

BEYOND THE ROAD AHEAD – Project Report

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INTRODUCTION

This report charts the work of an action research programme undertaken by the Rix Centre with service users with learning disabilities and various practitioners who support them in their daily lives. The project hinged on the production and implementation of a web portal and a set of linked, locally produced websites providing 'easy read' information about transition for people with learning disabilities. This report describes and evaluates the experience of development and trialling of the Transition Portal Project with people in and around the London Borough of Newham and presents the findings of the project, some conclusions and proposals for the development of this innovative area of work.

'The Road Ahead' programme

The 'Beyond the Road Ahead' Transition Portal project has earned its name and established its terms of reference from a programme of research that originated in 2003 with the commissioning of 'The Road Ahead' by SCIE. This programme explored the information needs of the learning disability community around transition, and its literature described one of its aims as the development of a 'really brilliant website' on transition for young people with learning disabilities.


Click here to download an "easy" summary of the key themes 



Fig 1. 'The Road Ahead' accessible website from the first Road Ahead report www.scie.org.uk/publications/tra/easyread/index.htm

'The Road Ahead' (Townsley, 2004; Tarleton, 2004) was a research project undertaken by Norah Fry in partnership with North Somerset People First that charted the available information for people with learning disabilities and their families to support transition and described what service-users felt was needed.

The study identified a shortage of usable and accessible information about transition in formats that suited young people with learning disabilities. Models of content that user testers with learning disabilities identified as useful were particularly either those created by young people themselves or content that used rich media (animation, photos and graphics) to share people's individual experiences. The research also found, however, that these information sources were often dispersed and difficult to locate and that there were significant gaps in the provision of guidance on certain topics. For example the young researchers found insufficient material that addressed issues about sex and personal relationships.

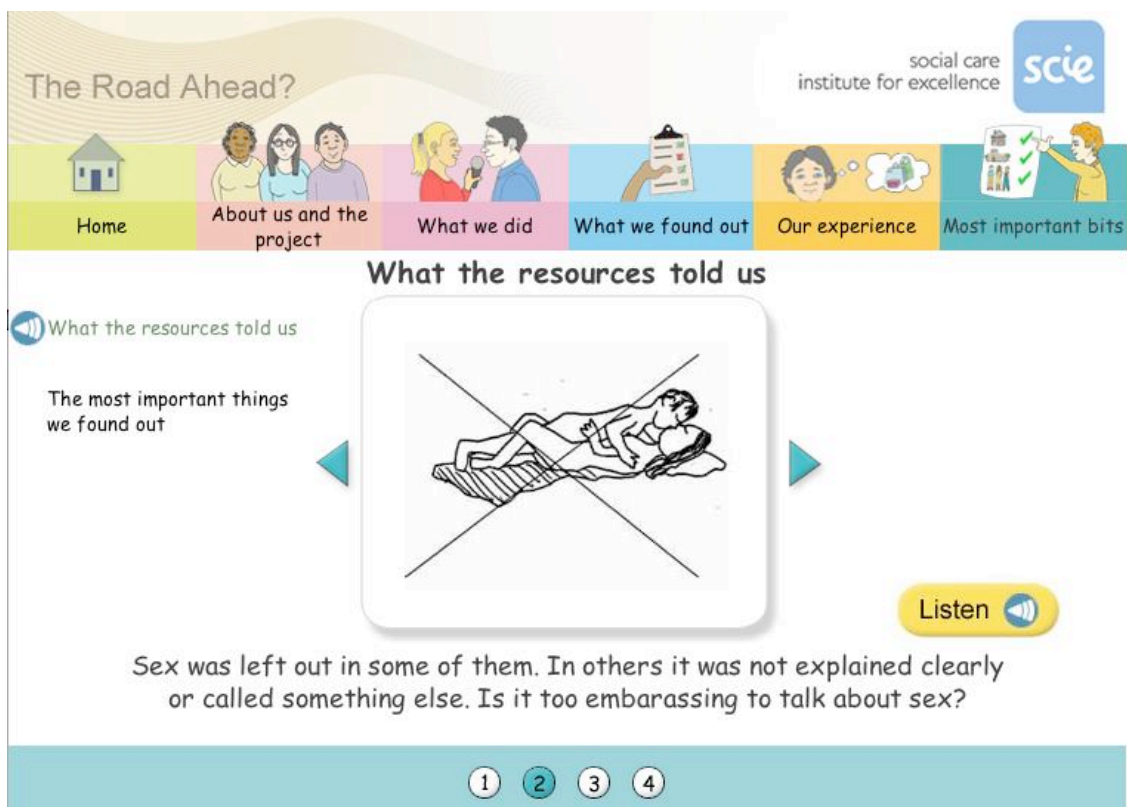


Fig 2. A page from 'The Road Ahead' accessible website about the what the group felt to be the 'Most Important Bits' www.scie.org.uk/publications/tra/easyread/docs/conclusion/resource2.htm

Research on 'The Road Ahead' clearly endorsed the need for accessible information for people with learning disabilities in a spectrum of media formats. The service-user researchers particularly identified a positive model of transition information provision in the Trans-active website (Mencap & the Rix Centre 2002) and teased out the elements of this package that effectively provided for their needs. This resonated with the original ambition of the Programme to tackle the perceived need through a web based solution and SCIE subsequently commissioned a feasibility study called 'Following the Road Ahead' to review the existing content available and describe a possible model for implementation of this approach.

The Rix Centre was first commissioned to develop an accessible account of 'The Road Ahead' research to go online and worked with the researchers at North Somerset People First to make this using simple multimedia production techniques. The experience prompted the consideration of applying the same multimedia advocacy approach to respond to the issues highlighted in the report in the next phase of 'The Road Ahead' programme.

'Following the Road Ahead' was produced by the Rix Centre and explored the potential for development of a Web 'portal' specialising in transition and learning disability to address the information issues highlighted in 'The Road Ahead' report. The premise was that this would provide links to the dispersed content available in various sites scattered across the Internet, in the process providing a 'one-stop shop' that would cover the broad range of topics on which information is required.

The feasibility study reviewed the existing website provision in a systematic way and explored the circumstances in which they had been made with the various organisations responsible.

The 'Following the Road Ahead' study:

- Affirmed the popularity and quality of existing peer produced content, particularly in multiple media formats for both service-users with learning disabilities and their families, but also recognised the scarcity of this type of content available
- Identified potential benefit of a collaborative network of organisations to collate such information sources online around a web portal, but noted a shortage of available accessible information to make such a project a success
- Highlighted factors that have led to this shortfall, including:
 - A trend for websites to be funded as one-off projects and so date quickly and enjoy only a limited useful lifespan
 - The high cost of multimedia content development with service-users
 - A need for tools and guidance to facilitate DIY content development by people with learning disabilities and their supporters

Subsequently, SCIE commissioned this project; 'Beyond the Road Ahead' to pilot the implementation of a working model for inclusive website production to address the information requirements of young people with learning disabilities in transition. The Study deployed a website 'Content Management System', a relatively recent site-building approach that enables the website's owners to populate and update their own sites, rather than requiring the input of professional web developers. Similarly the idea of users generating and distributing their own multimedia content had become increasingly simple to realise with easy to use hardware and software packages and had recently become a really popular activity for young people with the ascendancy of websites such as 'My Space' and 'YouTube'. The project subsequently applied an especially accessible model of this DIY approach in a trial with young participants with learning disabilities.

The objective of this latest phase of collaborative Research and Development on 'The Road Ahead' has therefore been to finally realise the development of the 'brilliant website' for transition of people with learning disabilities that the programme originally proposed. This project draws from the previous research and feasibility study to propose a specific solution using the capacity of the Web and associated technologies and processes; rich media, content management systems, cheap and easy to use digital cameras, freely available online content creation software and recent popularisation of user-content generation.

The 'Beyond the Road Ahead' project pursued the aim to work with service-users and social care staff to shape the appropriate combination of technology, training and support to realise a sustainable model for the provision of accessible information on transition for people with learning disabilities. This report thus describes project work with roots in a thorough and inclusive action research programme and has attempted to define a viable working approach to address the challenging information requirement of the learning disability community.

The Project's key themes for social care

The Project has explored a set of important issues for social care service users generally with specific reference to the 'case-study' presented by people with learning disabilities facing the challenge of transition to adulthood. These themes are:

- Accessibility of information for people with learning disabilities
- Service user knowledge and participation in social care
- The benefits of multimedia advocacy and e-learning

These themes are briefly mapped below to present a critical framework with which to evaluate the practical experience of the project trial.

Accessibility of information for people with learning disabilities

Legislation exists that demands accessible communication for people with disabilities in general but there is not full inclusion of those with learning disability. In particular, The Disability Discrimination Act and WCAG Standards and Guidelines are both significant yet not fully effective in catering for the significant information needs of social care users from the learning disability community. The introduction of the Disability Discrimination Act in 1995 made the provision of accessible information a legal requirement in terms of goods and services, yet the particularly challenging range of accessibility needs of users with learning disabilities are rarely considered in response, with focus of attention rather prioritising users with physical and sensory disabilities, especially those with visual impairment. Organisations are required to make 'reasonable adjustments' to their Web communications to address the needs of people with disabilities, a term usually interpreted as a requirement to conform to the Web Content Accessibility Guidelines (WCAG) produced by the W3C Consortium, which is the usual point of reference for Web accessibility globally. Under the lobbying pressure of organisations representing the interests of people with learning disabilities, work on the guidelines has increasingly acknowledged the special accessibility requirements for those with 'cognitive disability', however the standards broadly feature the same bias towards consideration of users with physical and sensory disabilities at the expense of cognitive.

Evidence is nevertheless accumulating to suggest that the Web presents real opportunity as a vehicle for keeping people with learning disabilities informed based on a combination of 'easy read' text with rich media. In practice there has been a wealth of innovative and creative web development dedicated to people with learning disabilities, many of which have made the most of the 'rich media' capability of the Web, using photos, graphics, symbols, video and sound clips to present information in multiple ways to suit an audience that will probably not have conventional literacy skills. While alternative accessibility standards for people with learning or intellectual disabilities have not been proposed, perhaps sensibly given the great diversity of their accessibility requirements as a singular 'user group, there is an emergence of typical accessibility solutions that fit under the broad heading of 'easy read' that at least addresses the semantic challenge posed by complex text for this population.

Valuing People and the Mental Capacity Act

Social care legislation flags the special needs of those with learning disabilities as well as the fact that there are possible solutions proposed by multimedia formats. This understanding has its origins in decades of imaginative work by speech and language specialists and others who have deployed the various means for effective communications with service users without conventional capacity for speech.

Current Government legislation requires proactive effort to consider the special information and communication needs of people with learning disabilities as a means to ensure their equal treatment and effective consultation in service use. The 'Valuing People' white paper (DOH 2001) describes UK Government strategy for learning disability in the 21st Century and aims to address the lack of choice and control that people with learning disabilities have over their lives. This specifically recommends the use of various media formats to enable service providers to fulfill this obligation and the Government expects organisations to develop communication policies and procedures and produce and disseminate information in accessible formats and states in the white paper that 'for those with severe disabilities this may require individual communication techniques and effective use of new technology'.

The Mental Capacity Act (DOH 2005) includes in its statutory principles 'The right for individuals to be supported to make their own decisions – to be given all appropriate help before anyone concludes they can't make decisions'. The Act states that every effort should be made to provide the individual with required information 'in the way that is most appropriate for them and which will assist their understanding as much as possible'. Para. 3.17 cites the specific example of a person with a learning disability who may need to have information read to them and supplemented with pictures. Para. 3.19 suggests 'aids such as notebooks, photographs, video and voice recorders as strategies to help an individual to access and retain information so as to use it effectively to make a decision'.

Service user knowledge and participation

The inclusion of service users as active participants in shaping their social care provision reflects further sentiments expressed in 'Valuing People'. The Service Users Advisory Group, which worked with the Department of Health on this strategy for learning disability, emphasised user involvement by incorporation of the slogan, 'Nothing about us without us'. It also reflects a trend in Europe, exemplified nearly 10 years ago by Inclusion Europe, which also urged the active participation of people with learning disabilities in the production of information for them (Freyhoff et al 1998). Today there is wide recognition of the potential value of service-user's knowledge and experience as part a culture of accountability and participation in social care research, policy development and professional training. SCIE's own Knowledge Review paper, 'Types and quality of knowledge in social care' (SCIE 2003) cites the 'growth of user and carer-oriented initiatives' that mark a 'sea change' in social care provision over the last decade, comprising a 'movement with a range of different ambitions, ranging from "giving users a voice" to "increasing user participation" to "ceding to user control"'.

Multimedia advocacy and e learning

The concept that new digital media provides valuable opportunity to improve the quality of lives of people with learning disabilities has prompted a range of project and practice initiatives in recent years. In 2004 the Rix Centre was established to help bring those working in this field together and to help to research this and to develop technologies, models of best practice and training to establish the optimum benefit for the learning disability community. The Centre has coined the term multimedia advocacy to describe the various ways in which new media can positively impact on the lives of people with learning disabilities.

The Rix Centre's definition of multimedia advocacy is that it enables people with learning disabilities to:

- Organise their thoughts
- Reinforce their memory
- Enhance their communication and
- Develop their social and support networks

The term is designed to accommodate the range of types of advocacy that can be facilitated and improved by the use of multimedia with service-users. This includes self-advocacy work that deploys digital photography, authoring software etc. to enable people with learning disabilities to make multimedia person-centred plans that are uniquely accessible for them. Multimedia advocacy as a concept also incorporates the use of new media as a tool for professional and peer advocacy and the work of 'Beyond the Road Ahead' broadly embraces this definition of the term. The East London organisation, 'Acting Up' pioneered this way of working with people with profound and multiple learning disabilities in the 1980s and established an important rule about this approach to support (that they termed 'Acting Up Multimedia Profiling') that the *process* of working in this way is of greater importance and value to service-users and staff than the resulting product.

