Building capacity for excellence in service provision for people with disabilities

Analytical paper on Information and Communication Technologies in rehabilitation of persons with disabilities

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I. Introduction

Information and communication technologies (ICT) have become increasingly prevalent in today's society and in all aspects of life. Over the past number of years they have led to a fundamental change in the way business is carried out. Whereas new opportunities keep arising, the price of ICTs reduces, and an increasing part of the population has access to and is familiar with ICTs.

ICTs can transform the lives of those with greater disabilities far more than they can the lives of those with fewer disabilities - or no disabilities. They allow people with disabilities to enhance their social and economic integration in communities by enlarging the range and the quality of activities and services available to them.[1] The increased availability of ICTs, the decrease in costs associated with implementing them in the service provision, and a more widespread user-base has made new technologies not only desirable but invaluable in the rehabilitation sector.

This paper focuses on the use of Information and Communication Technologies (ICTs) in providing disability-related services. It concerns the delivery of health, social care or education to individuals within the home or wider community outside formal institutional settings, with the support of devices enabled by information and communication technologies. Examples of ICTs used in rehabilitation are: monitoring sensors and SMART home facilities, distance learning, accessible web-based job-search tools, the use of social media with clients, administration of clients' data, etc.

The paper does not deal with the use of Assistive technologies (ATs) which are any item, piece of equipment or product system that is used to increase, maintain or improve functional (body) capabilities of individuals with disabilities. This specific topic would deserve to be covered by another analysis.

II. ICT in rehabilitation: what are we talking about?

The wide variety of ICT available and useful to the rehabilitation sector prevents from listing all items individually. It makes more sense, thus, to identify categories of ICTs according to their different uses/implementation areas.

- *Customer management*

Nowadays, many (potential) clients are familiar with new ICT and social networking tools (internet, facebook, distance learning…). Consequently, rehabilitation service providers should increasingly use those new tools and channels to approach potential clients (marketing via internet), but as well to provide already assigned future clients with initial information (about the centre, programmes, city/region). In some cases, ICT can be used to prepare future clients for training (e-learning to fill gaps before starting the programme). During the rehabilitation process, on-line exchange of information can be used for permanent help-desk functions and to provide the client instant access to all information or data of the own rehabilitation. Finally, new media and ICTs are often used to stay in touch with clients after they have left the centre for follow-up actions, evaluation, etc.

[1] http://www.unesco-ci.org/ict-pwd/images/ND%2024-26%20November%202014%20-%20Concept%20paper.pdf

- *Education and training*

Alongside the emergence of ICT-based learning technologies, modules, etc. there has been a growing recognition of alternative theories for learning. The main focus of these new learning ideas is supporting constructivist principles in rehabilitation. This approach focuses on social interactions in the process of learning and cognition. Prior to the development of this approach rehabilitation was based on the approach whereby rehabilitation workers lead patients through a structured learning approach to achieve a desired goal. This new more dynamic approach to rehabilitation allows for individuals to strive toward their own targets, and thus taking a more active approach to their rehabilitation process, thereby constructing knowledge or moving forwards, rather than simply receiving knowledge.

- *Medical rehabilitation*

The use of ICTs in medical rehabilitation often relates to the concepts of 'telemedicine' and 'telehealth'.

Telemedicine is the use of telecommunication and information technologies in order to provide clinical health care at a distance. It helps eliminate distance barriers and can improve access to medical services that would often not be consistently available in distant rural communities. It is also used to save lives in critical care and emergency situations. Early forms of telemedicine achieved with telephone and radio have been supplemented with videotelephony, advanced diagnostic methods supported by distributed client/server applications, and additionally with telemedical devices to support in-home care. The introduction of ICT and telemedicine alone is estimated to improve efficiency of health care by 20%.[2]

Telehealth is the delivery of health-related services and information via telecommunications technologies. Telehealth is an expansion of telemedicine, and unlike telemedicine (which more narrowly focuses on the curative aspect) it encompasses preventative, promotive *and* curative aspects. Originally used to describe administrative or educational functions related to telemedicine, today telehealth stresses a myriad of technology solutions. For example, physicians use email to communicate with patients, order drug prescriptions and provide other health services. One of the most significant increases in telehealth usage is the home monitoring of conditions by patients whose clinical trials in the UK have shown to decrease mortality.

Other advantages of telehealth are that doctors are now able to gain access to electronic medical records, real time data (transmitted through wireless and wired links) and records of the patient's condition (body temperature, blood pressure), activities (physical activity, medication, food and water consumption), and changes in their life environment. Professionals will be supported further by decision tools, which will assist in creating personalised, rehabilitation plans for patients whilst providing daily feedback to them. All of these modules are web-based to enable professionals to access them at any time and location.

