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The Hollybank Challenges: AT for People with Profound Disabilities

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Abstract. The use of Assistive Technology with people with profound and multiple disabilities is a specialised subfield. Drawing on its authors' experiences and observations at a UK charitable foundation that offers specialised educational, residential and therapeutic facilities, this paper describes the distinct challenges that present themselves when applying AT to address the needs of this often-overlooked sector of the community. It is hoped that this will help raise awareness and contribute to improving the overall quality of AT provision in this area.

Keywords. Profound and multiple disabilities, experience report, praxis.

1. Introduction

Hollybank Trust is a charitable foundation created in 1954 to cater for the needs of children and adults with profound and multiple disabilities of a physical and cognitive nature. It runs a school, purpose-built residential homes for children, adult daytime activity programmes and community adult homes in Yorkshire in the UK. The Trust's main site at Mirfield, West Yorkshire, is the location of the day school, which in its most recent inspection has been rated 'outstanding' by the UK Government's Office for Standards in Education. The whole site is designed to provide learning and leisure opportunities along with a high level of round-the-clock support.

Hollybank has around 100 residents, of whom about one-fifth are aged 19 or under and attend the school, and employs some 500 people. While the Trust's activities have traditionally focused on younger people, since 2004 it has been committed to providing 'quality of life for life', to meet the needs of individuals with complex disabilities who would otherwise have few choices for continued development into adulthood. In terms of AT provision, Hollybank has a dedicated and highly trained team, consisting of AT specialists, speech and language therapists, occupational therapists and physiotherapists, who work with the pupils and residents to assess needs, and to suggest, provide, and evaluate AT solutions. To better understand the practicalities of AT provision in this specialised field, one of the authors, an academic researcher with a background in applied technologies made a number of visits during 2016 to the Trust's main site. This paper is based on his observations, and his interactions and discussions with residents and staff, condensed into a number of general AT 'challenges' faced on a daily basis in an environment such as that of Hollybank.

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2. The Hollybank Challenges

Lancioni et al. [1] point out two general requirements if users with profound and multiple disabilities are to obtain the greatest benefit from AT: first, that they are given the technology that is best suited to their needs, characteristics and environment; and, secondly, that the provision is made in the context of a carefully designed intervention that enables them to exploit the technology to the utmost. Already we begin to get some sense of the complexity of this area; in the light of the Hollybank experience we can identify a number of distinct challenges to meeting these fundamental requirements.

2.1. *Overcoming the Myth of the Typical Service User*

There is no such thing as a 'typical' AT service user; this is as much a truism at Hollybank as anywhere else: each is an individual, with her own needs and wants. The children and adults are affected by a range of profound physical and cognitive disabilities; most have restricted mobility, and most have severe learning and communication difficulties. This means that a service user at Hollybank is rarely able to adapt her behaviour, activities or environment to accommodate generic AT solutions; either extensive modifications or bespoke solutions will be required. AT must be flexible and adaptable, and not tied to rigid use cases.

2.2. *Solving Problems and Creating Solutions: Applied AT as Bricolage*

AT provision at Hollybank typically requires a painstaking interaction between the user and the AT specialists and therapists to understand her needs or aspirations and motivations, to assess her capabilities, and to relate these to available technologies, the practicalities of providing and operating them, and the wider social and learning environment. Moreover, each and every one of these factors will vary with time, entailing a continuous process of reassessment. They have to get to know and understand the service user, and propose AT that is sympathetic to her needs and to those of the wider community. In addition to more formal skills [2], developing and applying an appropriate AT solution thus requires imagination and creativity, sympathy and empathy, the application and ad hoc modification of technologies to hand, an aptitude for problem-solving and a great deal of trial-and-error. This task is perhaps best described as *bricolage*, as much an art as a science in its inventive and pragmatic approach to problems, and requires creative and 'emotionally intelligent' people.

2.3. *Operating in the Assistive Environment*

It is easy to forget that AT is never used in a vacuum: it is applied in a complex social environment of other people, things and technologies. For instance, if its power cable presents a trip hazard a particular AT cannot be used, no matter how good it otherwise is. Does it interfere – physically or technically – with other AT that the user has? Will the AT be disruptive in the classroom? Can the AT be secured to a wheelchair? And so on. Moreover, environments such as Hollybank can be hostile ones for AT. Expensive equipment can and does fall – and is sometimes thrown – from wheelchairs or tables. Juice is spilled on it and sticky fingers handle it. It must be robust and resilient.