This project has been developed with this in mind and as a result the research and evaluation approach adopted for the Beyond the Road Ahead programme has paid considerable attention to both the process and product dimensions of the innovative application of the multimedia advocacy that this project enshrined.

A further step along the spectrum of applications of new media that this project explores concerns e-learning. The accessibility of new media for people with learning disabilities suggests that learning with rich media materials may be of particular value to this population. This project explores this concept through development and dissemination of learning materials on transition themes through our Web portal. The project also takes this a step further through the development and trialling of a set of sample e-learning objects targeted at trainee social care professionals that are built around the content that has been developed by the project's participants with learning disabilities.

AIMS AND OBJECTIVES

Project aims

The overall project aim was to explore the potential for the capture and sharing of social care service-user knowledge through the use of multimedia and the Web and, within that, to:

- identify how collaborative production of a Website package might present new beneficial ways in which to share experience, insight and information between service users with learning disabilities, their support staff and families.
- explore new models for the active participation of service users in social care and that this might positively impact upon the quality of social care provision for people with learning disabilities around transition.

The project effectively used learning disability and transition as a case study for exploration of a set of themes through a practical pilot trial and evaluation:

- Service-user knowledge and information issues
- The specific potential of the Internet, the use of multimedia and the generation and sharing of content by users
- The use of 'blended' e-learning and face-to-face training for service-user knowledge capture and dissemination
- The ways in which various organisations need to work together to make such an endeavour operational and sustainable
- The effect of such an initiative upon the participants and the culture of service provider organisations that engage in the work
- The effect upon the target service-user audience

Project objectives

The Project objectives included delivery of a set of specific outputs:

- A prototype accessible and inclusive web portal for transition and learning disability fed by up to 40 websites developed by 'front-line' organisations and supported through a 'blended' combination of face-to-face training sessions and online learning materials for participating service-users and professional supporters
- A set of e-learning objects developed from website content created by service-users on the project, designed for use in Higher Education level Social Care education and trialled with University students.
- A research report detailing and evaluating the project experience and outcomes, to include impact study of the project on its intended beneficiaries and subsequent recommendations for the use of a web portal for inclusive social-care knowledge management and service-provision.
- Identification of further useful research and development directions for this work

Research Questions

The following Research Questions informed the analysis and discussion of the project's findings:

- What are the logistics of developing and managing a web-based approach to knowledge sharing for social care across various organisations?
- What are service user's and their supporter's experience of participation in this approach?
- How can e-learning be used to support knowledge sharing and embed the resultant service user knowledge in social care training?
- How effectively can this approach provide for the information needs of young people with learning disabilities and their families?
- What sort of impact can this way of working have for the specific example of transition for people with learning disabilities and how might these translate to social care provision more widely?

THE PROJECT APPROACH

The organisational structure of the project is outlined below with explanation of the rationale of the various component parts of the portal's development and pilot implementation.

Technical Configuration

The Project's proposed technical configuration hinged around the concept of a **Web Portal** that would provide a focus for collaboration between a range of organisations with interest in providing accessible information for young people with learning disabilities around transition. A Portal is a large website that connects together content from various different other websites around a particular theme or for the benefit of a specific target audience group. It may simply provide a host of web 'links' but can typically also incorporate online 'community' tools such as forums or chat rooms for users to discuss issues and share knowledge or feature independently produced content of relevance to the Portal's specialist subject and audience, such as latest news or announcements.

For this project the Portal aimed to provide a scaffold for joint working of a range of groups and enable the establishment of a 'consortium' of these organisations to improve the joining up of different transition information services for the benefit of individual users. The Portal would also incorporate a combination of learning materials and support that the feasibility study identified as a requirement to enable their development of Website content on an ongoing basis. This was undertaken, being described as a 'Mother-ship' model for sustainable use of the web for accessible information provision.

Approximately 40 '**Satellite websites**' were to be produced and the content from these sites would populate the portal. By the end of the project, 44 sites were built, each one around an 'easy-build' website template that deploys a Content Management System (CMS), designed to be sufficiently accessible so that people with learning disabilities can participate in making the websites alongside support staff. The system also prompted Website builders to arrange content one or two sentences at a time and to present a photograph, graphic or video clip with each sentence to reinforce its meaning or message. In addition the CMS enables the easy incorporation of an audio file that would normally provide a spoken version of the text used.

A further key dimension to the 'infrastructure' required to make the project a success is the ICT facilities available for the organisations and their staff and service users taking part in the project. The Rix Centre was able to provide a limited number of cheap digital cameras on loan for participating groups but would be dependent on organisations being appropriately equipped with PCs and Internet connectivity at their own premises.

Portal Management

There were two anticipated dimensions to the management and moderation of the project's transition portal, one to do with the provision of locally specific information on transition services and the other concerning information about general transition issues for people with learning disabilities that could be suitable for wider dissemination. The project targeted East London local authorities to identify a potential management and moderator organisation for a regional portal and also discussed the potential for wider knowledge sharing through management of a second portal by the Transition Information Network, a coalition of national transition organisations.

Recruitment

The project aimed to attract organisations to take up satellite website development with their staff and service-users by offering the use of easy-build templates to create their own sites, coupled with the offer of an induction workshop session with subsequent training and support at no charge. Print and online publicity materials were produced

inviting participation of organisations that worked with people with learning disabilities alongside an accessible easy-read account of the project's aims for service-users. In addition, the project team attended events to recruit local East London organisations as satellite Website producers. The Rix Centre ran a two day conference, 'ME! Multimedia and e-learning for people with learning disabilities' that attracted potential participants with learning disabilities and professional supporters, who were able to attend an introductory hands-on workshop where they built a website from scratch, using the easy-build template in under an hour. Newham council also put on two events at West Ham Football Club during the recruitment phase, focusing on the use of ICT for inclusion and the accessibility of local services for people with disabilities respectively. The project team exhibited a display to recruit participants, handed out flyers and made presentations about the opportunity for participation, networking with a spectrum of local organisations and influential people. These efforts were backed up by internal communications about the project within the borough and some direct recruitment of council service-provider units by managers in the Local Authority.

Induction and training

The Rix Centre would provide inclusive induction and training workshops that introduced the opportunity to staff and service users and then engaged them in the planning of their own websites on transition themes. These sessions included a brief review of transition information needs and accessibility issues for people with learning disabilities, followed by practical instruction in planning for your own website, digital photography, audio and video recording and use of the easy-build content management system. Various formats of training were offered, both from the Rix Centre's University base and on-site at the premises of the organisations taking part. In addition the 'Mother-ship' website was developed to house a set of instructional materials to guide users on how to plan, gather content and populate their satellite websites.

Independent website production with support

This key phase of the project was designed to explore how organisations would fare with the ongoing development and maintenance of their websites independently after the completion of the induction and training process and hand-over of their sites. A range of support would remain available for participating organisations, including provision of 'refresher' training sessions and drop-in support sessions, provided at the University of East London, where the Rix Centre is based. In addition telephone and e mail support from Centre staff would be made available for both staff and service-users alongside the e-learning materials, provided from the 'mothership' website on the portal.

PROJECT EVALUATION

Methods

Evaluation draws from dialogue, interview and participant observation activity with service users and staff and the story of their experiences on the project that emerged from this process, including:

- Logs and notes taken throughout the project by the research team:
 - Meetings
 - Training sessions
 - Progress reports produced during the project
- Interviews with participants:

- Service-users with learning disabilities
- Supporters of individual participants with learning disabilities
- Staff leading development of websites
- Managers of participating organisations
- User testing of:
 - Technical tools for website building
 - Satellite websites and the portal
- Content evaluation by theme, authorship and usefulness.

Results

Results are described in terms of:

- Portal project set-up, management and implementation
- Recruitment
- Induction and training of participants
- Independent use of the system with support
- The service user's and social care professional's experience of participation in the project pilot trial
- The project outputs including:
 - The Portal as a product, its content and value as an information source
 - The e-learning materials developed from service user content for use with Social Work trainees
 - A study of the context and potential impact of the portal for young people with learning disabilities, their supporters and their families in Newham
 - A strategic plan for continuation of the portal beyond the project on a sustainable basis

Portal project set-up, management and implementation

The project negotiated with the Learning Disability Community Care Team for the London Borough of Newham to participate, and this unit took charge of the management and moderation role of the Portal. This was achieved through the secondment of a member of their team to the Rix Centre for the project's duration, from which base she was able to lead on the recruitment of organisations and the provision of training and support. It has proved valuable to develop the project around a specific job role within the local authority and, by incorporating the seconded member of staff into the project research team at the Rix Centre we have gained additional insights into the required practical dimensions of portal management and moderation. This has helped to establish a detailed profile of the skills, resources and organisational strategies required to realise this model of knowledge and information management, particularly in the context of a local authority.

The process of securing support and engagement from the Local Authority was complex and time consuming, requiring a string of meetings to demonstrate the key principles behind the project to representatives from various council departments to secure their cooperation and identify potential resource for council staff input. The project team made repeated presentations about the special accessibility requirement of people with learning disabilities and the shortage of appropriate transition information, explaining the potential for these needs being met through a combination of the use of multimedia (photos, graphics, audio and video as well as text) and the facilitation of user content generation. The potential additional benefits of this model of service-user participation

were described alongside the principle that peer learning and the sharing of the knowledge of people with learning disabilities between themselves and their supporters would contribute to their empowerment and wider social inclusion.

There was little understanding of the special information needs of people with learning disabilities outside of the specialist learning disability team. The provision of online 'easy-read' information was not perceived as a key priority for the existing council communication strategy in the context of users with learning disabilities but once demonstrated the easy read presentation of content was recognised as being potentially valuable, particularly for the provision of information for audiences without English as a first language or those with low literacy skills. Website work to improve the provision of public information was in process across the authority and there was some use of video to address these audiences, but there was not a remit for 'easy-read' content. An information task group for Transition was in place however, and this helped to prepare the ground for support from council departments beyond Learning Disability services. Above all, once the proposed project was demonstrated to staff with samples of what the websites would look and sound like, support for the project in principle was forthcoming from the ICT Unit, Equality and Diversity office of the Primary Care Trust and the Borough Communications Department. Ultimately funding for the Borough's active engagement via the secondment of a member of staff as Portal moderator was provided from a combination of Local Authority departments, including Children's Services, Learning Disability, Community and Culture and a fund dedicated to 'New Ways of Working'.

A tangible 'result' from the Borough's take up of the management role for the transition portal was the recognition, in the Service Inspection Report produced by the Commission for Social Care Inspection (CSCI) in October 2007, that this demonstrated a positive commitment to tackling information issues for people with learning disabilities. The CSCI Report highlighted the 'limited amount of public information' provided by the council 'in accessible formats for people with a range of communication needs' and cited specifically the absence of 'picture text on the themes of bullying, harassment or safeguarding' on the council's website. The work on the transition portal with the Rix Centre is cited as evidence that the local authority 'had recognised the need to ensure that information was accessible' and was taking tangible steps to address these issues.

The project's ambition to secure the engagement of a national information provider agency to moderate and manage a second generic portal for transition and learning disability was not successful. The Transition Information Network supported the project in principle but was unable to provide the required resource of staff time for the pilot. The project did however establish a generic portal, hosted by the Rix Centre, to demonstrate this concept for participant organisations outside of East London.

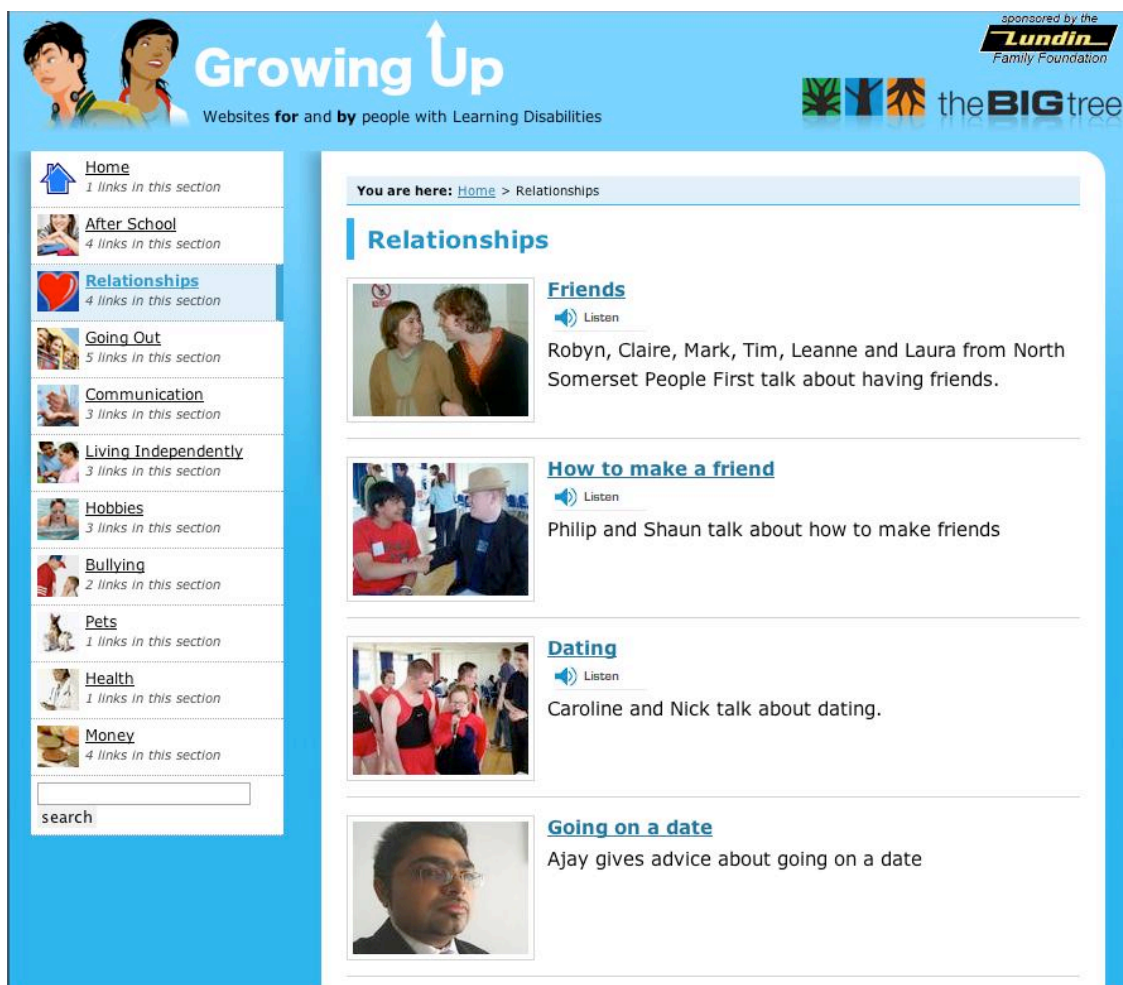


Fig 3. The 'Growing Up' website was an early prototype created to demonstrate the portal concept and how the smaller satellite sites feed into it iamtesting.net/growing_up/relationships.html

Recruitment

A total of 49 organisations were recruited to participate in the project and take on the responsibility for developing their own satellite websites. The initial recruitment at organisational level in the Borough proved more challenging than anticipated and entailed a significant amount of personal effort from the member of council staff seconded onto the team. The publicity approach using flyers and events solicited considerable interest, but only resulted in one direct organisational recruit, although further participants were ultimately secured via this route where initial interest was followed up persistently in person. The commitment of organisations mostly originated from direct personal approaches made by the project's seconded council representative, following up existing contacts and connections and benefiting from some internal encouragement and pressure from managers within the council Community Care team. There was widespread evidence of interest and appreciation of the potential value of the project from across the local learning disability support community, but this was frequently countered by concerns as to the workload, plus the technical challenges and the unfamiliar practices that participation would entail for their organisations.