[2] https://ec.europa.eu/digital-agenda/en/ehealth-and-ageing

- *Independent living and Telecare*

Telecare refers to the idea of enabling people to remain independent in their own homes by providing person-centred technologies to support the individual or their carers. In that sense, telecare is specifically different from telemedicine and telehealth (see above for medical rehabilitation).

Telecare is a term given to offering remote care of old and physically less able people, providing the care and reassurance needed to allow them to remain living in their own homes. The use of sensors may be part of a package which can provide support for people with illnesses such as dementia, or people at risk of falling. Most telecare mitigates harm by reacting to untoward events and raising a help response quickly. Some telecare, such as safety confirmation and lifestyle monitoring have a preventive function in that sense that deterioration in the telecare user's wellbeing can be spotted at an early stage.

III. Benefits of ICTs in rehabilitation

- *Increase cost-effectiveness*

The long term care expenditure in the EU is projected to double between 21010 and 2060. Long term care however only represents parts of costs, and long-term care costs are associated with more than disability only – for example chronic illnesses that may not be recognized disabilities, or ageing.[3] The main factor in saving costs is that ICTs will take over parts of tasks carried out by staff on the one hand, and that they will ensure that some other activities can be implemented with more efficiency on the other hand. Besides, fewer clients need to be in the centre, which implies that the infrastructure and utility costs can be reduced. Finally, transport costs for ambulant services can be decreased. In times of economic crisis and budget cuts in social services, this rationale will become increasingly important.

- *Decentralisation and proximity of the service delivery*

Providing rehabilitation at any place and close to the client is not necessarily an innovative approach, but the concept has become much more viable and effective with the extended scope and increasing development of ICTs. This can be especially beneficial for those patients with decreased mobility capacity as at home development, rehabilitation and reintegration programmes can be live and instantaneous. It can also provide a solution for clients living in rural areas, and as such reduce the growing gap between urban and those rural areas.

- *User-centered and empowering approach*

Through online technologies, rehabilitation has become a flexible activity that is no longer set within programmed schedules and slots. Service-users are free to undertake therapy or education sessions

[3] Communication from the Commission to the European Parliament, the council, the European Economic and Social Committee and the Committee of the Regions eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century, COM(2012) 736 final

at a time more convenient to their lifestyle, more suited to individual time schedules, and more in tune with their needs.

Moreover, the clients take more control over their own growth and pathway into the social environment, and the service through ICTs reduces the dependency on professionals. ICTs by their very nature are tools that encourage and support independent and tailor-made learning. This new more dynamic approach to rehabilitation allows for individuals to strive toward their own targets, and thus taking a more active approach to their rehabilitation process.

Finally, clients have a greater choice between service providers as the geographical location does not play a crucial role. Besides, ICTs enable service providers to put in place real 'customer management systems' through which the client has at all times full access to any data and information on his/her rehabilitation process.

- *Better quality of service-provision*

Involving expertise from distance in the rehabilitation process allows the service-provider (within the financial boundaries) to apply on the best expertise for every client, also when this expertise in not present or available in the centre.

Moreover, the systematic use of ICTs facilitates a multi-disciplinary approach and the continuum of service-provision, as all professionals dealing with the same client can consult (of course with respect to confidentiality) or even be directly involved in actions and results of other elements of the rehabilitation plan.

ICTs sometimes just open up new technical opportunities that improve the quality of the service. Examples are better monitoring sensors and SMART home facilities that allow independent living for a much wider target group, or sophisticated methods for distance learning.

Last but least, the use of ICTs is also beneficial for the client in relation to gaining employment and everyday living, as the ICT skills have come to be a central factor in terms of employability. It has become increasingly important for individuals seeking gainful employment to not only have high level of knowledge in the area the area working in but also in the knowledge of ICTs and skills.

- *Management and accountability*

In times where there is ever more emphasis on measuring, monitoring and reporting on every aspect of rehabilitation service-delivery, the use of ICTs can reduce the enormous time that need to be spent on paper work and bureaucracy. This allows dedicating more time to the client and his/her rehabilitation process, and can thus enhance the motivation of professionals.

IV. Risks and barriers for using ICTs and ATs

- *Ethical issues*

Rehabilitation services are still services to people in need, and it should be carefully assessed what forms of personal care and contact are abandoned with the use of ICTs. Secondly, one may wonder what the consequences and risks are when responsibility for the monitoring and quality of the intervention is delegated to machines and informal careers. Finally, the use of ICTs always involves

particular problems in terms of data protection, which is more outspoken when dealing with vulnerable target groups and with an asymmetric relationship between professional and client.

