISEN-Lille	HUB-KAHO	The Health and Europe Centre
Consortium	École Centrale de Lille/CRNS, University of Kent, University of Essex, East Kent Hospitals University NHS Foundation Trust, Groupe Hospitalier de l'Institut Catholique de Lille Collaborations: Fondation de Garches, CRNT-APF, Kent Brain Injury Forum, Centre Jacques Calvé de Berck sur Mer, Rehabilitation Center Hélène Borel, Medical home La vie devant soi Industry: Dynamic Controls	sTimul: care-ethics lab, Institut Catholique de Lille, ZorgSaam Zeeuws-Vlaanderen, HZ University of Applied Sciences, East Dorset District Council	Groupe HEI-ISA-ISEN, University of Kent, East Kent Hospitals University NHS Foundation Trust, Institut Catholique de Lille, HZ University of Applied Science, University of Essex, University College HUB-KAHO (Phase 2) Associated partners: University College HUB-KAHO (B) (phase 1), FAM La vie devant soi (FR), PATH ASBL (B)

Characteristics of SYSIASS – DIC – EDECT



Elsa Bourdeaud'hui
Occupational Therapist (F)

An Occupational therapist in France who advocates that if we want to have useful Assistive Technology, that it will be necessary for the user to want it and have the capabilities to use it. Moreover it will be mandatory to take into account the user's life goals.



The geographical locations of the EDECT partners

CHAPTER 2

DEVELOPING USER-CENTRED ASSISTIVE TECHNOLOGY



Engagement of a 92-year-old woman

The goal of EDECT is to develop our understanding of how best to empower the user, improving their quality of life whilst not increasing their stress through the introduction of what may seem to them as complex and unreliable technology

Questions to be addressed by EDECT

One danger for health care professionals and carers – whether family or paid carers – is to assume that they know what is best for the person for whom they care. The chosen intervention may be correct in terms of treatment and care, but from the perspective of the person who is to receive the care it may not be the right choice. Sometimes the care receiver is too confused, distressed or frightened to want to receive care. Sometimes the care network is unable to provide the support needed to deliver the most appropriate care.

The goal of EDECT is to develop our understanding of how best to empower the user, improving their quality of life whilst not increasing their stress through the introduction of what may seem to them as complex and unreliable technology. The dignity of the individual has to be considered and this involves their care network being empowered to support them in the long-term use of Assistive Technology.

Identifying and then providing the most appropriate technology for users will always be a challenge. For some users the stress of introducing new technology into their lives and the lives of their family may outweigh any benefits they perceive. For users with

rapidly progressing conditions, the challenge to minimise stress and to keep pace with that deterioration can be significant for the user, their family, carers and health care professionals. Given the need to incorporate users' views on technologies in the development process, a further question arises. If there needs to be user involvement in the development process, how can that be put into perspective and combined with the concerns of others?

It is recognised that the user may have a different perspective from carers and health care professionals on the role and impact of technology in their lives. For example increased

independence is good. However the user may reject that technological solution through a misplaced fear of reduced social interaction because the carers may no longer visit so frequently. Therefore it is not only important to keep both the user and the carers involved in the development process, but to be aware of the possible misunderstanding of the function of Assistive Technology.

The core questions to bear in mind are, therefore: how can the delivery of technology and the initial training of users and carers be supported? What are the long term maintenance and support issues, for example what happens when the equipment fails and the user has become dependent on it? What happens as the user's needs change?

For example the user's ability to use the technology may improve, in which case there may be need for adjustment to that technology to take into account the increase in expertise. Conversely the user's ability may deteriorate, in which case there will be need to read just that technology to compensate for that change.

Raising false expectations followed by a bad experience can lead to a refusal to try any further technology, even when the problems have been dealt with. Additionally raising false expectations may discourage or even depress the user and their carers when those expectations are not met.

France

The National Health Insurance (i.e. Sécurité Sociale) (2700€ to 3900€) built on public law

Private Health Insurance (if the user has any)

Compensatory disability benefit (the user must request it from the MDPH (Maison Départementale des personnes handicapées))

Netherlands

The health insurance system comprises a national social insurance (i.e. AWBZ) built on public law, insurance built on private law that incorporates robust guarantees under public law (i.e. health care insurance law) and supplementary private insurance.