In addition, Hollybank is a place of work: away from the dedicated attention of AT specialists and therapists, the daily needs of Hollybank residents are addressed by the

Trust's care staff. At Hollybank, as everywhere else, there is a high turnover of staff in this sector of the economy. This means that personal bonds between carers and residents are continually broken, with each new carer in turn having to get to know the residents in his care, and their needs, wants and abilities. And all this takes time, which, with the carer's other duties to attend to, is always at a premium, and so it can be difficult to appreciate the role that AT plays in a resident's life. Moreover, care staff tend to have little or no formal training in the use of technology, and can be intimidated by complicated and expensive-looking AT, and reluctant to assume the responsibility of helping a resident use it. The importance of involving the carer at an early stage, training and empowering them to use the AT, should not be overlooked. The carer plays a key role in successfully embedding the use of AT.

From the above it should be evident that AT must present simple interfaces; and that, especially in the context of a place such as Hollybank, it should take into account not only the service user, but also the AT specialists and therapists, teachers, carers, friends and family, and also technical interfaces with software and hardware such as switches, and so on. In short, AT needs to present a friendly interface to each and every actor in the assistive environment.

2.4. Disruptive Practices: Technological Innovation and Obsolescence

The latest technology can open up exciting possibilities, and tends to capture the interest of those who want to seize opportunities and lead (or create) markets. However, this risks excluding those who don't have (and can't afford, and maybe don't want) the latest thing. Moreover, there is a danger that the new technology will break existing (ad hoc) adaptations, and disrupt the lives of those who have become accustomed to (and sometimes reliant on) 'old' technology. The same disruption can be felt when technology becomes obsolete or unsupported, and it can distress users. Of course, providing long-term support is difficult, and something no business can guarantee, but providers should be committed to their users and feel obliged to offer support. And while disruptive (and even not so disruptive) innovation in technology can have undesirable consequences, this is not to say it is never a good thing: certain advances genuinely do widen participation, open up new possibilities and improve lives.

2.5. Measuring Success in the Assistive Marketplace

Although a number of evaluation frameworks have been proposed [3], evaluating the success of AT can be difficult in any situation, since the degree to which it enables a more independent, fulfilling and productive life is subjective with no accepted norm to adhere or aspire to. In the context of Hollybank these difficulties are compounded by the inability of most residents to express verbally their satisfaction or otherwise with the AT. Small milestones can have a significant impact for this client group; what may appear a trivial advance could be the means by which an individual can exercise control over their immediate environment: a passive individual becomes an active participant.

The difficulty of measuring the success of AT contributes to the difficulty of assessing its cost-effectiveness. Developers, manufacturers and suppliers (and academics too) all have a commercial interest: there needs to be a market for devices and associated services to secure funding or reward investment. In effect this tends to exclude bespoke, non-mass-producible solutions, along with 'difficult' disabilities and groups such as children, where it is difficult to capture requirements and co-produce

solutions. In other words, precisely the sort of service users to be found at Hollybank. Unfortunately, in a society with constrained health and social care budgets, funding for AT for people in full-time residential care is a low priority; and that for people who will never achieve total independence is an even lower priority. The value of AT provision for individuals at Hollybank is not always understood or considered by commissioners, and the lack of financial resources is a real barrier to provision.

3. Conclusions

It should be evident that Hollybank Trust presents a particularly challenging environment for the application of AT. The issues raised above can seem daunting, and certainly it is not a space to enter without serious consideration of the hard work ahead. However, the intention here is not to dissuade serious engagement; on the contrary, the aim is to convey the complexities, to raise the profile of this class of service users and to help providers enter the field with eyes wide open, and thereby to improve AT provision. The rewards of helping people such as the residents of Hollybank to lead full and fulfilling lives are great and amply repay the additional effort required: AT can and does make a real difference to the lives of (all) the people at Hollybank.

To conclude, we propose the following ‘ten commandments’ for those providing AT for service users with multiple and profound disabilities:

- Consider the user as an individual;
- Strive to improve quality of life, wellbeing and autonomy;
- Allow and encourage creative use and adaptation;
- Design technically and socially compatible and robust devices;
- Avoid unnecessary complexity and gratuitous disruption;
- Present friendly interfaces to all users;
- Involve, train and empower the carers;
- Feel responsible and obliged to provide support as long as possible;
- Measure rewards in non-financial as well as financial terms;
- And finally: be patient, empathetic, sympathetic and wise!

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