Professional motivation for involvement in the project

Where organisations responded positively to recruitment efforts, their staff were quick to grasp the potential of engagement and were often motivated by positive professional aspirations to raise service-user participation, realise self advocacy and *'Give people the support to act themselves, rather than us doing it for them'* as this and the following quotes show:

'It's a way of showing how young people can have their say and of getting them involved in planning for their future'

'Giving people the support to act themselves, rather than us doing it for them'

'I wanted to help and support my service users to create information'

Staff recognised that this approach could help engage service users more actively in the ethos and work of their organisations and expressed the hope that participation would *'be good for the service and the service-users, especially service users as they start to own it'*. This aim was echoed by some service-users too, who identified a role for themselves on the project *'...to tell people what we do at the Centre'*

Website development with the 'easy-build' template and the back up of inclusive training and support was recognised as providing real opportunity for joint work for staff and service users that would benefit each party and help develop the inclusive culture of participating organisations;

'I had not used the Internet with service users before.'

'Building up IT skills as a group learning experience.'

'...to get a better understanding of problems that people with learning disabilities have when using the internet'

Staff also recognised how participation would complement their existing work to develop accessible information material for clients with learning disabilities and this too served as an incentive for taking part.

'The project sounded interesting and it was in line with the work that (we) wanted to do. We have been trying to work out the best way of creating accessible information.'

'We produced a leaflet about benefits with less text and pictures with Newham People first. This project was ideal for us!'

Although the project was designed to enable service users with learning disabilities to actively participate in the development of information, the recruitment effort soon attracted organisations that simply perceived a tool that would help staff tackle the difficult process of promoting their services in accessible formats for people with learning disabilities. This resulted in the recruitment of a significant proportion of professionals who would then work on their own or with staff colleagues to develop websites without service users taking part;

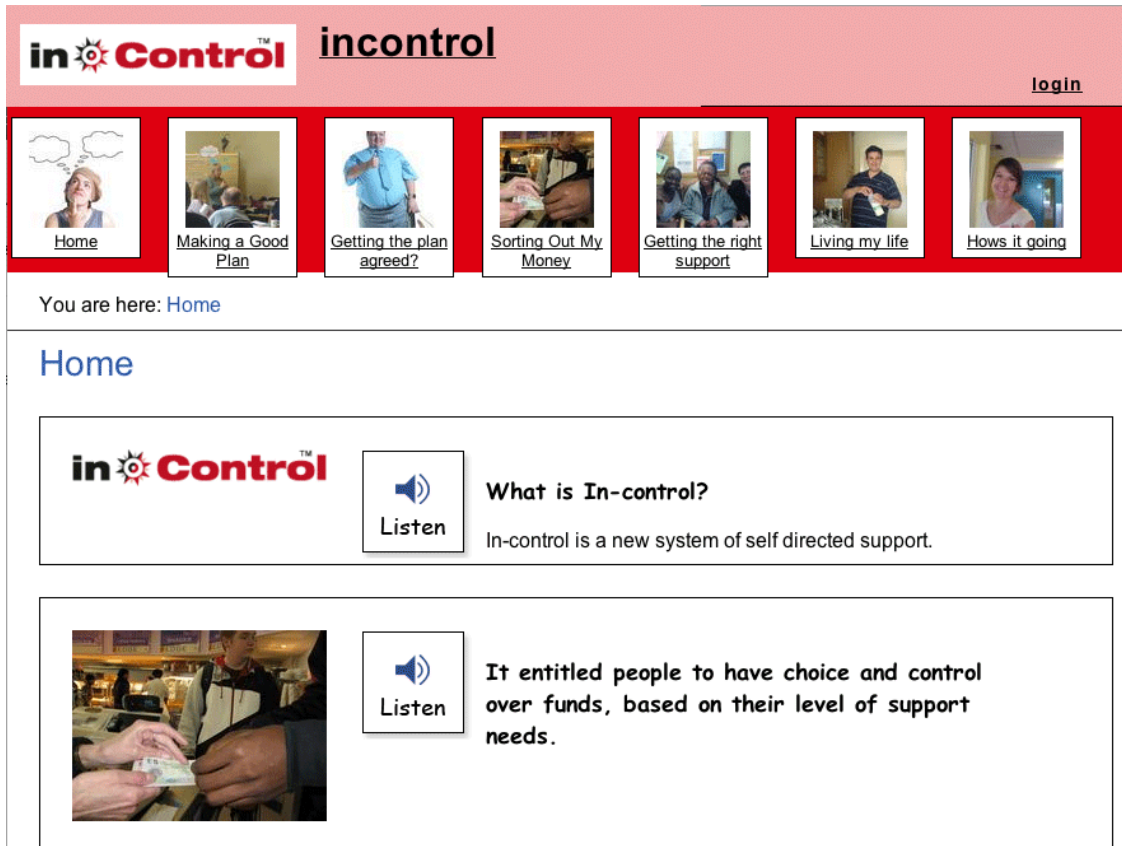


Fig 4. The 'In Control' website was developed by a professional working for Newham Social Services - Learning Disabilities Team web.thebigtree.org/incontrol

'It was something we felt that was missing from our service. We have not got a website and what better way of making a website which is accessible. It was something different. The website would promote our service and let others know about the service we offer. It would be accessed by disadvantaged people, letting them know what we do in a way they understand.'

In these instances the project simply provided a web development toolset and training resource for production of accessible websites for people with learning disabilities. While such work did not incorporate the full spectrum of service-user involvement intended by the project, there was recognition that the resultant satellite site content would help to populate the easy-read portal, complement service-user's own material and help to meet the informational objectives of the project.

Personal motivation for participation

It was interesting to note that for both service-users and professional participants the opportunity to engage with ICT and multimedia technology was an important *personal* incentive for taking part in the project. Service users affirmed that they wanted to get involved because they *'wanted to learn how to work on a website'*, they *'like computers'* or were *'...interested in media'* and wanted to *'get more understanding'*. Similarly support staff saw *'an opportunity to make a Website, I've always wanted to make one and never got around to it'*. They affirmed that they were *'...interested in how to create a website. I like doing multimedia stuff. I think it is a great way forward for our service.'* And

that they wanted *'...to learn more about the other side of computers, the back end of websites.'*

The progress with recruitment effort was reviewed after six months. This enabled the team to identify some thematic areas that were under represented, despite the spectrum of more than 20 different organisations that were already participating. The Learning Disability Service leaders were asked to identify appropriate people and organisations that might be approached and recruited by offering them an opportunity to attend a special 10-week course at the University designed for service users as well as professionals and promoted as a 'Champions' Course'. The aim was to train some key individuals who could then lead the process of reaching missing organisations and influence them to take part in relevant further content generation. An additional aspiration was that specialist 'champions' could then keep an eye on the range and quality of information that was subsequently produced in their specialist fields and play a content moderation role. Where necessary, they would encourage and supporting further new participants to become involved and fill the gaps in the range of knowledge that was being collated on the Portal. To this end the Champions' Course was set up and the senior learning disability staff in the borough were asked to identify appropriate students. In practice only three council staff were proposed: one was an administrative assistant with a learning disability, and the others were the Transition Social Worker and an administrator who had been responsible for setting up the existing Website for the Community Team. The Portal Editor was thus obliged to deploy the canvassing approach to recruitment, which again was labour intensive and did not yield the spectrum of missing specialist subject expertise identified as missing from the Portal.

Induction and training

Throughout the course of the project, a range of different types of training were applied and a total of 89 different sessions were carried out with participants. These included 23 one-day workshops and the 10-week (one day per week) 'Champions' Course' delivered at the Rix Centre base at UEL. A further 21 sessions were provided onsite at organisation's own premises, 20 one-to-one training sessions and 27 'drop in' support sessions were also provided. Six organisations participated on the project without face-to-face training, using online and telephone support only. All participants were able to access instructional materials from the project's 'mothership' website. In total more than 200 people with learning disabilities, supporters and professional advisors were trained as part of the project trial.



Fig 5. The project's 'Mothership' website has online training materials for creating satellite websites web.thebigtree.org/howto

The purpose of training was to equip individuals to plan, develop and start populating the satellite website for their organisation and subsequently to cascade the skills that they had learned to service users and staff back at base, so as to imbed ownership across their group and ensure continuity, maintenance and active Website development on a sustainable basis. Preliminary training or induction sessions would introduce the project with a discussion about transition and the types of knowledge and information that service-users and professionals could provide. Then there would be explanation about the planning and setting up of the website, with participants being asked to decide on a name for the website. Training would then go into the different functions of the template in detail, using the printed instructions to explain how to customise website appearance, edit sections, add sub-sections and then paragraphs with text, pictures, audio, video and links. Within the training, students were also showed how to use a basic audio software programme and shown how to upload video clips with the aid of the 'YouTube' website's facilities. Trainees were asked to bring some prepared content to add or would create dummy content to upload as part of the session, applying the principal of hands-on 'learning by doing'.

Feedback from trainees, gathered at the end of each session, was universally positive. Comments ranged from those who simply found it *'nice to have an afternoon doing something different'* to those for whom attending the University and accessing high-standard technical facilities promoted a sense of professional pride. There was appreciation of the accessibility of the training packages on offer, with emphasis on how instructions were straightforward and easy to follow, especially where one-to-one support was available to back it up:

'I found that the one-to-one sessions worked better for me. It was easier for me to understand the best way of creating accessible information. I was able to get my head around it. I did get a bit confused at the beginning of the training about each section, paragraph and subsections. It was fine after I got used to it. I find that if I am physically doing the work it is much more memorable.'

Issues with Inclusive training approaches

Generally, training was offered in inclusive classes, combining service-users and professional supporters in ratios that varied from class to class. This worked well in terms of establishing the inclusive principles at the heart of the project, but also created some difficulties. Support staff who were inexperienced in ICT use found that the challenge of learning these new skills at the same time as supporting service-users put them under too much pressure;



Fig 6. An inclusive training session at the Rix Centre

'I found the first session with the service-users very challenging because one of the guys was getting agitated with everything and was stressing about going to the UEL. So now I have decided that I will make sure that I learn the skills first and then work with the service-users.'

This strategy did make training more effective and the best examples of support and advocacy with service users on the project were realised by staff once they were trained and comfortable with the use of digital cameras and computers to at least a basic level.

Training off-site and technical issues

A further issue around training related to the location in which this was provided. While staff and service users enjoyed attending courses and workshops 'offsite' at the University, they often then found it difficult to translate what they had learned to context of their places of work in the community. A recurring issue was that skills learned in the refined technical environment of a University ICT laboratory were far more difficult to implement with organisation's more limited ICT resources. This was often, predictably, as a result of computer systems in day centres etc. being of lower technical specification; computers were old and not well serviced; Internet connections were slow and cameras often did not work properly.

Some of the training workshops were therefore held on-site at the premises where participants were based to enable us to assist organisations to address some of their infrastructural issues. The first phase of research had already proved that the local computer set-ups for participating organisations were often in need of attention so that they could serve the needs of the project, also that every system had its own quirks that the trainers could usefully help users to tackle. Generally trainers dealt with the issue that surfaced, locating available image upload and manipulation software and quickly running through it with users for example.

The use of 'rich' media or multimedia makes some extra demands on computer processing power and available network connection, particularly the bandwidth and speed capability for data transfer between local PCs and Internet servers. In addition use of outboard devices such as digital still and video cameras, scanners and microphones demands available software and the appropriate configuration of desktop computers. Users and the trainers supporting them on this project experienced a range of obstacles in this area that impacted on effective participation for all, reinforcing the sense of technical disempowerment that several people taking part already felt about using new technologies.

In some settings computers were also seen as existing strictly for staff use and working on this project had to be scheduled around times when offices were not being used by staff. In some more positive instances work on the project challenged this arrangement and prompted at least for a time, the breaking down of what was recognised as being an unnecessarily exclusive arrangement.

