Disrupting the world of Disability: The Next Generation of Assistive Technologies and Rehabilitation Practices

Catherine Holloway¹ \bowtie , Helen Dawes²

¹Computer Science, University College London, Gower St, UK

²Elizabeth Casson Trust Chair, Movement Science Group, Oxford Institute of Nursing and Allied Health Research (OxINAHR), UK

 \bowtie *E-mail: c.holloway@ucl.ac.uk*

Published in Healthcare Technology Letters; Received on 26th October 2016; Accepted on 31st October 2016

Designing, developing and deploying assistive technologies at a scale and cost which makes them accessible to people is challenging. Traditional models of manufacturing would appear to be insufficient at helping the world's 1 billion disabled people in accessing the technologies they require. In addition, many who receive assistive technologies simply abandon them as they do not meet their needs. In this study the authors explore the changing world of design for disability. A landscape which includes the rise of the maker movement, the role of ubiquitous sensing and the changing role of the 'user' to one of designer and maker. The authors argue they are on the cusp of a revolution in healthcare provision, where the population will soon have the ability to manage their own care with systems in place for diagnosis, monitoring, individualised prescription and action/reaction. This will change the role of the clinician from that of diagnostician, gatekeeper and resource manager/deliverer to that of consultant informatics manager and overseer; perhaps only intervening to promote healthy behaviour, prevent crisis and react at flash moments.

1. Introduction: In the UK alone it is estimated that there are 11.6 million disabled people [1]. These people will require both assistive technologies and rehabilitation to conduct activities of daily living (ADL). There are two pressing issues when it comes to assistive technologies: (i) people do not have access to the technology they need, (ii) the technologies are frequently abandoned. The WHO estimates that of the 70 million people who need a wheelchair, only 5–15% have access to one [2]. The majority of these people live in lower income countries, but others live in higher income countries but still do not have the means to acquire the assistive technology they require to complete their ADL. This is shocking.

An assistive technology is defined as any product which has the primary purpose to maintain or improve an individual's functioning and independence, and thereby promote their well-being [2]. These can be especially produced or generally available, and might also be used to prevent impairments and secondary health conditions. There now exists a priority assistive products list which lists the 'highly needed products which are of an absolute necessity to maintain and improve an individual's functioning and which need to be available at a price the community/state can afford' [2]. The wheelchair is one such product, as are, fall detectors, hearing aides, incontinence products, orthoses, communication aides and pill organisers.

In this paper we explore the reasons for this lack of access and abandonment; then look ahead to a coming revolution in the way assistive technologies are designed and manufactured. We look briefly at the role of positive computing on rehabilitation practices, noting that ubiquitous sensing and a focus on user-centred design methods can produce truly joyful assistive technologies and engaging rehabilitation therapies. Finally, we explore the challenges inherent in embedding these new practices into clinical practice.

2. Abandonment and the role of the user: Assistive technologies are frequently abandoned by the user. The numbers vary but a reasonable estimate is that a third of all assistive technologies will be abandoned. This was the figure reported in a recent survey of 227 people [3]. However, certain types of assistive technologies are abandoned more frequently, for example upwards of 50% of wheelchairs provided to people with a spinal injury [4]. In a recent survey in Italy it was found that of the 17% who had

abandoned their technology, 40% had never used it [5]. The reasons for abandonment are complex but are centred around a mismatch between user needs and provision. In some instances people purchase the easiest to obtain technology, though it does not best fit their needs; in other instances the needs of the users change and therefore the technologies to better match user needs is clear. There is however a change in paradigm from user-centred design of assistive technology, which is now standard as well as best practice to co-creation. This shift involves the user of the technology in the making as well as the design process. This reflects a changing paradigm in disability and design, which when combined with the rise of sensing modalities allow for a disruption to the way in which disability is thought of within society.

The e-nabling project is the best example of this change in culture lead by the evolving and growing maker movement [6]. The project makes use of open-source design and 3D printing to allow people to customise and print their own prosthetic hand. Frequently the designs reflect the personality and fashion consciousness of the user, and rarely if ever to they look or feel like the more traditional prosthetics. This is in keeping with a change of attitudes which can be seen across the disability and assistive technology use, where people frequently refer to assistive technologies as a form of wearable technology, for example 'wear my wheels' rather than simply being a wheelchair user [7]. One of the authors of this piece is the founder of Hack On Wheels an organisation that is looking to establish the first open-source digitally fabricated wheelchair designs, it is a founding project of the newly established Global Disability Innovation Hub [8] They aim to follow in the footsteps of the e-nabling project, helping to provide wheelchairs to those who currently do not have one but are in need of one. In both the e-nable and Hack On Wheels projects the users are central to the movement and have direct access to design and designers. Through more traditional provision methods, the key relationship for wheelchair provision is between the user and the clinician.

