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Applying a Universal Design Approach to Empower Children with Multiple Impairments in Assistive Technology Assessment

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Abstract. Rapid developments in technology, coinciding with the shift in educational ideology towards the inclusion of children with multiple disabilities, has led to increased calls for a Universal Design (UD) approach to promoting, user-friendly, proactive, transparent, and accessible environments and to the importance of Assistive Technology (AT) applications. For children with disabilities, technologies provide opportunities for greater and more flexible access to activities than traditional interfaces if applied and matched successfully. Relatively high abandonment rates of assistive technology have been documented, often due to a lack of user involvement in the assessment process. The field of Universal Design is showing that collaborative approaches enable users to be active participants and enhance their engagement in activities and social inclusion. This paper provides a background to AT service provision in Ireland and outlines the adaptation of the Irish Matching Person with Technology (IMPT) tool from text based to a multimodal digital format for children with disabilities through a universal design approach.

Keywords. Universal design, Assistive technology, assessment, multiple disabilities, children, Irish Matching Person with Technology

1. Introduction

Assistive technology (AT) can play a critical role in the social inclusion, independent living skills and education for children with disabilities. It can provide opportunities for

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greater and more flexible access and benefits children with multiple disabilities to participate in activities of their choice [1][2]. AT devices are among the most widely prescribed, yet, abandonment rates of devices, continue to be critical, ranging from 17-30% [2][3][4][5]. Some of the most frequently cited reasons for abandonment of AT devices are an unaccommodating environment and a poor assessment which fails to take account of the user needs, chosen activities, technology and their environment [6][7][8]. Abandonment causes needless waste of time and funds and leads to frustration and upset to the user, their family and friends and their support staff [9] and devices that do not fit or do not give due consideration to the culture of the environment are more likely to be abandoned [10]. Olsen & DeRuyter suggests that if an AT practitioner asks just one question of the user, it should be to find out has the technology made a difference to their life's [11].

Almost 6% of the child population or 66,437 children in Ireland have a disability [12]. In Ireland disability services, delivered by the HSE and non-statutory organisations, have developed independently over time, so there is wide variation in the services available in different parts of the country and for different categories of disability, with some children and their families having little or no access to services [13]. The assessment of AT need is currently largely carried out, independently, by both the Department of Health (DOH) and Department of Education & Science (DEIS). A significant issue is that the departments are currently not co-ordinated and AT devices sanctioned by the DEIS are for educational use and aids and appliances, sanctioned by the DOH are predominantly for access to daily activities and not necessarily integrated as part of the child's education. Within the health services AT devices are mainly considered as rehabilitative and remeditative tools rather than enabling technologies which can enhance functional access, social participation and independent living [14]. AT services in Ireland have been described as inconsistent, fragmented and uncoordinated, and specialist services, in particular, can be difficult to access and not readily available to all [15]. Data analysed through the National Physical and Sensory Disability Database and the National Disability Survey of 2006 suggest a high level of unmet need for AT, but there is little evidence of any overall strategic approach and provision remains under-developed and describes AT services as "highly complex" and fragmented, which makes it "very difficult for service users to navigate" (16 p139).

An NCSE report on the provision of AT services within education concluded that a Universal Design (UD) approach to the requirements of children with disabilities within education would alleviate many of the pressures currently on the system. Approaches to assessment, planning and delivering services should anticipate diversity and proactively build in supports and adaptations at the start to meet the needs of the widest range of children, and a UD approach would provide a flexible, adaptable and inclusive environment which would benefit all children [17]. An earlier report also commissioned by the NCSE on the delivery of service for children with special needs advocated that training programs for professionals in education should be developed around principles of UD and inclusive pedagogy expertise [18]. Similarly, an HSE report also called for a universal approach as the preferred option for the delivery of services [19]. The Disability Act 2005 legislates that a UD framework is the preferred approach when designing and planning services and products, as it provides an approach that takes account of the diversity within society but also takes account and recognises the person's individual needs and experiences [20].