The wheelchairs are financed by the Social Support Act.

UK

The Wheelchair Service National Health Service will assess the user. If they meet the criteria for provision, then after assessment a chair will be provided, paid for and owned by the NHS. The NHS will then retain responsibility for the maintenance and repair of the wheelchair.

The user will be reviewed and the prescription modified according to clinical need.

Belgium

The support for wheelchairs is given by the National Institute for Health and Disability Insurance (RIZIV: Rijksinstituut voor ziekte- en invaliditeitsuitkering or INAMI: L'Institut national d'assurance maladie-invalidité). The regional organizations in individual assistance for people with disabilities (AWIPH (Walloon region), PHARE (Brussels region) or VAPH in Flanders) give compensation for the maintenance contract (including repairs) and possibly for the purchase of a second wheelchair. If the wheelchair has an ancillary equipment such as environmental control, VAPH can give a supplementary allowance.

How powered wheelchairs are funded

State of play in the 2Seas area

There is a range of Assistive Technology available, and some may be prescribed without proper consideration of the user's desires and carer's requirements. The challenges in developing effective and suitable, and thus desirable, Assistive Technology are as follows:

1 It must be recognised that the interests of users

for whom the technology is developed may differ from those of other stakeholders such as the following:

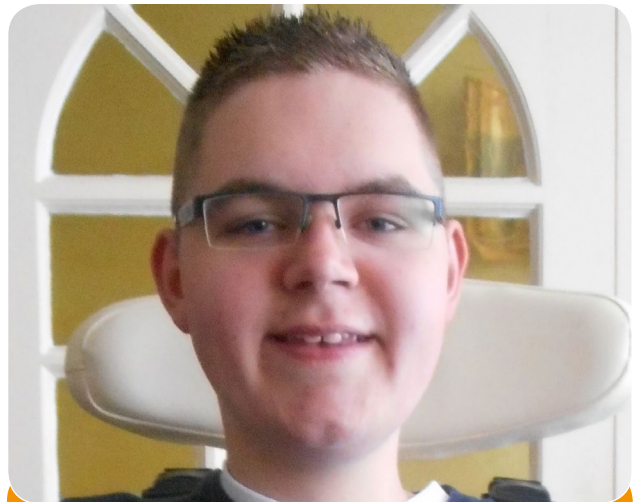
- Policy makers
- Health professionals
- Family members
- Carers
- Researchers
- General public
- Employers
- Manufacturers

Even within this group, the agendas of stakeholders may differ and in some areas be in



Vincent Collin
Academic (B)

Academic from the Université de Namur Belgium states that useful assistive technology should integrate into the lifestyle of the user, be easy to use, be ergonomic, adaptable to the user's needs, and accessible financially. The technology must give a positive image of the user and be accepted by the user's family who need to be involved in the choice of the devices.



Joël Beurkens
End user (NL)

End user from the Netherlands thinks that ultimately the functionality and robustness of Assistive Technology is most important. It is very annoying if the technology does not work. At that moment you feel handicapped. A beautiful design is nice but less important. Very important is to test whether or not the technology fits the client's situations.

conflict. Therefore they may often view each other with some suspicion, and various ethical issues such as the level of user autonomy, need to be investigated before technology can be properly developed.

2 Adaptability and/or adjustment to each individual's needs may necessitate that the technology be uniquely tailored to individual circumstances, robust, safe and durable. Therefore researchers need to concentrate on solving complex issues using new methodologies and approaches. This will only happen if researchers are immersed in the problem, and talking to relevant stakeholders and manufacturers, rather than remaining in the lab.

3 As the population ages, the demand for Assistive Technology will increase.

It is important that the technology is as simple to use and as cost effective as possible and is actually put to use rather than being discarded. If users have to contribute towards its acquisition then the cost of technology could be a barrier to its uptake. Therefore the funding route should also be as simple and transparent as possible. The table above shows that even for a standard and essential item such as a powered wheelchair, there is a variation in practice across northern Europe.