Sometimes however, the obstacles proved practically insurmountable. This was found particularly to be the case where organisations were housed within larger institutions, where ICT systems were usually up to date and well resourced, but configured in protective ways for security purposes. For example, some of the training sessions stalled where systems prevented the use of USB ports, the downloading of freely available software packages to record and edit sound, or the uploading of material via the Internet by users. These issues were particularly experienced in larger institutional settings such as colleges and community education centres where systems had been set up with zealous security measures by contracted ICT provider organisations. Typically the logic was that downloading software, uploading user's own material and the general use of large rich media files was open to misuse and therefore posed unacceptable security risks. For this reason it was often blocked as an activity. While trainers worked through some of these issues with users, this did still complicate and obstruct the process and led to participants losing interest, contributing to some organisations failing to remain engaged on the project once training had ceased.

Training needs and content themes

Supporters and service-users participants tended at first to see the purpose of training strictly in terms of gaining the required technical skills. While this was clearly a challenge that had to be tackled, the project trial also highlighted the need for other forms of learning, particularly for support workers. Transition issues were not fully understood and the principles of self-advocacy, service-user participation, person-centred practice and empowerment for independent living were all themes that needed further understanding and reinforcement for the project to succeed. It was a noted added value of the Champions' Course that, due to the longer period of teaching time available, these themes were more thoroughly explored and developed with trainees and then applied to more careful planning of website development with service users. Some of the stronger satellite sites appeared to result from added attention to these underlying values and social care principles. A further dimension afforded by the extended duration of the longer course was that of group working, with people from more than one organisation working together, enabling the exchange of perspectives from the different agencies involved in transition.

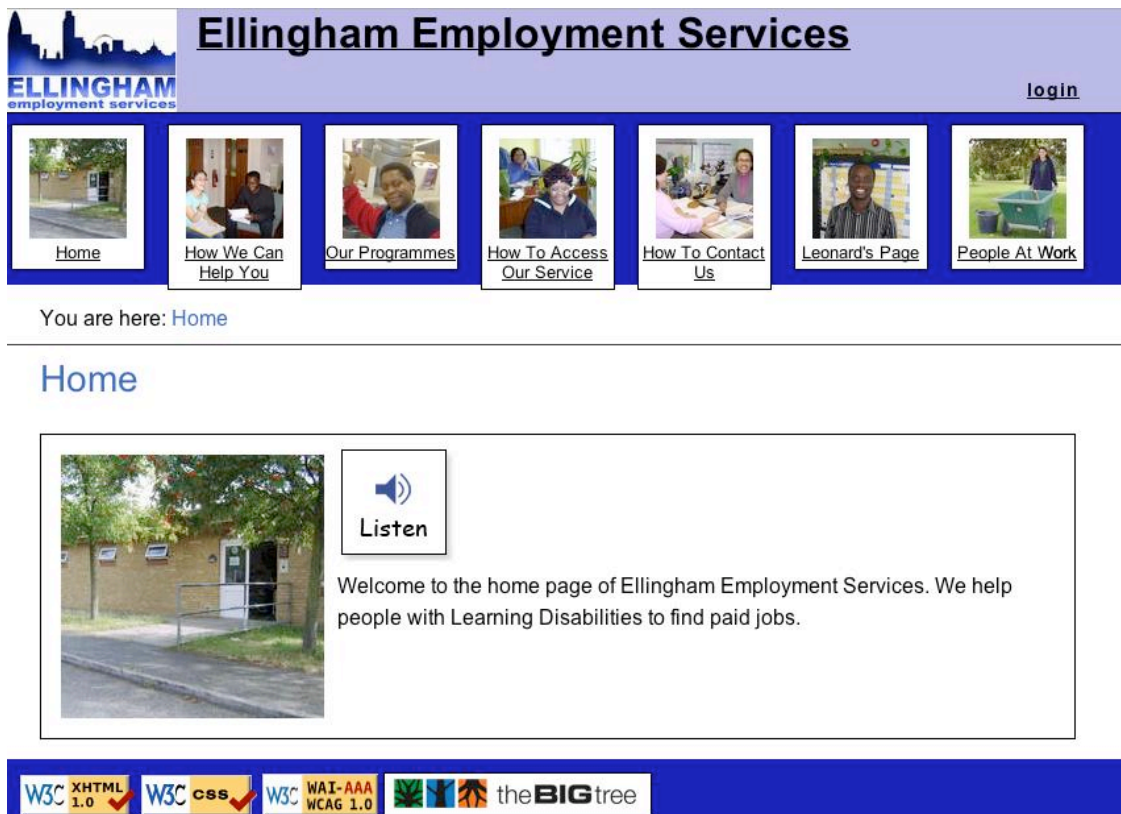


Fig 7. Ellingham Employment Services website began in a one day workshop and was developed further during the Champions Course. web.thebigtree.org/ellingham

The extended course also enabled trainers and students to tackle a recurring issue on the project that can be described as the challenge of leading people with learning disabilities into the role of peer or citizen advocates. It was found that service user participants were inclined, by default, to come up with ideas and material that was strictly autobiographical. They found the idea of generating advice or guidance for others a real challenge. The additional time afforded by a longer course enabled supporters to work

this through in one-to-one dialogue with service-users that led from recollection of personal experience to consideration of what lessons had been learned and how these might best be presented for the benefit of other, less experienced people. This process also helped staff to consider the range of roles that might be played by people with diverse capability in website creation, with some enacting their lived experience as a case study, while others provided analysis and translated this into advice that they could articulate themselves.

Although the longer Champions' Course produced these advantages, it did not result in the establishment of trained 'Champions' ready to moderate content in their specialist area, recruit others to take up Satellite Website development or cascade their skills on the further organisations, as was originally intended. What was achieved was the development of some exemplary websites, but the minimal content development by graduates of the Champions' Course since its completion affirms that the aim to kick start a self-propagating network of individuals, who would then stimulate the balanced development of content across transition themes was not achieved by this method.

On the whole it was observed that training was a critical factor in the success or failure of satellite website take up and that this hinged around a combination of enabling participants to appreciate that they could achieve the technical goals, establishing a sense of ownership of their site and helping participants to achieve the beginnings of a vision of particular ways in which the Website might be used within their organisations.

Independent use with support

Once training had been completed, support project participants were expected to continue with the development of their websites, adding new content and keeping it up to date within their organisations. This expectation was backed up with the offer of online help available through the 'Mothership' website, via e mail and occasional face-to-face support sessions offered by the portal editor. Of the 55 organisation websites that resulted from attendance of induction and training, just under 50% have not significantly developed their sites since the completion of their courses. The 40% of trained groups that have developed their sites independently since completion of their training have mostly been on the receiving end of considerable encouragement and support from the portal editor to do so. As the trial phase of the project concludes, six months after completion of the project's key 'Champions Course' only 10% of the organisations remain active in the development of content for their websites.

The key factors that have affected the lack of continuity of organisation's input have been difficulties with technical equipment and the shortage of available staff time. There is a discrepancy between participant's intentions and the reality of what they are able to achieve; in a survey recently conducted with a random sample of 15 inactive participant groups only one was clear that their group would **not** do further work on their website. Elsewhere there was a sense of optimism that this work would be pursued at a later date:

'Yes we'd like to do some more work, take more photos and get Paul and David involved too. We could add stuff about special needs visits to help people before they come, access for people in wheelchairs etc. We can allocate time and have computers'

'Yes, I would like other staff and service-users to be involved, it would be good to get everyone's views and experiences'

Perhaps tellingly, some respondents qualified their intention to continue with a request for further support and training, and more than one said that this would be conditional on finding the time. Two interviewees flagged that they had recently allocated the task to new staff, potentially signalling a need for further training and a third, based at a day centre, explained that they had simply stalled for a period:

'Yes, it's never ending and needs to be kept updated. We want to add extra activities as we do them. We will be updating all the time. The website is constantly building bit by bit'

Of the organisations that have maintained activity around the Website there is an equal split between organisations that have integrated the activity into regular educational sessions with service-users, around curricular themes such as literacy, ICT and preparation for work and professional advisory organisations that use their sites to provide accessible easy-read communications but largely do not work with service users to develop their websites.



Fig 8. First Line Supported Employment Service develop their website during educational sessions with service-users web.thebigtree.org/firstline

Service user and staff experience of participation in the project

Website development as an inclusive process

The project trial brought to the surface a range of positive outcomes as well as some challenging issues around the process of website development for professional participants and their service-users. Over all, there was agreement that this was an

activity with really inclusive potential. Service users were able to take various roles in the process according to their abilities. Activities that proved particularly popular with service users were those beyond the computer interface, such as working with cameras in public places, planning website content with flipcharts and pens, posing and enacting different scenarios for the camera and, especially popular, using the microphone, rehearsing and recording speech to accompany photos or for pieces to camera on video.



Fig 9. Using a microphone was very popular with service users during training sessions.

'I like doing multimedia stuff, taking picture and putting sound on it. We work as a team.'

'It was really so interesting. It gave me something new to learn and I enjoyed doing it and talking about animals.'

'I like using the microphone and adding my voice.'

'I liked using the camera, talking on the microphone and uploading music.'

Professional participants acknowledged the potential of the process as an inclusive activity that drew on existing skills of all participants, as well as presenting new challenges:

'I like doing the work with the whole group. The whole group is involved, even if they are collating the information by taking pictures and using cameras and doing the audio.'

'Service-users are able to express themselves better by using pictures, audio and video

'It was a good opportunity to get service-users involved. Taking and posing for pictures'

'It was great working with (service-users) to create the information. It was a chance for me to build a good relationship with both of them. It also helped me to know more about their ability.'

'Young people have participated in making it, they own it.'

Website development – new skills and challenges for professionals

The experience of participation for professionals was a challenging one. The process entailed learning and application of new skills and it took staff, as well as service-users out of their usual routines and beyond their professional 'comfort zones'. Challenges started with consideration of the service-users' information needs in the first place:



Fig 10. Training professionals at the Tower Project in East London

'It had been difficult to organise the information and to make it accessible. Understanding the level of information.'

'It took a long time to structure the information... The easy part is using the technology, the hard part was trying to structure complicated information, and finding time to do it.'

'I am used to making professional documents about (our service) to show employers, so when it comes to making accessible versions I can find it a bit difficult.'

'I liked the idea of breaking down information and making information easy to understand, but I found it difficult, (there is) too much information that needs to be broken down to make it easy to understand.'

Staff acknowledge that it was useful for them to tackle these challenges to develop content in accessible and easy read formats, but they were not always confident about how they should go about it:

'Planning of the website has proven to be difficult'

'I do feel a bit confused about what other information we can put on the website.'

'The wording for the website was difficult to get my head around, at first the information I wrote was too complex and I needed to make it easier.'


*'We had to do lots of different things. Thinking about different scenes
It was easy to write the text and record the audio once I'd learned the techniques.'*

'It has helped me to focus on information and how to make it easy to understand. It has really made me think about the perspective of people visiting the site and how to show the information clearly.'

A key aspect of the challenge of working in multimedia format was developing communications in forms that were neither verbal or textual '*...putting it down in a visual way*', as one supporter described it. Staff were not always confident about this aspect of the work and its effectiveness as a communication form:

'I used pictures (clip art) rather than photos because I found this easier and I felt it would be hard to set up exactly what I wanted to show in a photo.'


'Editing images was trickier. It was difficult to take pictures that were relevant.'

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Home



 **Welcome**

Listen Person Centred Planning is a process in which people gain control over their own lives and make decision about the way they want to live now and in the future.

Fig 11. The 'Person Centred Planning' website uses clip art and images downloaded from Google web.thebigtree.org/personcentredplanning

Technical skills were the major challenge that staff participants anticipated. However, there was less evidence of this posing problems once training had been completed. Nevertheless, the training team on the pilot concluded from the experience that a systematic induction of staff in basic ICT skills should be seen as a precondition for their participation on the project. This introductory level training proved difficult to incorporate into the programme alongside sessions in service user participation and instruction in the specialist technical skills associated with the use of rich media.

There was evidence that, while technical process presented unfamiliar hurdles for social care professionals, staff enjoyed a real sense of personal achievement meeting this challenge;

'Work on the website has enabled professionalism all round. It is useful to get service-users involved as well as gaining knowledge in building the website and using computers more.'

'I have found it beneficial to me because I have learned to use a computer more effectively. At first I was not too sure what I was doing and I thought I wouldn't be able to do it, but I now know that my skills have developed and I am comfortable in doing it.'

Practical obstacles for website development work

The main significant obstacles reported by participating professional staff were the problems encountered with technical facilities and the restrictions on staff time available to dedicate to the project:

'I've found it difficult to find time. Also, I share internet access with five other people and everyone needs to pick up their email. The phones ring all the time too...'

'When we came back here we didn't have sound on our computer. I got a microphone but it didn't help.'

'I would like to make a case study about one of my clients who has just moved to independent living, but the camera wasn't available when I went to see him'

'It is difficult to update website here because we only have one computer with internet access.'

'Yes, service-users contribution is time consuming, yes difficult.'

Clearly, the project tested support staff in new ways and the support of managers was reported as a deciding factor for success or failure of the endeavour:

'Yes, I was allocated enough time to meet with (the service-users). My manager also made it clear that I could order equipment if I needed to - leads and stuff.'

'She allowed me to take Friday mornings off to do the Champions' Course . She was very supportive.'

'We have staffing issues at the moment and it is difficult to get out of the building to come and do more training.'

Work on website development with clients was beyond the professional 'comfort zone' for some staff participants which also demanded tangible management level back-up as they tackled what were perceived to be unfamiliar risks;

'They just let you get on with it and did not give us any guidance in what was expected and what content we should add.'

'My main concern is about privacy and using service-users names. I made sure to point out that as long as surnames and personal information wasn't added it should be OK. I suggested he needed to talk to his line manager about this.'

There was similar concern expressed about the apparently casual way in which service users and supporters were being allowed to describe the Borough services on their websites, when staff are used to a rigorous vetting of copy by the Communications unit before anything is permitted to enter the public domain. There was even doubt expressed by one local authority employee about the legality of a website's reference to

the 2012 London Olympics, because of branding restrictions on the use of the logo and name.