2. Assessing children for Assistive Technology

Odom described research with children with special needs as "the hardest of the hardest-to-do science" because of its complexity and variability in the needs and abilities of the children [21](p.139). Children with special needs have their own unique abilities and unique understanding of the world which standardised tests often fail to recognise. Exploring the needs children with disabilities and those that may have cognitive impairment, can mean that traditional data collection techniques do not provide the framework necessary to investigate how technology and AT can support their needs. Most assessment tools use verbal techniques to interview and assess the needs of children, while text-based renditions of interviews often position the child as a passive object of teaching and research [22] and do not fully understand a child with a disability experiences or their multiplicity of abilities and needs.

To facilitate AT assessment, it is essential to understand not only a child's physical, sensory and cognitive abilities but the child's interaction with AT, the available environmental resources and the goals that the child and the family want to achieve [23]. Moreover, it is important to hear the child's input and opinion, it has been found that professionals assume a "taken for granted perspective" that children with disabilities are unable to make choices and that they would require adults to make choices for them [24]. For children with intellectual disabilities, it is frequently their parents, carers, or teachers who play the role of proxy or spokesperson. However, when communication is facilitated through technology, carers and designers are often surprised at the level and form of social interaction and expression of need. [25]. Current research demonstrates that it is not acceptable to exclude children on the basis that the research cannot be validated through traditional research methods and it is incumbent on a researcher to adopt methods that will afford inclusion. [26].

3. Irish Matching Person with Technology (IMPT)

There is a lack of empirically sound models and instruments of AT assessment for children with disabilities, however in a review of assessment tools, Desideri [27] found that the Matching Person with Technology (MPT) is the most tried and tested client-centered approach, it was developed in the US [28] and adapted for use in Ireland [29]. The MPT has been benchmarked against the International Classification of Functioning, Disability and Health (ICF)[30], which identifies facilitators and barriers within the environment that may prevent a person functioning independently. The MPT instrument consists of a progression of questions and subsets designed to find the most appropriate match of person and technology. It has been designed to help the provider and the user to work together to ensure the most appropriate technology for the user. The premise of the MPT is getting the right match between the person's characteristics and the AT application which is critical to the successful and sustained use of AT [31]. The instrument is used to determine issues such as:

Personal factors: What is the person's own assessment of their abilities and strengths, levels of function, mobility or hand function, cognitive function, are they able to participate in in their desired activities, meet their friends and how can AT support their participation

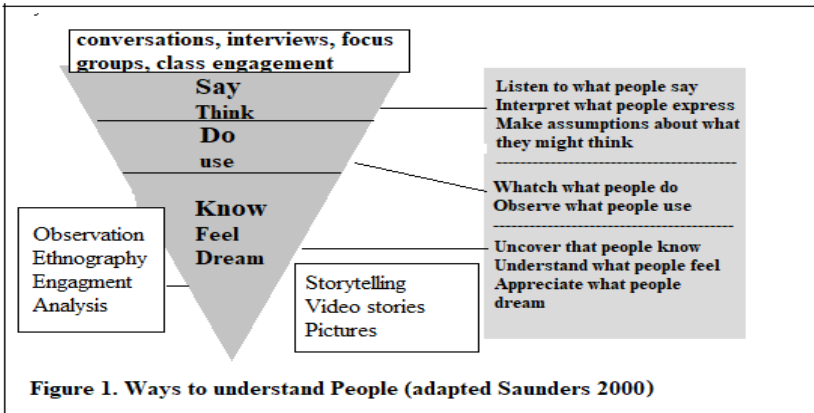
Environmental factors: What are the barriers/facilitators for the person participating in desired activities? Have they access to assessment, funding for devices, adequate training, the support and expertise of qualified practitioners?

Technology Factors: what is the person's experiences of technologies and how did the person progress using the device, were they happy using it, did it increase their independence and enhance their quality of life, are they still using it, did they switch to something else or abandon it and why?