3. Positive technology, connectivity and the Internet of Things (IoT): The world is increasingly more connected – nearly half

the world has access to the Internet [9] and over half have a mobile phone [10]. This offers a huge opportunity to change rehabilitation practices and assistive technology design, especially when combined with the rise in design thinking around positive design [11] and positive computing [12]. Positive design aims to link design to the subjective well-being of users such that the technology should support human flourishing. In much the same way positive computing looks to develop a similar theme but focussed on human-computer interaction. Both are applicable to the design of assistive technologies and rehabilitation practices.

Recent advances in the IoT combined with reducing costs and improvement in sensor technologies and a refocussing on technologies which adapt to user requirements are beginning to change the landscape of assistive technologies. For example, the Ubi-Sleeve is currently being developed which would allow prosthesis wearers and clinicians to review temperature, humidity and resulting prosthesis slippage as people go about their daily activities [13]. This effectively makes the interface between the user and the assistive technology a part of the IoT and allows a more detailed analysis to be incorporated into clinical practice, thus improving evidencebased practice of assistive technology choice. In other areas sensors are being attached to assistive technologies so that both rehabilitation practices and assistive technology use data can be captured. This research looks to categorise both elements of rehabilitation and accessibility, for example the types of surface a wheelchair user is rolling over can now be automatically categorised and added to a mapping database, while the style of pushing is also captured [14]. There is also a growing body of literature exploring the use of shared-control, where the control of an assistive technology is achieved through a combination of inputs from the environment and the user, which is fast changing the paradigm of human-robot interfaces [15].

4. Optimising rehabilitation: Rehabilitation sets out to restore to a condition of good health, the ability to work, or participate in other meaningful life roles. We currently do not know what is optimal for any individual rehabilitating or managing their disease. Even when we consider the findings from randomised controlled clinical trials; the gold standard that inform National government policy and World Health Organisation guidelines, we do not know what rehabilitation people did do (timing, content and dose) or how, when, and where they used their devices. The Tidier guidelines [16] are pushing researchers and clinicians to consider the planned content of rehabilitation, underpinning logic models and recording what people do. To date, this has been fraught with difficulty, but going forward we will be able to monitor all of this and so consider previous behaviour, genotype, phenotype, symptoms, environment and personal context to support individualised optimised prescription. New models for recording of rehabilitation interventions are needed so that monitoring of both previous and current behaviour can be used to inform our understanding of recovery and develop individual and population level integrated rehabilitation prescription packages.

5. Healthcare revolution: We are on the cusp of a healthcare revolution. The population will soon have information in their grasp that will enable them to manage their own care with systems in place for diagnosis, monitoring, individualised prescription and action/reaction. Clinician's roles will change from that of diagnostician, gatekeeper and resource manager/ deliverer to that of consultant informatics manager and overseer; perhaps only intervening to promote healthy behaviour, prevent crisis and react at flash moments. Considering the exciting new innovations that are available and will become available [17, 18], there is a need to consider new models of care so that appropriate parameters are monitored taking into consideration our current knowledge and updating as our understanding of the complexity of managing people's health evolves. Indeed what will the skill

base of a clinician become? Having data to consider the environment, context, phenotype and genotypic profile when deciding on action will become the norm.

For such a vision we will need to create a socio-technical integrated platform, to support rehabilitation services which combine medical, technical, health and care services, behavioural and social information. For success, which has previously not been achieved, we will need a platform that relies on information exchange between different types of professional and the public. For success, we will need to develop novel approaches and models of management, with all stakeholders involved in the co-creation, that engender on and off-line user and stake holder confidence [19].

6 References

- 'Disability prevalence estimates 2002/03 to 2011/12 (April to March)