Project outputs

The project realised the development of the intended set of outputs:

- a) The Newham Easy Read Website
- b) E-Learning objects for social care trainees and an evaluation paper
- c) Impact assessment for people with learning disabilities and families in Newham
- d) Recommendations for sustainability

Output (a) The 'Newham Easy Read' transition portal and satellite websites

Despite the array of challenges associated with the development of the web content highlighted in the discussion of the project's implementation above, the 'Newham Easy-Read' Transition Portal has been widely well received as an addition to information provision for people with learning disabilities in the Borough.

Newham
easy read

Transition and beyond.....

Search:

Home
2 links in this section

About this website
45 links in this section

Travel
12 links in this section

Safety
7 links in this section

Leisure
22 links in this section

Living On your own
8 links in this section

Relationships
6 links in this section

Work
26 links in this section

Money
7 links in this section

Support
8 links in this section

Day Services
3 links in this section

Education
3 links in this section

You are here: Home

Home

Welcome to The Newham Easy Read Website

Listen

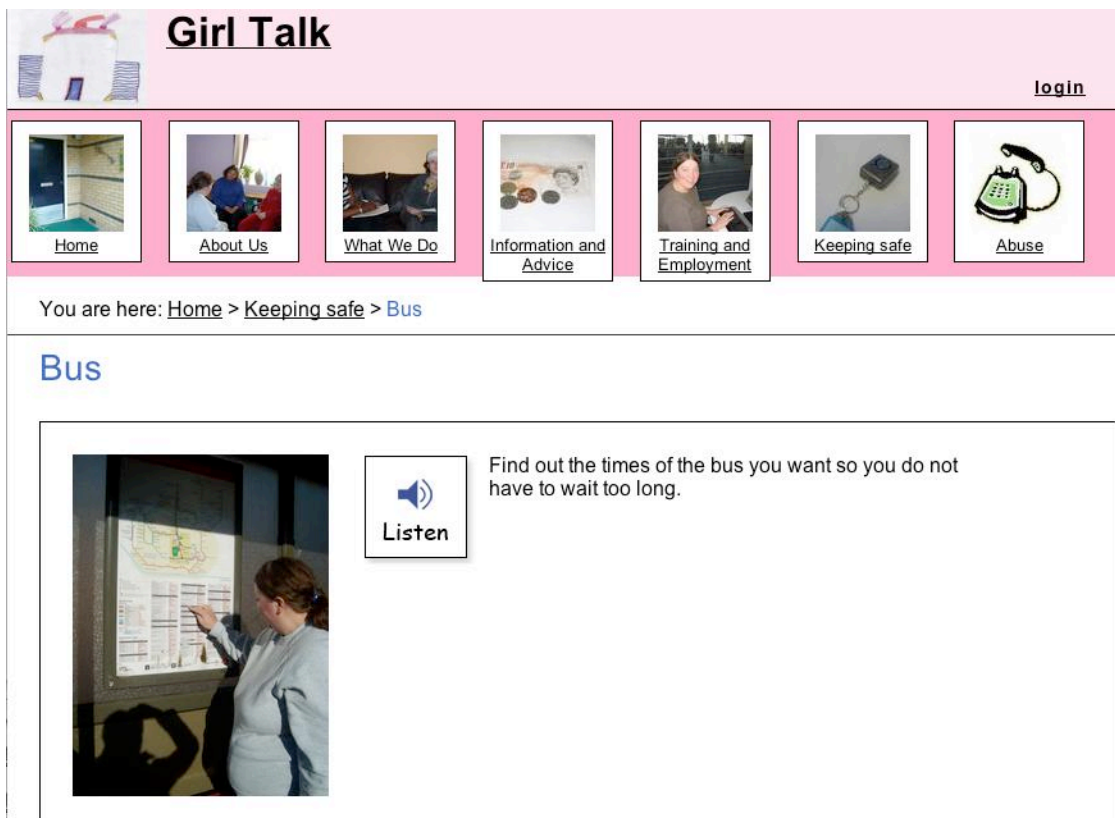
This website is full of links to useful information about transition. This information has been created to help young people with learning disabilities to make choices when leaving school or college.

Listen

Hello My name is Rasime. I am the editor of this website and my job is to link all the information from the different websites together.

Fig 12. 'Newham Easy Read' website - www.newhameasyread.org

Service user perceptions of the websites: Service users were positive about the portal and the various satellite websites developed on the project. They enjoyed recognising themselves, their friends and supporters, the places and the activities that were familiar on the various satellite websites. This was repeatedly seen as a source of pride for the project's participants. They liked the way in which websites would 'tell people what we do...' at their centres, they were pleased that people could 'look and know about us' and were also very positive about how easy it was to understand the portal's content with its simple, easy-read text. More able service users recognised the potential usefulness of the portal '...for other disabled people' One young woman who created material about safety on buses liked the fact that this would be 'useful for travellers' and some saw the portal as a vehicle for the general promotion of 'disability awareness'.



Girl Talk [login](#)

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Bus

  Find out the times of the bus you want so you do not have to wait too long.

Fig 13. The 'Girl Talk' website gives advice about travelling safely by bus web.thebigtree.org/girltalk/category.php?cid=582&pid=422

A significant proportion of service-users, however, were unable to grasp the concept of themselves potentially providing information, advice and guidance for the benefit of others. For some, the understanding of this element of the activity presented too complex a concept for them intellectually, others appeared to lack the self esteem to recognise that they had knowledge to share with peers and that they could take on an advisory role. There were also participants who were able to develop this role for the first time and support staff observed significant development of service-user's confidence and sense of self worth as they developed a peer support role for other young people with learning disabilities.

Professional perceptions of the websites and Portal – accessible information

The participating professionals who have responsibility for provision of transition advice for young people with learning disabilities were very clear that there existed a gap in information that was appropriate and in accessible formats for their service users, and even for their professional colleagues. Both advice and support staff saw the portal as a significant contribution to addressing this need:

'It is worthy to make information accessible, there is a lack of available content for professionals and service-users generally'

'The important services are on it to help young people to make decisions and a number of the services are suitable for their needs.'

'It is good for staff to relay information to colleagues. You can suggest to others to look at it to find information. It's great for sharing information. It is useful for a lot of people, service-users, staff and for carers.'

'It is very informative and has no jargon, it looks at the facts - like the benefits section – and it's user friendly and customer friendly! It is designed for people with learning disabilities but the design is still very professional looking, it's not intimidating and not judgmental'

'I have seen loads of information that will help them. Like the in control section and housing section.'

'It's very succinct, you can see what it is straight away. I like the way its divided up – the navigation is good.'

There was also some caution expressed about the site's capacity to be universally applicable and accessible for a full range of service users and a sense that only further user testing would tell if the site fulfilled its accessibility ambitions:

'Useful? I hope so. It's definitely got important information. But it's a complex subject and I'd really like some feedback from users.'

'It's hard to measure (its usability) as some service users' disabilities are more prevalent than others, so there could be too much information, or not enough.'

'A number of people will need support to access the information.'

Usability studies with people with learning disabilities were undertaken in various settings throughout the trial, including at the launch event for the Portal held at a public venue in the Borough, at a local secondary school outside the borough and in lab-based sessions at the Rix Centre. These studies solicited critical evaluation of the design of the Portal and Satellite website templates for ease of navigation and accessibility as well as some comparative evaluation of the Newham Easy Read Portal alongside Newham's mainstream website and a national website on transition themes for users with learning disabilities.



Fig 14. User testing at the portal launch event at Stratford Circus

Users identified elements of the portal that could benefit from re-design, simplification and some more flexibility to suit the various different ways in which they wanted to make their websites. The portal site's navigation design was criticised by some of the professional users as it became populated with a volume of content, making it a complex task to categorise material under the headings:

'It is difficult to know where to find information sometimes, for example; to learn about travelling safety – would you find it under the heading for Travel, Safety, or Living Independently? There's a need to tighten up the headings'

'Some off the menu titles are wrong; 'Living independently' should not have housing as a sub section for example, a separate menu title with just housing should be inserted.'

'From looking at this (menu) I would not know where to go to get information... you need clearer headings and easy way to navigate.'

The images used as part of the navigation menu were perceived as too small and the sub-menu too discreet to be easily noticed or used. The requirement to scroll down the page in order to see all the content was a significant problem for many users. This design issue was exacerbated by the large size of the portal and website mast-heads, which when combined tended to dominate too much of the screen space and relegate important content to page space 'beneath the fold' necessitating further use of the scroll bar.

The screenshot shows the Newham Easy Read Portal website. At the top, there is a masthead with the text "Newham easy read" and a navigation bar with links for "Home", "Activities", "Traving and holiday", "relationship", "EDUCATION", "WORK", and "WHERE I LIVE". A "login" link is also present. Below the navigation bar, there is a breadcrumb trail: "You are here: Home > relationship > making friends". The main content area is titled "making friends" and features a photo of a group of people. Below the photo, the text reads "say hello my name is....." and "Rita".

Fig 15. When following a link from the portal, the masthead from the portal and the satellite site take up so much of the screen that users have to scroll to get to the content.

In using the website 'back office' form structure to upload their website content, some staff and service users also experienced difficulty understanding which section they were populating. Users sometimes confused section headings with the 'element' spaces designed to hold their content text, images, sound etc.

In a comparative study with the Council's existing website at www.newham.gov.uk, service users expressed a preference for the Newham Easy Read Portal, which they recognised as being both for and about themselves and their peers, emphasising that they liked the use of pictures and audio. The mainstream Council website however was perceived to be 'not clear for information', with 'too much text' and 'difficult wording'. In short, the existing Council website was not seen as being for them:

'This information is not useful for me, I wouldn't want to look at that type of stuff'

'It might be interesting for people who work for the Council... nothing useful for me!'

'I would use the site if I could understand it, I like to know what goes on in Newham.'

Service users also compared the Newham Easy Read website with the ARC website for transition information, www.movingonup.info and flagged a preference for the menu and navigation design of this website that deploys a circular full-page menu for each subsection, rather than incorporating navigation alongside the site's content.



Fig 16. The circular menu on the 'Moving on Up' website was popular with our user testing group www.movingonup.info/en/health-wellbeing

Professional perceptions of the purpose of the portal and of the satellite websites
 There was some variation in the perceived value of the satellite websites on the one hand and the portal on the other. Those professionals involved in information provision were very focused on the portal as the route to the audiences that they needed to reach with their advice services and saw it as a useful place for visitors to find all the required information from various support agencies concerned with transition in the one place. For workers based in frontline service provider organisations and their service users the focus of attention was rather concentrated on their own satellite websites and some of these participants rarely even visited the portal. Several professional participants shared the service users' view that their organisations' websites were mostly a valuable way to share 'what they do' rather than contributing to a general transition information resource. For staff in the field the project provided a means of publicising the nature of their services and reaching wider audiences:

'I find the website very useful for me if I am explaining about our centre.'

'As a team it will be a great way to share what we do in a more accessible way.'

'It will make parents and people with learning disabilities more aware of what I do and what a social worker does.'

'It will help us and be good for transition and for users buying into services if they want to. Our website will show them a clearer idea of what happens in a day service.'

The purpose and value of the portal was ultimately recognised by more and more frontline staff as it became more fully populated with content over the course of the project. The growth of the portal prompted professional participants to consider an expanding range of ways in which the site could be used, identifying a wide spectrum of target audiences in the process:

'It's for parents and carers, also for young people themselves - children and young people with disabilities. Others as well; like social workers and professionals, and teachers - loads of people really'

I use the website in schools and anyone who wants to know about (our service) and I show the website to anyone with a learning disability who wants to get a job'

'Information sharing really links in with my own work. I am responsible for gathering information for what's going on in Newham and locally, it will really be a useful tool.'

'It might be interesting for people who live in other borough so that they can see what we do in Newham.'

Similarly, involvement with the project has prompted professionals to suggest a range of further applications that might be taken up in the future:

'It will be able to be used in drop in centres, for people to physically ask for information. Supporters will be able to access information through the website and so will social workers.'

'Our service always works with parents whose children are going through transition (...) A lot of young people work with their parents to look at the future. This website will eventually help them with this.'

'Once parents see this information they might want to be involved and to develop their own information. That would be great, to have information from carers themselves. Some parents and carers find it difficult to travel to places to find out about the services'

'When we do stuff like uploading the referral form then it will be really useful.'

Professional perceptions of the innovative value of new media

Overall, the project prompted some real enthusiasm from staff working in the Borough who recognised that this was a new and different approach, that the portal represented

real innovation and provided welcome new ways in which to develop and support their services:

'The website is a different way of promoting and getting the information out to the relevant people. We have never had a resource like this.'

'There's lots of information – which is growing - and there's not really anything like it, so this is developing into a very valuable resource.'

'I think this is the future and the way forward.'

The professionals saw the rich and multiple media aspect of the portal content as a clear asset. Information presented in various formats helped to meet the diverse accessibility issues for clients and a website could serve as a 'hub' for media that could be both imported and exported in different media formats to suit different purposes and users:

'...it does depend on the individual support needs of the service user, the audio on the site definitely makes it more useful and more accessible.'

'Taking and adding photos to the website is a way of showing what we do in an accessible way. I liked the fact that I was able to use parts of the footage from the DVD to add to the website, how else would I have shared it?'

'I think it will make it easier and quicker to find information rather than the paper file that I use at the moment. I will be able to refer people to the website and/or I could print off the information for them.'

There was some concern expressed about the potential ambiguity of meaning of images rather than text however and one professional expressed doubts as to the automatic accessibility of photos for the targeted service users audience:

'It's easy for me to find information because I can read and understand what the images mean. I think someone with a learning disability would find it difficult.'

Content analysis - authorship

The pilot project resulted in the generation of a substantive and diverse array of content, that has been assessed by information science researcher and learning disability transition specialist, firstly in terms of who was involved in the process of content creation and secondly in terms of the genre of the content produced by service users; whether it is experiential, advisory or informational in nature and whether it is deemed useful as learning or guidance material for the benefit of people with learning disabilities going through transition.