4 The treatment of chronic illness, dependency and disability requires an holistic view of health,

not only medical and health-related, but also one which encompasses a physical-mental-social dimension.

Communities, employers, and the general public need to pay greater attention to illness, deficiencies and disabilities rather than simply comply with regulations, which are often applied in such a way as to frustrate the disabled rather than assist them. Public perceptions will only change when the wider community is involved in the development of Assistive Technologies and can see how they enable users to lead an improved quality of life. As a result of identifying these challenges, EDECT has been capitalising on its collective experiences to begin developing solutions.



A few questions about the themes of EDECT to Anneliese Dodds, Member of the European Parliament (UK)

What are the benefits of taking part in cross-border projects?

As a former health care researcher who has participated in cross-border projects myself, it is clear that they offer a number of benefits. First, their size enables the pooling of resources to tackle some of the big questions of our age, such as those connected to the ageing society (which the EDECT cluster helps us to consider). Second, they enable researchers to develop novel perspectives on problems and to challenge their own preconceptions. Much can be learned from finding out about how different problems are dealt with in societies different to our own.

Why is EU research funding important?

A number of EU funding streams exist which can support collaboration between researchers across different countries, either in the process of research or in 'pump-priming' measures such as the creation of networks and holding of conferences. EU funding has been responsible for some of the biggest research projects in Europe and indeed the world. Not only have these research projects been important in helping us face up to some of the big challenges of the 21st century, they have also been an important driver of economic growth by promoting new innovations across a whole range of areas.

How can innovation across the EU promote health?

The EU's ageing society is often viewed uniquely as a problem, when in practice it represents the triumph of new health care technologies, improved sanitation and increased living standards. Nonetheless, it has meant that a larger proportion of the population is living with different types of mobility and sensory impairment for longer periods of time than before. Innovation in medical and medical-related technologies, as well as in pharmaceuticals, has the potential to help us overcome many of these impairments. As well as 'technical' innovations, however, we also need to bear in mind the societal context for new technologies and products, which is why I am particularly impressed by the EDECT cluster.

CHAPTER 3

INTEGRATING PROVISION OF ASSISTIVE TECHNOLOGIES WITH GOOD CARE PRACTICE



Devices for assisted navigation

It is recognised that to provide appropriate technology, support and training presents an enormous challenge to all stakeholders.

The Challenge

As discussed in chapters 1 and 2, it has been recognised that the goal for the development and provision of Assistive Technology is to improve the quality of life of users and their care network. This is a significant challenge. There are two key factors involved in good care practice, or the ethical provision of Assistive Technology. Both are well known but not well integrated. These two factors are firstly the provision of appropriate, long-term training and support for the user and care network, and secondly teaching the support-givers so they are able to empathise with the support-receiver. The support-receiver not only includes the user but also any member of the care network. An empathetic understanding of

the importance of the technology to the user, and what it is like to be without that technology, has been shown to be vital.

Therefore before the structures EDECT has identified to meet these challenges are presented, a brief overview of some of the challenges of ethical provision of support and training will be introduced.

Discussion within the EDECT cluster made it clear that it is important that the needs of the whole of the user's care network should be taken into account. This network not only includes immediate family and carers but also the health care professionals providing support and training to the users, their families and carers. It is recognised that this

network should also include the supplier and manufacturer. To do this effectively an empathetic relationship should be developed between those who provide support and the support-receiver. In the following discussion support should be understood to include the technical mastery of the Assistive Technology and the development of empathetic relationships between the whole team, users and care network.

Support and training

When Assistive Technology – or any technology – is appropriate, but provided without necessary support, that provision may decrease rather than increase the quality of life of the user and their care network. In that case the provision could be seen as unethical and not empathetic.

It has been learnt from the experience of the partners that ethical and empathetic provision implies that the following factors must be included:

- **Appropriate technology:** The technology must meet the real needs of the users in such a way as to improve their quality of life. This applies as much to Assistive Technology which is already proven and in the market as to technology which is in its development stage. The needs of the care network must also be taken into account
- **Appropriate support and training:** The ongoing needs of users and their care network must be part of the provision process so that the probability of the technology improving, rather than decreasing the quality of life of all involved is maximised. Learning to empathise is an important element of this care. It can be said that this holistic approach to training and support is absolutely vital to the effective provision of Assistive Technology

It is recognised that to provide appropriate technology, support and training presents an enormous challenge to all stakeholders.