 Publications GOV.UK'. Available at https://www.gov.uk/ government/statistics/disability-prevalence-estimates-200203-to-201 112-apr-to-mar. Accessed 19 October 2016
- [2] 'WHO Priority Assistive Products List (APL)', WHO. Available at http://www.who.int/phi/implementation/assistive_technology/ global_survey-apl/en/. Accessed 25 October 2016
- [3] Phillips B., Zhao H.: 'Predictors of assistive technology abandonment', Assist. Technol., 1993, 5, (1), pp. 36–45
- [4] Rose L.S., Ferguson-Pell M.: 'Wheelchair provision for people with spinal cord injury: 1', Br. J. Ther. Rehabil., 2002, 9, (10), pp. 391–400
- [5] Federici S., Meloni F., Borsci S.: 'The abandonment of assistive technology in Italy: a survey of users of the national health service', *Eur. J. Phys. Rehabil. Med.*, 2016
- [6] 'Enabling The Future', Enabling The Future. Available at http:// enablingthefuture.org/. Accessed 26 October 2016
- [7] 'Wheelchairs aren't used, they are worn', Scope Disability forum. Available at https://community.scope.org.uk/discussion/30040/ wheelchairs-arent-used-they-are-worn. Accessed 26 October 2016
- [8] admin: 'Design my wheels', Global Disability Innovation Hub, 30 July 2016. Available at https://gdihub.lets-go.live/projects/designmy-wheels. Accessed 26 October 2016
- [9] 'Number of Internet Users (2016) Internet Live Stats'. Available at http://www.internetlivestats.com/internet-users/. Accessed 26 October 2016
- [10] S.V. President and BCG: 'Number of mobile phone users worldwide 2013–2019', Statista. Available at https://www.statista.com/statistics/ 274774/forecast-of-mobile-phone-users-worldwide/. Accessed 26 October 2016
- [11] Desmet P.M.A., Pohlmeyer A.E.: 'Positive design: an introduction to design for subjective well-being', *Int. J. Des.*, 2013, 7, (3)
- [12] Calvo R.A., Peters D.: 'Positive computing: technology for wellbeing and human potential' (MIT Press, 2014)
- [13] Williams R.J., Holloway C., Miodownik M.: 'The ultimate wearable: connecting prosthetic limbs to the IoPH'. Proc. 2016 ACM Int. Joint Conf. on Pervasive and Ubiquitous Computing: Adjunct, New York, NY, USA, 2016, pp. 1079–1083
- [14] Holloway C., Herari B., Nicholson S., *ET AL.*: 'Street Rehab: linking accessibility and rehabilitation'. Annual Int. Conf. of the IEEE Engineering in Medicine and Biology Society, 2016. EMBC 2016, 2016
- [15] Mulder M., Abbink D.A., Carlson T.: 'Introduction to the special issue on shared control: applications', J. Hum.-Robot Interact., 2015, 4, (3), pp. 1–3
- [16] Hoffmann T.C., *ET AL.*: 'Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide', *BMJ*, 2014, 348, p. 1687
- [17] Steins D., Sheret I., Dawes H., ET AL.: 'A smart device inertial-sensing method for gait analysis', J. Biomech., 2014, 47, (15), pp. 3780–3785
- [18] Steins D., Dawes H., Esser P., ET AL.: 'Wearable accelerometry-based technology capable of assessing functional activities in neurological populations in community settings: a systematic review', *J. NeuroEngineering Rehabil.*, 2014, **11**, p. 36
- [19] Kani-Zabihi E., Coles-Kemp L., Helmhout M.: 'Information presentation: considering on-line user confidence for effective engagement', in Tryfonas T., Askoxylakis I. (Eds.): 'Human aspects of information security, privacy, and trust' (Springer International Publishing, 2015), pp. 517–525



Dr Catherine Holloway is a senior Lecturer in the Department of Computer Science based in UCLIC, and the UCL Engineering Lead for the newly established Global Disability Innovation Hub. Catherine is passionate about the design of usable assistive technologies and making cities accessible. She recently established and is CEO of Movement

Metrics, a community interest company focused on transferring the latest research in embedded and connected sensor technologies in assistive devices to market. Catherine directs the UCL– James Dyson Foundation Summer School each year on wheelchair design.



Prof. Helen Dawes is Elizabeth Casson Trust Chair, Director of the Centre for Rehabilitation, and Deputy Director of the Oxford Institute of Nursing and Allied Health Research (OxINAHR) at Oxford Brookes University. Helen is also Associate Research Fellow, Department of Clinical Neurology, University of Oxford. She leads research

across three themes: movement, clinical exercise and occupational sciences. Helen is deputy chair of the Scientific Advisory Board of the Chartered Society of Physiotherapy's (CSP) Physiotherapy Research Fund. Her research has focused on optimizing performance of everyday activities through rehabilitation. It requires cross-disciplinary collaborations and spans from exploring underlying mechanisms affecting performance through to service delivery of subsequently developed interventions and tools. Helen has set up a spin-out company – Clinical Digital Diagnostics – which uses IMU sensors to monitor and diagnose through movement and is chief science officer of the Clinical Exercise and Rehabilitation (CLEAR) Trust whose Patron is Mike Brown.