The website authors of the forty four websites produced were broken down as follows:

- Two were the work of service-users, trained but largely unsupported to upload their content,
- Twenty four were made by service users with supporters working together
- Eighteen were made by professionals independently, sometimes engaging service users as subjects and informants, but not as joint authors.

Content analysis - the 'usefulness' of the content produced by service users

The content produced by service users on the project was subject to analysis and evaluation in terms of its value as information for the target audience of people with learning disabilities through a combination of desk analysis and comparative study.

- Fifty three percent was 'experiential' content that described personal experience and views of service users (e.g. 'We like to keep healthy by eating fruit and vegetables and a balanced meal'). Of this type of content 38% was deemed 'off topic' and not useful or relevant as transition information (e.g. 'I like cats')
- Thirty nine percent was 'informational' content, providing facts or guidance considered useful (e.g. 'If you pay by credit card and goods are faulty, the card company should refund you for anything over £100'). 12% of this content however was not relevant to transition (e.g. 'Donkeys need hay and water')
- Eight percent was 'advisory' providing guidance that could be of value (e.g. 'Walk away from bullies') of which 25% was considered off topic (e.g. 'Cleaning out rabbits – sweep out dirty sawdust')

This study considered that 73% of the content produced by service users overall was of value for people with learning disabilities seeking information on transition themes. It also highlighted that more than half of the 'useful' information would be likely to require some further discussion or setting into context, probably by a supporter, to contribute value as general knowledge for transition. Given the supported nature of use of websites by many people with learning disabilities this was not considered to necessarily present an issue.

It should be noted that all forms of contribution of content were deemed to be of value and relevance to the portal's objectives. However this differentiation of content types prompted reflection on how service user-generated content might best be organised under headings, or supplemented or annotated by support staff to provide best possible value as transition information for its target audience.



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Safety at the farm



Be careful with tools

Tools are heavy and sharp you may get hurt



Listen and learn

Listen to the instructor who will keep you safe

Fig 17. This website has information about what to expect if you volunteer to work at Newham City Farm web.thebigtree.org/animals

Content analysis – by transition theme

An assessment of the content that was being developed by and with service users at a mid point in the trial affirmed that leisure themes were markedly more popular than other subjects conventionally associated with transition for people with learning disabilities. This study drew from the taxonomy used for transition themes by the Transition Information Network on their own website and assessed which of these subjects were being explored by content developers on the pilot study. The predominance of leisure themes seemed to be consistent with the 'natural' or typical preference of young people around transition age for going out and pursuing social, sports and cultural activity. The next most popular theme identified was 'personal security' which is not a top level navigation header for the TIN website and yet featured as a clear second order priority for service users, possibly indicative of the sense of vulnerability young people with learning disabilities feel as they step into adult life in the wider community.

Output (b) E-Learning objects for social care trainee students

Three e-learning objects were developed from the website content produced by service users on the trial and trialled with Social Work students from two Universities. The learning objects tackled three themes:

- Awareness of learning disability generally
- Understanding about transition from the perspective of people with learning disabilities
- The communication issues for people with learning disabilities and the role of 'total communication' as an approach to support



Introduction to Learning Objects

About the Learning Objects

The following learning objects were developed as part of the [Rix Centre Living Lab](#) project. They have been created using the content generated by people with learning disabilities in the process of making websites about transition. It is believed that this content can provide valuable insight into the world of learning disability. You are about to find out what matters to young people in transition age and how they prefer to communicate their likes and dislikes.

LEARNING OBJECT 1
Information for Transition

LEARNING OBJECT 2
Total Communication

LEARNING OBJECT 3
Learning Disability Awareness

scie R I X UEL

Fig 18. These are the learning objects that were trialled with social work students www.iamtesting.net/swlo

The learning objects were judged to be 'useful' or 'very useful' by all of the students who worked with them; 57% deemed the use of web content by people with learning disabilities to have been very useful for their learning, and deemed 'useful' for the remaining 43%. Student comments suggested that service user perspectives presented as e-learning for their training provided a valuable resource for better understanding of the learning disability community. Students identified that use of these materials had provided,

'An understanding of the needs of people with learning difficulties and the difficulties they may face.'

'Knowledge about transition and the medical and social models.'

'A reminder of some of the disabling barriers for people with learning difficulties.'

Social Worker trainees' experience of viewing service user knowledge in multimedia format also prompted insight into the potential merits of new media use for the support of this community, identifying:

'New ideas about how to raise students awareness of how ICT can be used to communicate and empower people with learning disabilities, to plan for greater independence and choice in their lives.'

'...how to present the information to people with learning disabilities, what the word 'transition' means for them, how to promote inclusiveness through the social model as well as how multimedia really can help us to communicate many things to people with special needs.'

Overall the participating students and their lecturers were very positive about the incorporation of service users own communications into learning materials and recognised the special properties of this approach to their training:

'...excellent decision for people with learning disabilities to present the material'

'Clear, thought provoking material, highlighting the range of issues to consider when working with service users with learning disabilities at the point of transition.'

'More of these types of learning resources could be used within the social work modules.'

Output (c) Impact assessment for people with learning disabilities and families in Newham

As part of the project, researchers at the Centre for Institutional Studies (CIS) at UEL are conducting an impact assessment study to explore the opportunities provided by the transition portal project for young people with learning disabilities in the London Borough of Newham. The research is exploring with young people and their carers and parents challenges and opportunities around transition and the making of choices about further education and employment, living arrangements, and well-being issues such as social life, friendships and intimate relationships. This is a longitudinal study that remains in process at the time of writing of this report, but interim findings help to set the project's endeavours into a richer context.

A total of nine young people and/or their parents and carers were interviewed at least once over a ten month period. Of the young people, three had mild disabilities, three moderate disabilities, and three had profound disabilities; five were male and four female; they ranged from 14 years to 25 years old; and, were ethnically mixed including White British, Asian Pakistani, Black African and dual race.

Impact assessment findings

Results so far suggest that transition is a time of great anxiety and uncertainty for parents and carers. Many were lonely, felt unsupported, and unable to carry out some of the tasks the 'care plans' demanded, such as buying in services for their children. Typically they were struggling to give attention to other siblings in the family, and in one case a mother was experiencing domestic violence. All the parents said that they did not know enough about the choices and options available to them. In cases where clear

choices had been made, e.g. to use particular care agencies or day care centres, there were still worries about whether social services would fund or continue to fund their choices. All the parents expressed the view that both they and their children need more help with making decisions. A lack of information, lack of co-ordination and gaps in service provision were all identified as problems for parents and carers and young people.

When asked about who their friends are the young people gave the names of their carers and staff at school, college or day centre, they rarely gave any information about other young people. During one interview with a father and a young woman he explained that initially they didn't know how to go about finding places where his daughter could go to socialise. It took them a considerable time to discover 'Squids' club, they went once and it has never happened again. The girl said that she '*would like to have friends*' and she used the portal to search for nightclubs and social activities.

These research findings demonstrate that the transition portal is being introduced into many families who are highly stressed and anxious. At the same time these adults would like to be better informed about the options and possibilities for their children. Thus the transition portal has the potential to offer new opportunities, and could be widely welcomed.

Experiences of using the portal

None of the young people and their families had heard of the Newham Easy-read Portal prior to being told about it by the researcher. The parents of two young people subsequently consulted the portal, one with her daughter, and stated that they thought the site was very good.

At the follow up interview the researcher took a laptop computer and opened up the portal with the young person. The following summaries indicate the wide variety of experiences of using the portal by young people. For the most part their experiences reflect the severity of their disability, and their familiarity with, and access to, computers. Using fieldwork notes from the researcher, an example is given from each type of disability:

Profound disabilities:

A 19 year old Pakistani male does not have the capacity to use standard computers or the internet and is unable to speak. He appeared to be cautious and afraid of touching computer, and when the researcher helped him onto the portal he was reluctant to touch the buttons. The portal was unable to engage his interest.

Moderate disabilities:

A 25 year old dual race woman with learning difficulties and cerebral palsy was not accustomed to using computers or the internet, but was able to do so very quickly and really enjoyed herself looking at and listening to two specific sections on the website: Jack Cornwell and Eastway sections, both day care services that she attends. Due to her visual impairment, poor hand mobility and inability to read or write, she required some assistance. Once on the site she was able to navigate by using the picture icons and listening to the audio information.

Low disabilities:

A white British woman with dyslexia who is articulate stated that she does not like using computers because she cannot read, and she does not use the internet or have a computer at home. She has recently started to use computers as part of her music course, and said that she finds this easy.

Using the site independently

Of the five young people who were able, and willing, to use computers and the internet, two said that they liked the portal and explored the site through their own choice.

A young woman with moderate disabilities who was asked to browse and explore the site, went to the leisure section straight away and through this on to the drinking wine section, then the Stratford Theatre Royal section, then relationships, and making friends. Her comment about the site was *'it's really good'*; when asked why she thought this, she said *'it's easy to use'*. The way in which she used the site was by clicking onto the sections she was interested in and listening to the audio information. She was most interested in the Kicking Kangaroo Section, and called in both her parents to have a look at this section.

A second young woman with moderate disabilities was not familiar with using computers, and was initially helped to go onto the internet and find the website. At first she was not very interested, and had difficulties due to visual impairments, and difficulties moving the mouse, due to poor hand mobility. However, once she was directed onto the pages of her day care centre she became very interested and enjoyed exploring the site. She quickly became more confident navigating around it, and was also interested in the sections on the website created by the day care services she attends. She was quite excited by these sections because she recognised the staff and buildings. She then started looking independently at other material about the centres - the sections on safety, recycling, and trips. Within a short period of time she became capable and confident in using the website on her own and without any help she spent some time thoroughly exploring the sections about the day care centres.

Output (d) Recommended strategy for management and sustainability of a Transition Portal

The project team has worked closely with the member of staff seconded by the Newham local authority to play the portal editor and lead trainer role on the project pilot to develop a viable model for the portal's long term sustainability as a resource in the borough. This has entailed discussions with her managers as well as with representatives from the Borough's Communications Department to develop a practical model for the continuation of the Newham Easy Read Website beyond the period of the project pilot.

A strategy has emerged from these consultations whereby the portal is managed by the local authority under the following terms that have been agreed to date:

- The Borough's Communications team will incorporate the management of the website into its portfolio of website provision for the local population
- The post of 'Accessible Information Worker' is to be established under the direction of Adult Social Services to work within the Borough's Partnership team for Learning Disabilities with key responsibility to 'review, monitor, update and modify the portal'

- The post-holder will have responsibility for the continuing function of the portal alongside other advisory and production duties for accessible information development

The seconded portal Editor has mapped out her own set of proposals for a viable and sustainable portal that includes:

- Senior managers in the Local Authority will need to direct and encourage service provider organisations to ensure that their services are represented on the portal and ensure that the appropriate resources are made available to make this achievable
- Further publicity effort from the Borough's Communications unit will help to engage with services, colleges, schools and local authority departments to make sure all areas of transition are covered in the portal
- Continuity of training and workshops provision will be required for both new and existing groups and services taking part, to include 'book-able' one-to-one and a regular drop in sessions for all participating groups and services
- The set up of an inclusive editorial team will help to facilitate a high level of input from people with learning disabilities to contribute to both the maintenance and development of the portal and satellite sites
- Proactive work by the Editorial team to engage and assist mainstream service providers in easy-read website development will enable the growth of the portal and of its usefulness for the target audience
- Ongoing development to the design and functionality of the satellite website template and the portal in response to user trials will help to facilitate the site's success

Ongoing partnership between the local authority and the Rix Centre's 'Living Lab' initiative that operates with charitable funding is perceived to be a requirement for the project over a the coming period while the portal becomes an established feature of Council provision with accompanying budget allocation. It is hoped that this will be required for only one to two years, while the business model for the site's self-sustaining status is developed. There is consideration of potential income streams from sponsorship and advertising revenue as part of discussions between the Council and the Rix Centre and development of a service-level plan.

ANALYSIS AND DISCUSSION

This analysis and discussion of the project's findings explores answers to the project's research questions and reviews results with reference to its aims and objectives. It provides a summary of the lessons learned from the trial about the benefits and risks of using the development of a web portal as a way of tackling the information needs for young people with learning disabilities around transition. The analysis also provides the beginnings of an overview of the potential application of the Internet and associated new media practices to inform and improve social care provision generally, with various recommendations that draw from the pilot experience and its evaluation.

The participation of Newham Borough Council

The experience of working with Newham Borough Council has demonstrated that a Local Authority represents an appropriate body to manage, administrate and moderate a Portal and to host the Satellite websites that provide this with its content. There is a need for this arrangement to be formally agreed at the highest level and then instituted from the top down so the endeavour is structurally embedded in the organisation and

cooperation of employees at all levels is maximised. The take up of the project by the Council Communications Department represents a positive mode of positioning the project within the Local Authority structure, flagging that easy read website provision is part of the Council's core public information provision.

The establishment of a dedicated professional post for this work by Newham has proved an indispensable feature and it is very positive that this is now an ongoing position in the Council. The seconded Editor's proposals for continuity provide a good working model, built on experience and insight into the workings of the Council and of the portal project. The proposal for the establishment of an inclusive editorial team is consistent with the service-user participation benefit that the project has successfully modelled. The proposal also identifies the requirement for the continued engagement of a training and support agency input and the Rix Centre staff team concur with this suggested strategy.

The existence of the portal, as an exemplar of an easy read, rich media approach to accessibility has already prompted a steady stream of new thoughts and ideas about how such a package might serve other audiences and integrate with and enhance the Council's communication approach in the future, beyond the confines of learning disability. In fact, the accreditation of the council's work on this project sets an interesting precedent, considering that mainstream accessibility standards do not provide explicit incentive to develop easy read and rich media models of accessible content for people with learning disabilities. CSCI's expectation that measures are taken to meet the information needs of the learning disability community can potentially provide leverage for the learning disabilities sector to campaign for resources to be made available for precisely the kind of work developed on this project.