Our experience of using standard technology in our own homes often leads to frustration and abandonment of that technology e.g. learning to program the TV or to solve computer errors. This is much more critical for users of Assistive Technology where frustration may lead to

abandonment of technology which is meant to enhance quality of life.

In order to insert technology ethically into the lives of users and their care network EDECT recognises the need to continue to develop strategies to identify what may be required to provide long term support. Some of the challenges identified by EDECT are:

- Is it possible to identify the needs of the user and their care network
- Can the identified training be planned to meet the needs of users and their care networks
- The needs of each user and the members of their care networks will differ - can these variations in long term support needs be identified and met
- How can the integration of Assistive Technologies in the life of the user and care network be encouraged? For example a user may be provided with telecare, powered wheelchair, environmental controls, Augmentative and Alternative Communication etc. Usually these technologies are provided by different agencies which may have carefully guarded but unclear boundaries for funding reasons and because of professional barriers. The ideal solution may be a 'one stop shop' where support for these integrated needs can be provided through one point of contact.
- As the training and support needs of the user and their care networks will vary from user to user, planning ongoing training

and support is both complex and challenging. For example two of the factors are:

- **User diagnosis:** For example, how will the training and support needs of a user with a rapidly changing condition such as Motor Neurone Disease differ from that for a user who has a relatively stable condition such as Cerebral Palsy?
- **The technological ability:** How will the differing technological abilities of the users and their care network affect the planning and provision of training and support?

- How can these factors be identified for each situation and the appropriate support provided? If these factors are not recognised and the appropriate support provided then provision may fail, raising the question of whether the care is ethical.

EDECT is also aware of the differences in health care models across the EU (an example of this is given in the Table 'How powered wheelchairs are funded'). Any model of training and support must allow for the regional and country variations that exist in the provision and funding of such activities, including the recruitment and training of the trainers themselves. It is recognised that implementing a more comprehensive and ethical system will increase costs of service delivery but in the long term will doing this not only be more effective in terms of outcome but also in terms of the overall cost to society? These are all factors in the challenge of the ethical provision of Assistive Technology.



Ian Palmer **Technology Manager**

Is the New Technology Manager at Dynamic Controls who have been at the forefront of power wheelchair development for more than 30 years, creating many of the leading technologies. Obstacle avoidance has long been an aim to enable people with high needs to navigate about everyday environments. A simple doorway can present a major challenge for quadriplegic with limited input control. With the addition of collision avoidance technology it could significantly increase the independence of a high needs person in a power wheelchair. However the challenge of creating effective collision avoidance is complex. With new cost effective sensing technology and access to cost effective processing power, creating an effective solution is getting ever closer.

The real issues to be solved are providing repeatable solutions that work for all conditions. Understanding the environments where the wheelchairs are actually being used for, identifying and understanding sensor blind spots. Developing hybrid solutions which can accommodate sensor limitations and create the right balance between the amount of control the user has and the amount of control that the electronics exert. All sensors have blind spots which is used in isolation could result in a unsafe drive condition which adds additional complexity and hurdles for this technology to overcome before it can be realized in the market place additional funding and research is required to overcome this concern.

For Dynamic Controls this exciting new technological development opens up the opportunity for their electronics to meet the needs of people with a high level of disability who previously would not have been a candidate for independent mobility. This not only aligns with commercial growth but supports their over-arching purpose of enhancing the life of those with disabilities. Whether it be enabling those with impaired motor skills to more easily move through doorways, prevent impact damage to their homes or just further provide certainty and confidence of safety, Dynamic Controls supports and is enthusiastic about the development and eventual the commercialization of collision avoidance technology.