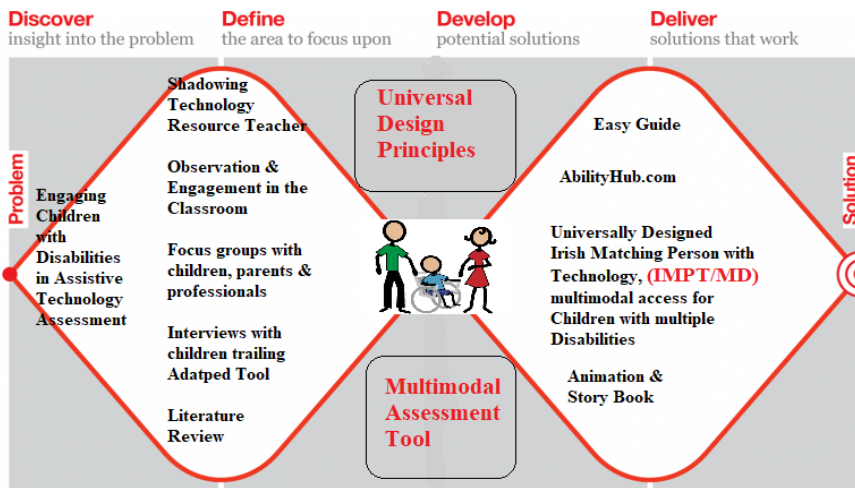
The IMPT instrument is applied to a specific individual (idiographic measures) rather than comparing that person to group norms (normative measures). Characteristics within these three primary components of the model -- the child, the technology, and the environments can each contribute either a positive or a negative influence on technology use. If there are too many negative influences, the chance of the technology being successfully used is greatly reduced. In fact, the technology itself can appear perfect for a given need, but without the appropriate person/social characteristics or the necessary environmental support, that perfect technology may go unused, or it may be used inappropriately causing frustration and expense for all those involved. Both instruments have been used and validated in several studies [32][33]. However currently the instrument is text based and it is the purpose of this study to adapt the tool to a multimodal digital based tool for children with disabilities. The NCSE study on the use AT in Irish schools, found that the level of positive impact did not differ in terms of the type of AT being used but was significantly related to personal factors as measured by the IMPT. The research recommended that the AT assessment and matching process should be developed based on the principles of universal design with an emphasis on pupils with severe and more complex needs [34].

4. Universal Design (UD) Framework

Universal Design (UD) is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability [35]. A UD Framework encapsulates the whole system with a person-centered approach at its core, that is based on a user participation from the start of the design process for any product or service. It is based on the understanding that the user can offer unique insights into their everyday life and their own abilities and, therefore, by ensuring that user input plays a crucial part, a user-centred assessment and intervention/support tool can be developed. When users are fully included during the AT assessment, it is more likely that appropriate assistive devices are prescribed that meet their personal needs [36] Children with multiple disabilities cannot always understand information that is presented in traditional formats, so it is important that appropriate alternative methods and best practices for communicating are determined [37]. The cornerstone of UD is good design based on three key elements accessible, easy to understand and easy to use. To ensure understanding and usability, service and product designers need to focus on human stories and insights, build empathy for users, and ensure ideas and solutions being developed are relevant. To understand how people engage, Liz Sanders argues, [38] we must go beyond what a person or a child needs or what they say, to looking at how they do things, to how they feel, and experience things through a range of facilitated interactions as shown in the figure below.



A central element of UD is understanding through observation and ethnography, the experiences of the children, their own perception of their lives, their social interaction and their desired activities, interests, priorities and concerns. In this project the child and their parents were engaged in the whole process through observation, group discussions, focus groups, face to face interviews and engagement within the children in the classroom to ensure the IMPT/MM tool was designed and represented in an accessible format which was understandable and usable by as many children as possible. This was an iterative process developed over 18 months broken down into four stages based on the double diamond 4D design process [39].