Finally, the Newham experience has resulted in a significant quantity of generic transition information that is not specifically local in its focus. The project's original aim to establish a national transition portal may ultimately be achieved by the combination of numerous Local Authority portals taking the approach developed for Newham in Beyond the Road Ahead and then sharing their generic transition information through a national portal.

The Portal and web accessibility obligations

It is significant in terms of the perceived responsibilities of local authorities for accessible information provision that the CSCI Service Inspection Report grappled with accessible information needs of people with learning disabilities *and the need for rich media solutions to be applied*, given that this goes beyond standards that are conventionally seen as 'reasonable adjustments' for people with disabilities generally. The Report was critical of the absence of web-based materials in rich media formats on bullying for people with learning disabilities and complimentary of the Borough's participation in the project in this respect. This would appear to be indicative of pressures for local government through social care inspection routes for consideration of this otherwise marginalised form of accessible communication provision. To some extent it reflects the forward thinking of legislation such as Valuing People in this respect over and above the more constrained standards set by WCAG standards. The 'easy-read' and rich media solutions to inclusion of web users with little or no reading ability do constitute a new definition of the responsibilities of local authorities for accessible information provision – it is no accident that Newham Council's 'New Ways of Working' funding was assigned to help cover the costs of this pilot for the Borough. Newham are now effectively pioneering

the provision of such a website as part of a local authority's standard information service, complete with its innovative inclusion of service users as content developers. This sets a significant precedent for other local authorities to consider, particularly when it is backed by the CSCI Report's recommendation of this line of action as an appropriate measure for the more effective safeguarding of vulnerable adults.



Fig 19. In response to the CSCI report's recommendations, the 'Say No to Adult Abuse' website was set up on 1 July 2008 web.thebigtree.org/safeguardingadults

The failure of the project to secure a portal management partner at the national level is probably also indicative of the innovative and therefore risky nature of the approach. There are few resources in the learning disability sector available for experimentation when funding is tight, even for basic care provision. It is hoped that, as with our experience locally within the Borough, the development of a demonstrator website that illustrates the potential of such a solution for information in accessible formats, will encourage national information service providers to consider this as an option in the future.

Recruitment and training

A number of points emerged with regard to this aspect of the project. First, it became clear that recruitment will be achieved more effectively where take-up by senior staff in the local authority is in place first alongside their top-down support and allocation of resources for their staff. This will also enable further encouragement and for local authority commissioned organisations to participate. To this end, the project should be vigorously publicised to highlight its benefits, especially the personal benefits for

participants that include the development of their ICT and web media skills. The accreditation of training will also help the recruitment of individual staff.

With respect to the mode of training, the face-to-face learning proved popular, particularly for bringing different agencies together for exchange of insight and experience. The training provided on-line was also perceived to be of value and has prompted consideration of further development of this provision. An on-line community of learning suggests a potential means of providing training and support to dispersed groups and organisations.

The lack of prior technical skills was something of a surprise to the training team. The training programme showed that baseline ICT skills are a requirement for effective participation and would be a sensible core requirement for social care professionals alongside health and safety etc. Inclusive training sessions are of great value but are best built on this baseline ICT training.

Finally, the provision of a technical audit and advice service for participating organisations seems a sensible proposition in place of trainers being required to snag poorly configured technical resources. In addition the provision of a minimal technical specification for participation would be of value to help prepare the ground before training is undertaken. Further discussion and resolution of ICT security concerns is required so that the fears of ICT managers can be addressed and suitable solutions identified that do not restrict participants or present a risk for the security of systems.

Social care information providers' experiences

Although a number of care workers participated in the project by providing accessible information without the participation of service users, the majority were recruited to work with their charges on the development of the individual sites. It was clear that the latter participants were motivated to take part in the project specifically by the prospect of collaborative work with service users and new approaches to their participation, advocacy and knowledge sharing. This demonstrated the commitment of many frontline social care staff to exploring new person-centred approaches to their work. For others the combination of technology use, accessible information design and service user participation clearly presented a new challenge. This prompts reflection about the changing definition of the role of the social care professional in a culture in which expertise in information and technology are increasingly recognised as required skill-sets for staff. The project seemed to reinforce the perception that social carers are increasingly information workers as well as care providers.

It is perhaps indicative that trainees expected to meet challenges around technology use as part of their project participation, but ultimately found the task of formatting information in accessible ways both with and for service users was frequently a more substantial challenge. The 'Information' and 'Communication' aspects of the ICT acronym are, it would appear, not as readily recognised and negotiated as a training requirement for professionals as they take up new Technology tools. The testimonies of professional participants that emerged from interviews demonstrated many ways in which work with service users on the websites provided a fresh and promising platform on which to build new ways of communicating between staff and service users as well as new ways of shaping and sharing information.

A clear conclusion from the project is that ICT training holds considerable merits as a standard aspect of the qualification of social carers, and also that acquisition of ICT skills raises staff self-esteem and their perception of their own value as professionals. If we add to this the opportunity for developing staff's communication and information management skills that was demonstrated on the project as part of a rounded professional training in the use of ICT, then we have a valuable platform on which to work. This approach can both meet Continuous Professional Development goals *and* strengthen the staff skills and understanding of communication issues that are required for effective person-centred ways of working with people with learning disabilities.

The extra demands on staff commitment and capability of genuinely involving service users as authors and participants in website development were strongly visible and it is recognised that an effective training package will need to clearly capture what constitutes best practice for professionals in this new field of social care work. In other words, what are the new professional skills that today's 'social care information workers' need to acquire? The experience of providing training and the research team's observations have led to a checklist of various values that need to be understood and applied to realise the potential benefit for service users of this way of working. These include understanding of:

- social model of disability;
- the challenge of transition for young people with learning disabilities,;
- person-centred planning;
- total communication;
- issues of consent and security for vulnerable adults;
- accessibility and information needs of people with learning disabilities.

In other words the values that lie behind effective new media work with service users are effectively those that underpin best practice in advocacy and support across social care. Work on this project has affirmed for us that a valuable and comprehensive curriculum can be developed for professionals around their use of new media with service users and that this embraces the most important key skills for contemporary best practice in social care. The fact that this curriculum can be learned and applied in inclusive classes, developed within one's professional practice, passed on between staff members and developed in teams that include service users suggests considerable merit to this way of developing social care practice. The merits of such training can usefully be reinforced through the development of clear professional pathways for CPD and the accreditation of training in this 'multimedia advocacy' approach.

A further dimension of this work that warrants consideration in terms of training requirements concerns issues of media representation. As social care professionals take up the challenge of media production work with service users they assume some of the responsibilities traditionally associated with journalists and media professionals about how they choose to represent people and their lives. There is a considerable literature in professional and academic circles about the powers and responsibilities associated with photography, programme making, journalism and new media production that should not be overlooked as social care professionals take up these practices. Practitioners should consider questions about the integrity of the communications that they co produce with service users, and the ways in which, as photographers or editors, for example, they can safeguard the wishes and preferences of the people they are working with as media subjects as well as social care service users.

Technical issues

Although there is much talk of how ubiquitous new Internet technologies now are for people in western cultures, this project has highlighted some of the gaps that clearly exist between this vision and the reality for today's citizens. Alongside unexpected examples of ordinary people demonstrating extraordinary technical skills on this project - including people with learning disabilities - there were many examples of people whose lack of confidence in the use of new technology contributed to a sense of personal disempowerment, or even failure, resulting in a sense of 'techno-phobia'. In the best cases the provision of effective training demystifies the use of these tools for both staff and service users in a positive way, boosting self-confidence generally. The experience of the project has underlined the value of developing genuinely easy to use technical processes that are effectively taught to trainees and ensuring that equipment and technical infrastructure is set up and fit for the purpose that it is there to serve.

Our experience on this project points firstly to a need for service provider organisations to be equipped with robust computer and digital media equipment along with a broadband Internet connection, an expectation that is increasingly achievable on a small budget. The second requirement is that such systems are configured in ways that allow for the use of rich media, the upload of large files such as video clips and photos and the download of free to use software packages from the Internet. The challenge for ICT support organisations is to provide these facilities without compromising valid concerns about security and system misuse. Our conclusion from our experience in some of the community learning centres in which we worked with participants, is that too often priorities align with the safety of the system at the expense of the functional requirements of its users. This represents a culture that is not responding to the emerging patterns of use associated with Web 2.0 and that thereby threatens to cancel out some of the opportunities for new ways of achieving effective social care, that have elsewhere demonstrated their merits on this project.

It is noted that there are some clear tensions between the new 'freedoms' associated with 'Web 2.0' practices such as user-generation of content, un restricted new media file sharing and social network building and the valid concerns of social carers to protect adults who are vulnerable from harm. One of the conclusions of this project is that there needs to be further attention to best practice in respect of the safety and security of service users as they deploy these technologies and engage with online activity. Our ambition is that this is be achieved from the starting point that service users should be supported to enjoy the benefits of new technologies to the fullest possible extent and that the task is simply to develop fail-safe working approaches, assisted by affordable, but not prohibitive technical systems.

System configuration – portal and satellite design

The combination of small locally produced satellite websites and a central portal was seen to be an effective combination for this work. The satellite websites gave local participating organisations opportunities to work in all sorts of very different ways, each organisation effectively owning its own web-building project, managing how it worked as a piece of project work and dovetailing that with its other agendas such as learning or independent living support, employment etc.

The portal then provided the centralised hub from which to select content for its particular purpose, in this case transition information for adults in the community. Portal design needs to be reviewed to grapple with the volume of content that the process produces. It may, for example, be of value to consider developing separate portals for locally relevant information or independent living skills etc that could remain linked to an umbrella transition portal site. There was evidence on the project of the potential for different audience segments to have their own hubs drawing from same pool of content but selecting this and arranging its presentation for particular uses and users e.g. in schools for early transition teaching. In essence this simply proposes a further tier of navigation as a means of organising content for different audiences or themes. This would enable improved usability of the portal.

A tree structure emerged around the satellite website and portal structure as numerous organisations got involved in the project. Effectively this structure incorporates checkpoints whereby each participating organisation can manage its own editorial and 'gate-keeping' arrangements. The same network with its secure management capability would possibly serve a social network set up for vulnerable adults well, providing for example opportunity to network together users of a particular day centre or even of a set of service users who are working on a particular activity. This can establish secure and safe online social networking for vulnerable adults as well as providing a safe space in which people can learn how to use social networking sites in a secure way, learning what to do and what not to do before enlisting on a mainstream social network such as Facebook.

The portal and satellite website content

The variety and range of different types of content is a considerably positive feature of the project's outputs. Inevitably its quality and perceived usefulness varied considerably. Some of the content created was quite unorthodox and eccentric, this would seem natural given that people with learning disabilities were being given the opportunity to express themselves and we are gaining an insight into how they see things, their perceptions and their preoccupations. Above all people are having the opportunity to have their 'say' in whatever format they wish to communicate. We should not underestimate how little the voices of people with learning disabilities are conventionally heard and, in particular, how rare it is for those communications to be published and shared.



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love

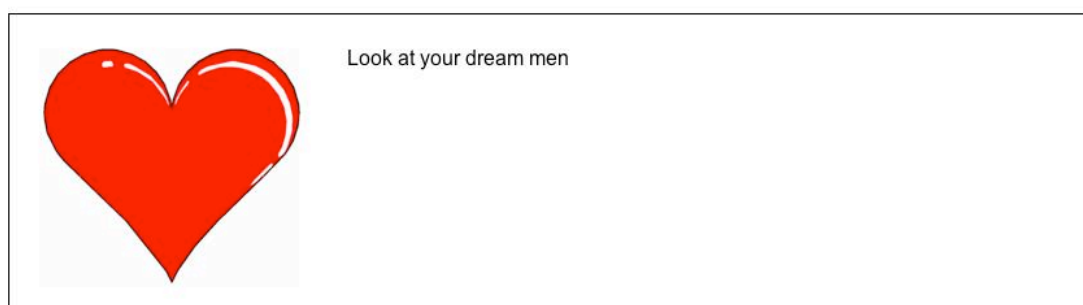


Fig 20 Laura shares her views on love on her website at web.thebigtree.org/lauraslinks

Despite the fact that some of the content was somewhat unorthodox, the portal nevertheless contains a lot of useful information, to which perhaps not all young disabled people would have access otherwise. For many young people computers are used for socialising and recreational purposes. In order to attract young people and retain their interest in visiting the portal, it would be beneficial to make the site more interactive, for example, by having message boards, discussion forums, blogs, problem page, and by having a Myspace type facility where young people can share music, send in their stories etc. One of the issues which came up consistently during the course of the research is the lack of opportunity for the young people to make friends. Positive friendships promote emotional and mental wellbeing, and allow the young people to broaden their horizons and learn from each other when making choices about their aspirations and their future.

The majority of the parents of the young people going through the transition period expressed distress about their current situation, lack of support and a feeling that they did not know what choices and options were available to them and their child. It would be very helpful for the transition portal to have a section for parents, where they can also access information and advice and provide each other with support.

Learning Objects

Given the tendency for people with learning disabilities to be somewhat hidden and their views and experiences unheard in our society, it is clear that the service user- content generated on the project provides a new and valuable resource for the training of professionals. There is vast potential for this to be developed as a progressive spin-off activity that engages effectively with themes like service-user participation, their

information needs etc. The use of service user knowledge for training effectively enables them to contribute to the training of their supporters about their lives and their needs.

The E-Learning objects present a good model for the effective deployment of service user generated content. The work of annotating service user content and contextualising it alongside theory, policy and practice standards proved to be a vital and complex task. The experience has prompted consideration of further research to describe a set of protocols for how to work with service user generated knowledge in new media forms. Such work would need to consider ways in which to maintain the self-advocacy integrity of content while organising it into useful formats for training or other uses.