Disseminating the assistive technology to clinical staff and industry

Benefits of cross-border working

The following benefits have been apparent in the EDECT cluster:

- a positive environment in which to learn from different cultural attitudes, which helps understanding of how and why we operate as well as to learn from similarities
- a way to develop strong working relationships and identify common areas of interest for future collaborative work

- a network to develop innovative projects with a multidisciplinary and multicultural team with whom working relationships are already proven
- an opportunity to develop cross-disciplinary research projects needing different skills

Therefore, for EDECT the Interreg IVA 2 Seas programme provided a great opportunity to capitalise on the expertise of both partners by building a bridge between the world of Assistive Technology and the world of the provision of good care. It stimulated the formation of a multidisciplinary team with expertise in engineering, science and health care. Additionally the

team's experience of different cultures and health care systems strengthened the value of this interaction, especially in the area of understanding the differences in health care provision across the regions. This knowledge was an additional motivation to design a model for the development of Assistive Technology and for the support of users of Assistive Technology that would be valid across these regions.

EDECT has also discovered that technical training and support of the user and their care network, even if excellently delivered, is not enough. There is also a need for empathy. Carers need to understand the importance of

technology to the user. Carers must also understand the negative impact on the user's quality of life if they do not have access to that technology or are not adequately supported in its use. Carers need to be able to empathise with the user - even if they find use of technology challenging - and to be determined to support that user, whatever struggles they may have with that technology.

Additionally the members of the care network need to empathise with their fellow carers, especially the closer family who may struggle with coming to terms with the user's disability and with the challenges of using technology. The carer may also be technophobic and find being the first line of support very stressful.

As a result of collaborating within EDECT the partners have become more aware that the successful development and implementation of Assistive Technology is also dependent on how the care network is trained and supported. Similarly their awareness of the way in which care organisations respond to the introduction of new technologies and the need to include the total user care pathway has increased. However, the condition of many users will change - some users will develop their ability, others will deteriorate. For example users with progressive conditions, some of which are rapidly changing (Motor Neurone Disease), will require a continually adapted technological prescription. Therefore their training and support and that of the user and the members of the care network

will need to be planned in order to respond in a timely manner.

The formation of EDECT has resulted in the consideration of the role and impact of Assistive Technology within the context of providing ethical care. Incorporating Assistive Technologies into the learning process of carers through experimentation and reflection can improve these methodologies. This should also provide more robust feedback which in turn should help the development of more user-friendly technology and better training methodologies for users and carers. Introducing the methodologies back into the development process will improve the synergy between all stakeholders involved in the provision of care services.

Holistic provision of Assistive Technology

The goal for the development and provision of Assistive Technology is to improve the quality of life of users, their families and their carers. However, if that technology is provided without the necessary support, it may actually decrease rather than increase the quality of life of the user and their care network.

EDECT therefore has begun to discuss what it means in practical terms to develop and/or provide technology in an ethical and empathetic way. It is recognised that to provide appropriate

technology, support and training presents an enormous challenge and a number of issues will need to be addressed. These include identifying and responding to the technological and training needs of users and their carers, the level of support required and integration of Assistive Technology into the user's life. Obviously a more holistic care model has resource implications and these will be different across regions and countries.



Test and trial chairs: The development of assistive powered wheelchair technology requires an academic test platform (left) to develop and test algorithms and sensors, which when functional are then transferred to the clinical trial platform (right) for users to evaluate.

Identifying and analysing these factors is a significant piece of work and EDECT has only just started the process. However, the question remains, if these issues are not identified and addressed and the appropriate support provided, can the care be ethical?

EDECT's Framework

EDECT has developed a framework to tackle the challenges of developing Assistive Technology and identifying and providing appropriate training and support needs.

To address the issues raised, EDECT has worked to develop a framework through which new methods can be used to establish the criteria for the ethical development and provision of Assistive Technologies. This framework is based upon experiences learnt from the partners' previous projects.

It provides a reflective structure and feedback to understand better concerns of users and to develop new and appropriate technologies which will benefit all stakeholders. The following need to be taken into account:

- Assessment of stakeholder requirements
- Understanding stakeholder concerns
- Critical examination of current technologies used to fulfil those requirements
- Role-reversal for ongoing training and assessment during the development of technologies
- Production of empathy-focused guidelines for all stakeholders regarding implementation, usage, updating, replacement, and disposal of technology.