5. Engagement with the Children

- Stage One:** Gathering children's experiences through engagement in the classroom, focus groups and individual interviews.
- Stage Two:** Engaging the children in the design of the instrument
- Stage Three:** Interviewing and conducting focus groups with parents, teachers and key practitioners, demonstrating the adapted IMPT and getting suggestions for further refinement
- Stage Four:** Trialing, discussing and reviewing new elements of the IMPT.

The parents of thirty-five children, randomly selected, from services for children with multiple disabilities, were written to with an outline of the purpose of the project and an invitation to come to an information session. Twenty parents signed a consent form and were subsequently texted to arrange a convenient time to come to an information meeting about AT and the project. The children were aged between 8 and 18 years old. Although, all the children were using a variety of technology at home, iPads, laptops and smartphones and twelve of the children were using mobility devices, only three of the parents had ever been given information on AT and how it could support their children. The parents expressed delight at how AT could facilitate their children's activities and independent living.

"He would love to be able to write his own emails, he cannot read or write but he is very articulate, and I write his emails, but he is now 17 and wants to do them himself."

"We got a lift put in, we saw it at the ideal homes exhibition but we never realised that she could open her own curtains or turn on the light, it would be great for her"

Following the two information sessions with parents and ensuring their signed consent, observations began three mornings a week in the classroom, joining the younger children at "show and tell" and the older children during discussion time, working with groups to find out their views, experiences and activities. Initially working in pairs or small groups, the children used technology to make stories about their activities in and out school, we used Book Creator, Clicker and Google animation, drawings and paintings.

The design and format of the multimodal IMPT followed the key principles and guidelines of Universal Design for Learning (UDL) in the development which ensures children with multiple disabilities can be an active participant in the assessment of their needs by providing

- Multiple means of representation to give the children various ways of access
- Multiple means of expression to provide children with various ways to express themselves
- Multiple means of engagement to provide various ways for the children to engage in the assessment process.

Taking a group of 5 children we discussed the activities that they like to do and how that could be demonstrated in a digitally designed IMPT tool. Initially several cartoon type figures were used but in consultation with the children and an advisory team of teachers,

therapists and AT practitioners, it was considered symbol-based system would be more appropriate, particularly for children who were nonverbal who were using symbols as a communication means. Two symbol-based systems were trialed, with the children preferring the Symbol Stix Prime. The symbols were also easier to access with an online subscription and over 40,000 symbols and over 92,000 images. However, it should be noted that the symbols were not used as alternative and augmentative communication (AAC) but as a picture base to depict the contexts of the questions. Each question was depicted as symbols and reconstructed initially on a power point presentation, so it was easy for the children to see and to change the symbols.

Several items were rewritten in a simplified form to ensure children would understand their meaning and a number of the self-evaluation items were reduced, this was possible as each item has been individually validated in previous research and were corroborated by the original authors of the MPT and IMPT respectively. Ultimately, the decision on the number of items is a matter of professional judgment, scales containing from 6 to 10 items per subscale considered sufficient in reliably capturing the essence of the construct in each question [40]. A further element of the questionnaire design was selecting the response options that will be used for each item. Scales have been reduced from a 5-point Likert scale to 3-point scale in consideration of the capacity of children to understand and respond to the construct [41]. Substituted faces depicting degrees of happiness or sadness as a construct that would appeal more to children as a scale have also been successfully used and validated [42]. The IMPT 5-point Likert scale was reduced to three-point scale depicted through smiley, neutral and frown faces to make it easier and more age appropriate.