- *Costs*

In recent years, although funding for science based projects in the ICT sector has increased, the funding available for the purchase and use of such equipment has been lagging behind. This means that the rehabilitation service provider needs to make considerable initial investment in ICT equipment. From the other side, one needs to be make sure that the clients dispose of state-of-the-art equipment, fully accessible, and access to high quality and high speed internet connections.

V. EU policy developments in relation to ICT in rehabilitation

- *Accessibility Act*

Despite all progress made in the development and implementation of ICTs in rehabilitation, they are nothing if they are not accessible to users. The proposal of the European Commission for an Accessibility Act, published in December 2015, reminds of the Commission's commitment to accessibility of ICTs as a catalyst for social inclusion: *"The European Commission is committed to equality of opportunity for people with disabilities, in full respect of the UN Convention on the Rights of Persons with Disabilities. This includes accessibility to the physical environment, transportation, information and communications technologies and systems (ICT) and other facilities/services."*[4] It is expected that this initiative will improve accessibility of ICTs to all people with disabilities and overcome the barriers set by producers or national legislations.

- *European eHealth Action Plan 2012-2020*

The first eHealth Action Plan3 was adopted in 2004. Since then, the European Commission has been developing targeted policy initiatives aimed at fostering widespread adoption of eHealth throughout the EU4. Member States have dynamically responded by demonstrating a high level of commitment to the eHealth policy agenda, notably through their participation in major large scale pilot projects such as epSOS. The adoption in 2011 of the Directive on the Application of Patients' Rights in Cross Border Healthcare and its Article 14 establishing the eHealth Network, marked a further step towards formal cooperation on eHealth, with the aim to maximise social and economic benefits through interoperability and the implementation of eHealth systems.[5] It presents and consolidates actions to deliver the opportunities that eHealth can offer, describes the EU's role and encourages Member States and stakeholders to work together.

The goal is to improve healthcare for the benefit of patients, give patients more control of their care and bring down costs. While patients and health professionals are enthusiastically using telehealth

[4] http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=COM:2015:0615:FIN

[5] Communication from the Commission to the European Parliament, the council, the European Economic and Social Committee and the Committee of the Regions eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century, COM(2012) 736 final

solutions and millions of Europeans have downloaded smartphone apps to keep track of their health and wellbeing, digital healthcare has yet to reap its great potential to improve healthcare and generate efficiency savings. Given the fast growing uptake of tablets and smartphones, the Action Plan[6] also includes a special focus on mobile health (mHealth).

- *Technology-enabled Services for Older People Living at Home Independently: the JRC report 2015*

This report presents six policy lessons that could help public authorities at all levels of the EU Member States for use new technologies in long-term care service provision for older people. These policy lessons have come out of the ICT-AGE research project carried out by the JRC-IPTS and funded by DG EMPL, based on the cross-analysis of good practices in technology-enabled services to help older people live independently at home.[7] The 6 policy lessons identified are:

1. Establish a policy framework to support the creation and implementation of these services in public long – term care systems, with policies and funding
2. Build a sustainable business model able to generate social and economic returns, and make the service affordable and accessible to the users. The evaluation of impacts and building partnerships between public and private organisations are relevant for this sustainability
3. Engage all the stakeholders -care providers, the older people and their carers, technical providers, researcher centres, professionals, localities and policy-makers-to build confidence and trust
4. Use a well - established entry point for the new service
5. Share experiences of design and implementation of the services with other localities, regions and countries through exchanges, cooperation, and participation in development and innovation projects
6. Be alert to issues of interoperability, that are particularly important in relation to ICTs.

VI. Conclusion

The fast pace of change in the ICT area certainly keeps surprises to service providers and users in the rehabilitation area. ICTs, well-resourced and well used, are a great tool for progress towards more independent participation of people with disabilities in the community, and more manageable condition.

Yet, these fast developments also require to upskill and invest both time and money in insuring that staff and users are trained to comfortably handle the technology at their disposal. Awareness-raising actions are also essential, as a lack of motivation amongst many users follows from the belief that

[6] http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:52012DC0736
[7] http://publications.jrc.ec.europa.eu/repository/bitstream/JRC96022/lfna27256enn.pdf

what exists is sufficient, or that other, not accessible things exist. Therefore, policy-makers should as a sine-qua-non condition pay guarantee the accessibility of ICTs.