EDECT's framework has three elements – these are workshops, a cross-border network and an International Expert Group

The workshops

In order to incorporate Assistive Technology into the lives of individuals in a respectful manner it is necessary to include these individuals in developing both the technologies and the support and training measures that they require. The workshops require:

- testing technology in real-life situations, finding suitable places for organising experiments
- the gathering of a significant network of participants involved in using such technology to identify the issues for each actor involved
- the refining of the design and the experimental condition of Assistive Technologies with the actors involved in order to match the needs and expectations better and to identify the support and training needs of carers
- identification of the issues around the use of these technologies for the organisations involved (health care or medico-social institutions, professional institutions and even primary organisations such as the family, etc.)
- identification of the issues around development of

interactions between actors involved in health care and support. The development and use of Assistive Technologies are not only influenced by how professionals are trained, but also by the way in which organisations approach the adoption and use of new technologies. This aspect of the use of Assistive Technologies which is part of the care and support processes will be further developed in this approach

- developing assessment methods which are permitted and required for this type of approach.

The cross-border network
The EDECT cluster has given partners the opportunity to combine ideas and resources and one outcome has been the establishment of a network of locations across the Interreg region where cross-border workshops using the framework can be held. The network can be used collectively or individually across borders and cultures. In addition to the EDECT partners and associate partners, the cross-border network includes:

- Headway the brain injury charity, Canterbury, UK
- Kent Brain Injury Forum, UK
- Hôpital de Garches, France
- Association des paralysés de France
- Centre Jacques Calvé, Berck-sur-Mer, France
- Centre Hélène Borel, Lomme, France

- Dienstenscentrum GID(t)S, Belgium
- Independent Living Movement, Ghent, Belgium
- Revant, Goes, Netherlands

The International Expert Group

EDECT created an International Expert Group (IEG) drawn from partner organisations to steer, moderate, and assess the ongoing process of using and developing the framework and to manage the workshops at which the Assistive Technologies can be evaluated. These workshops will provide the opportunity to incorporate the needs, desires and concerns of stakeholders in order to refine the research and development process, the delivery method, stakeholder training and technical long-term support.

EDECT believes this will deliver technological innovations that are more likely to be developed by industry and subsequently brought to market.

The International Expert Group consists of the following cross-border elements:

- Appropriate academic discipline researchers from across the network
- Assistive Technology clinical engineers and technicians
- Health care worker training organisations (consultatively)
- Manufacturers and industry (consultatively)
- Prescribers of the technology (consultatively)
- End user organisations (consultatively)
- Policy making bodies (consultatively)



Paul Neilly
End user (UK)

End user from England looks forward to the time that assistive technology can level the playing field. It would be nice to work and contribute to society rather than feeling unable and unwanted, he says.



Device for safe navigation mounted on a Dupont Medical powered wheelchair



The EDECT partners

Managing Editor: Véronique Weyland-Ammeux,
Director of the Interreg IVA 2Seas Programme

Authors and contributors: Alice Chapman-Hatchett (co-ordinator); Janet Merza, Tom Molloy, Matthew Pepper, Annemarie Kokosy, Michael Gillham, Olaf Timmermans, Nicolette de Klerk-Jolink, Leen Stevens, Mo Sakel, Pierre Boitte, Anneliese Dodds Jean-Philippe Cobbaut, Ladan Najafi, Mohamed Sakel, Klaus McDonald-Maier and Hu Huosheng.

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This cluster is led by the Health and Europe Centre. The cluster partnership also includes: East Kent Hospitals University NHS Foundation Trust, University of Kent, University of Essex, Institut Supérieur de L'électronique et du numérique de Lille, Université Catholique de Lille, University College HUB-KAHO, University of Applied Sciences.

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INTERREG IV A 2 Mers Seas Zeeën

Secrétariat Technique Conjoint / Joint Technical Secretariat / Gemeenschappelijk Technisch Secretariaat
Les Arcuriales - 45/D, rue de Tournai - 5^e étage - F-59000 Lille
T : +33 (0) 3 20 21 84 80 - F : +33 (0) 3 20 21 84 98
contact@interreg4a-2mers.eu



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