Component	IMPT items	IMPTMM Items	Variables
Goals	2	2	Motivation
	2	2	Self-Esteem
Current Capabilities	13	13	Self-assessed Capabilities
			Self-assessed Prognosis
Subjective QOL	14	11	QOL
Technology Utilisation	10	8	Use
	10	8	Satisfaction
	2	2	Further AT needs
AT Device	13	10	Device Impact
Self-Evaluation	40	20	Self-Concept

When the IMPT/MM was complete, it was presented to the parents, teachers, therapists and AT practitioners. They all agreed that it was accessible, easy to understand and easy to use. The tool has now been designed on an Access database with automatic saving of responses in an excel format for analysis. The interface is designed for touch screen, switch access and will be further developed for eye gaze. Although the children can easily interact with the screen, the IMPT is still conducted as part of a conversation with

the child either on their own or with their parents or teachers. To reduce the length of time taken to administer the questionnaire, questions regarding the type of the technology previously used, how long it was used and how often, of if there were any problems can be answered before the interview by parents, while still asking the child for their opinion within the assessment.

Twenty children with multiple disabilities took part in the project with a pre-assessment interview using the IMPT multimodal format, the children had multiple disabilities with significant learning difficulties, fourteen children with mobility impairments, four children were non-verbal and nine had poor hand function. Importantly by using the IMPT/MD tool, the children were able self-identify activities which could be facilitated through AT use.

“I would like to be able to do my own emails, my mother does them for me now because I cannot read” (18-year-old just about to leave school)

“I would like to walk” (10-year-old waiting for powered wheelchair for two years, he then used his fore finger to demonstrate he wanted power mobility)

“I would like to read” (17-year-old in last year of school)

“I would like to read better and play music” (15-year-old in secondary school)

“I want to get rid of my feed and I want to read”

(12 year with peg feeding tube who using a wooden box on wheels, like a doll’s pram, to carry his feeding equipment around with him. The project was able to get him a rollator with a small discreet black bag to fit the feeding equipment in. The young boy was delighted, and his mother said with the support of the rollator they were now able to go out without his wheelchair)

“I would like to turn on the TV myself and get my own programs” (17-year-old identifying a need for environmental controls)

The most quoted identified need was computer access to Gmail, social media etc., indicating computer access outside of educational use, also ten of the children identified a need to read, six children identified environmental controls such as turning on the TV, opening the doors. A recurring theme which almost all the children talked about, was the lack of opportunity to meet with friends outside of school, been unable to join local clubs or play outside.

“I want a friend to move in next door” (9-year-old)

“My brother goes to his friend’s house down the street, but I cannot go” (11-year-old)

“I never see friends when I leave school, they are too far away, and my mum does not drive” (16-year-old)

Due to issues with the AT service, the children were either waiting for full assessment or sanctioning of equipment. The waiting lists were 6-9 months in one service and in another service, there was no AT expertise for assessment at the time of the interview.

Sanctioning of devices was a further 2-6 months depending on the services available at the child's location. The present project funded 5 of the children with AT devices, who are now waiting for training and review.

6. Conclusion

The full validation of the IMPT/MD tool requires several elements yet to be completed, including a full AT assessment, the sanctioning of the devices if required, followed by a 3-month trialing of the AT and then subsequent post assessment outcome measurement by the adapted IMPT tool. There is no estimation of time and services remain significantly under resourced and difficult to access [43][44]. Although there has been enormous growth in accessible mainstream technology and an increase in the number of AT devices, few advances have been made in the provision of a quality AT delivery system. AT is internationally recognised as key to inclusion, but there are critical issues with service provision, standards and funding in most countries, which is leading to service gaps and it is the end user that loses the most [45]. In Ireland, with two systems operating separate AT provisions, the value of integrated technology solutions is based solely on outdated historical system requirements and a lack of implementation of UD solutions. Both national and international guidelines have identified that a UD approach to the application of AT would be best served through a universally designed, inclusive process, which would take account of the increasing overlap between mainstream ICT, ICT for learning and AT provision [46]. The aim for all services and products should be to provide for diversity through proactive planning and good design rather than accommodation [47]. A UD framework applied to AT services is a paradigm shift from the traditional AT service in that it takes a broader view of what are the key barriers and facilitators that impact on the delivery of a quality assessment process. The NDA report recommended "a coherent plan to ensure consistent and easy access to AT for those who need it by balancing universal access to ICT for general use with timely individual access to AT when this is required" (70 p.48).

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