Independent use and support

- Planning for 'how I am going to take this back into my organisation' needs to be part of training alongside the production of a simple plan that can be shared with managers and colleagues to ensure their cooperation.
- A further audit of the organisations facilities at the end of training can also help encourage independent use after training.
- Further development of on-line support and creation of a social network of various participating organisations can also contribute positively to the prospect of continuity.
- The best examples of organisations achieving continuity of engagement in web development occurred where they were able to integrate the web work into existing agendas, for example; FE colleges placing the work into the ICT curriculum, or day centres developing and maintaining web sites to publicize their organisation and its activities.

An explanation for the fact that website development work tended to halt soon after people stopped attending courses is that organisations are as yet neither equipped properly or culturally prepared to incorporate new media production practice as part of their standard service provision. There are a set of step changes that this form of work is asking practitioners and their organisations to embrace. These include changing power relations with service users around innovative technology and new communication practices that present something of a level playing field for practitioners used to being in control. Although these were recognised for their positive benefit by staff participants during training at the University, going back to base and implementing these changes at their workplaces, alongside their established duties and with other staff who have not been converted to these positive new ways of working is a significant challenge.

Although 'web 2.0' practices are increasingly part of people's leisure life they are not yet embedded in professional settings and the process will be inevitably slow. Cameras and microphones are not as yet part of the social care tool set and even computer use is often minimal. There remains a way to go before these practices are recognised as potentially integral to quality social care provision. The accreditation of training and development of clear ethical and professional guidelines will help to achieve this progression and establish workplace cultures that can incorporate web-based work with service users.

To understand the failure of the project goal that organisations maintain their websites and develop content beyond their period of their training it is useful to consider the factors that led to web development progressing so well while course attendance was in progress:

- Trainees had a routine with set time aside for the work
- They were able to leave the workplace to attend the course
- They had support from skilled teaching and technical staff
- They meet face to face with other trainees on a regular basis
- They were part of a group of peers from various organisations behind them but interests and objectives in common

Further work could look at how many of these factors might be effectively reproduced within a local authority or across several via a combination of online e-learning and face-to-face activity. This could be a valuable application of the projects secure network structure described above that could be configured to connect fellow developers together from different organisations, to provide regular training and support slots, to enable discussions about peoples different experiences, to celebrate achievements and to publicise best practice

One conclusion drawn from our experience is that a blend of face-to-face and e-learning or social network support may constitute the most workable solution for the ongoing development of satellite websites. This presents a potential further role for the inclusive Editorial group that has been proposed to support the management of the portal. As they develop confidence and skills, this inclusive team could help to service the requirement for face to face activity by staffing drop-in sessions for example, or providing web developer surgeries off site at the premises of participating organisations.

Accessible Information

- Feedback from the project affirms this approach is an effective solution for the provision of accessible information for service users.
- Success was directly proportionate to the quantity of content produced and the scale of participation achieved.
- The range of diverse new media formats used helped to address the various accessibility needs and communication preferences of the target audience.
- Participant staff have identified a rich array of ways in which the websites might be used with service users, for example; as a resource for individual advice sessions, as a resource for printing out information sheets, or as part of an information booth set-up in a centre. There is further research potential for mapping these possibilities.
- The website content should be made available in formats to suit multiple uses, pages should be easy to print out or save onto file for offline use, or even recorded as a sound file for use by people with visual impairment. This is a necessary part of a required effort to ensure the website content is accessible and relevant to people with profound and multiple learning disabilities.

CONCLUSIONS AND RECOMMENDATIONS

The project achieved the development of a popular, functional web portal that delivers an array of accessible information about transition themes in formats that are accessible for a large proportion of people with learning disabilities. The promise of take-up and continuity of the easy-read portal by Newham Borough Council is also somewhat indicative of the project's achievement of its objectives. The trial and its evaluation has in addition provided substantial evidence that the use of new media technologies can make a positive contribution to social care provision for people with learning disabilities. Specifically, the deployment of some of the so-called 'web 2.0' practices such as user-

content generation, sharing of rich media content online and the development of web-based communities, has been seen to provide new and beneficial patterns of collaboration for the various participants including support staff, service and information provider agencies, voluntary and statutory organisations and, crucially, service users with learning disabilities and their immediate circles of support.

The project also resulted in the identification of a raft of risks, obstacles and barriers that can make the adoption of these new ways of working both difficult and challenging. In addition some of the limitations of the methods deployed were also highlighted. In general however, these were often eclipsed by new ideas that came from many participants as the project progressed, about how these innovative methods might be applied for more effective social care and the improvement of the life experience of people with learning disabilities and their families.

Participation on the project provided a wide array of fresh working conditions for staff and service users in which the possibility of developing new genres of support relationships, patterns of learning, communication and socialising were identified. Professionals referred to the opportunity for teamwork for example that engaged staff and supporters on equal - or sometimes equally insecure – footings. The process of developing new media content presents a rich range of roles for all to play; as photographers or as ‘subjects’, as script writers or narrators, as website planners, actors, journalists, as critical consumers or ambassadors of local services and as advocates and advisors. Participants showed a readiness to explore these types of roles in flexible a varied ways.

The key opportunity that the project model provides is for service user participation and the breaking down of established boundaries and even power relationships between service users and professional supporter. This process of engaging service users more effectively on terms that they can understand helps to shift sometimes-entrenched relationships between staff and service users. It can challenge patterns of behaviour and role play providing opportunities for service users to undergo some reinvention of themselves and their identities. This is imminently suited to transition, which for most young people represents a period of changing power relations, with parents and other adults in the wider community. As most young people move into the adult world they enjoy the opportunities to re-invent themselves and perform new versions of their identities and reject some of the old ones. Working with new media tools around a website provides a safe way for people with learning disabilities to undergo some of the same processes of personal transformation.

To finish this report, it is worth reflecting on the possibility for a sustainable future for the model developed and tested in this project. Clearly, this would demand the investment of further subsidy as the model is refined, more partners are attracted, and the portal is further populated. The team at the Rix Centre are convinced that the model could work, sustain itself, achieve continuous growth and be of low cost. Indeed, it could even be profitable, given 1.5 million people with learning disabilities in the UK, their spending power, the neglected market that they represent etc. A thriving, self-perpetuating portal would realise the aims of Valuing People, The Road Ahead and Beyond the Road Ahead in that relevant, accessible information would be provided for – and, crucially, *by* – people with learning disabilities, giving them a real voice, and offering them real choices and a much greater degree of autonomy than they may experience at present.

APPENDIX: CASE STUDIES

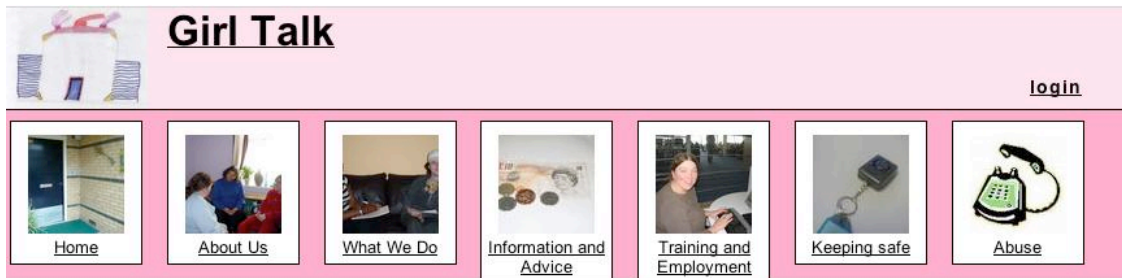
Case study: Beverley Lewis House

Beverley Lewis House (BLH) is a residential home in Newham where eight women with learning disabilities are learning to live independently.

At Beverley Lewis house they have one online computer in a very cramped office that the residents are allowed to use. They have recently been given a digital camera but although it was still boxed when members of the Rix team visited, the lead to connect it to the computer was missing. The computer in the office had been disabled so that new software couldn't be installed so sound recording was impossible. The five residents met by the team were so unenthusiastic that the training had to be abandoned.

The one-day workshops that the group attended were more successful. However, often when workshops take place at the university it is not possible to take photographs of subjects discussed (e.g. 'going shopping'), and people need to improvise. At a workshop in March 2007 two residents from BLH worked with two supporters to explore ideas and capture 'going on holiday'. The supporters were enthusiastic, inventive and resourceful and helped the residents take pictures of magazines in the student shop to represent holiday brochures and the cash point machine for saving. However, indicative of the difficulties in creating representative images, the residents didn't seem to fully understand the significance of the images.

In July a different resident with the same member of staff from BLH also attended a one-day workshop at UEL. Although the supporter was not very skilled in using ICT, the previous training had obviously helped a great deal. She really understood the purpose of the project and supported the resident to make a very useful and accessible web page about women travelling safely.




You are here: [Home](#) > [Keeping safe](#) > [When out and about](#)

When out and about

Fig 21. Women travelling safely from the 'Girl Talk' website at web.thebigtree.org/girltalk/category.php?cid=268&pid=422

Again because the training was at UEL the photographs were all taken within the vicinity of the university, but this time it was possible to find relevant subject matter. The page includes photographs of the resident standing at a bus stop just outside UEL, her freedom pass, and her personal alarm. All the ideas came from the resident and she very confidently recorded audio to support what she wanted to say.

A different supporter and a different resident attended the 12 week Champions' Course at UEL. The liaison between staff about the project had obviously been good because the supporter totally understood how she should support the resident to carry on making the website (which they named 'Girl Talk'). The supporter was very confident using the technology and this seemed to inspire confidence in the resident too. They attended 11 of the 12 sessions and made a comprehensive website. Of particular note are the sections on "keeping safe" and "abuse". These are the biggest, most comprehensive and richest in content and they were shaped, developed and produced by the resident. Some of the other sections, about the services that Beverley Lewis House offer, were clearly written with greater input from the supporter.

 **Girl Talk** [login](#)

[Home](#)
[About Us](#)
[What We Do](#)
[Information and Advice](#)
[Training and Employment](#)
[Keeping safe](#)
[Abuse](#)

You are here: [Home](#) > [Keeping safe](#)

Keeping safe

[When out and about](#)
[Cash Machine](#)
[Home](#)
[Phone](#)
[Bus](#)
[If in trouble](#)


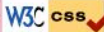







Fig 22. The index page of the 'Keeping Safe' section links to six pages of accessible content created about this topic web.thebigtree.org/girltalk/page.php?pid=422

Case study: Debbie

Background

Debbie is a middle-aged woman with a learning disability. She lives at Luton Road, an independent living scheme, in Newham.

Debbie's involvement in the project

Debbie features in four of the satellite websites that have been made for the project.

The screenshot shows the website for Luton Road. The header features a large image of the building and the title "Luton Road" in a dark red bar. A "login" link is in the top right. Below the header is a navigation menu with seven items: Home, Luton Road Project, Luton Road Customers, Activities, Staff Team, health and safety, and Contact Us. A breadcrumb trail below the menu reads "You are here: Home". The main content area has a "Home" heading and a "Listen" button with a speaker icon. To the right of the button, text reads: "For more information about Look Ahead Housing and Care, please follow link. Related Links: [Look Ahead Housing and Care](#)". The footer contains several accessibility and standards logos: W3C XHTML 1.0, W3C CSS, W3C WAI-AAA WCAG 1.0, and the BIG tree logo.

Fig 23. web.thebigtree.org/lutonroad

- Luton Road

Newham Hotshots [login](#)

[Home](#) [section 1](#) [section 2](#) [dining out](#) [section 4](#) [section 5](#) [section 6](#)

You are here: [Home](#)


Home

 sandra debbie and susan we are the newham hot shots and we make news on the web. we hope you like our web page.

W3C XHTML 1.0 ✓ W3C CSS ✓ W3C WAI-AAA WCAG 1.0 the **BIG** tree

Fig 24. <http://web.thebigtree.org/eastlea>

- Newham Hotshots

 **EMPLOYMENT CHAMPIONS** [login](#)

[Home](#) [who we are?
who we are?](#) [Section 2](#) [Section 3](#) [Section 4](#) [Section 5](#) [Section 6](#)

You are here: [Home](#)

Home

Welcome to the Nulife Employment champions Website




Fig 25. web.thebigtree.org/employmentchampions

- Employment Champions



Fig 26. web.thebigtree.org/stbarts

○ NuLife St Bart's

Although Debbie has only a mild to moderate learning disability she needed lots of support to participate in the project as she finds it very difficult to use computers. She also has trouble communicating and is illiterate. In two of the websites (Luton Road and Employment Champions) there are pictures of Debbie taken by supporters and uploaded by the site's developers, but in the others, Debbie has been much more active in making content and developing the sites.

Training and support

Debbie first became involved in the project at a workshop at Eastlea College in June 2007. At the workshop she worked with two other students with learning disabilities to make a web page to start their local "good restaurant guide". This was the team's second visit to Eastlea, having been a few weeks earlier to explain the project. Two of the three students who had volunteered to be part of the project had done a considerable amount of preparation. They had devised a marking system for grading the restaurants, made score cards, visited local restaurants and taken pictures of each other outside holding up their scores. They had also typed some comments about what they thought of each one. The team don't know how much input Debbie had in the preparatory process but she can be seen in all the photographs on the webpage holding up her scores.



Fig 27. Debbie and Sandra rate a local café on the Eastlea website web.thebigtree.org/eastlea/page.php?pid=378

Debbie was very enthusiastic and engaged during the training on adding her photographs to the website. During the session she was helped a great deal by her fellow, and more literate service user, Sandra, to upload photographs and record sound. Progress was slow but Debbie and Sandra were undeterred and after a three hour session with only a short break they wanted to carry on even though the college was closing! Unfortunately Debbie and Sandra were unable to continue with their good restaurant guide because the college changed the session from ICT to yoga – a good illustration of one of the difficulties in the autonomous continuation of website development by the participant organisations.

We next saw Debbie when she was one of the three people with learning disabilities to attend the twelve week Champions' Course. At this time, Debbie worked with two supporters to make the St Barts website about the Day Service which she attends. In an attempt to involve Debbie in the process she has recorded all the sound for the website and some short video clips but the language and content suggest that her supporters have told her what to say.

The screenshot shows the website for the Nulife St Barts team. At the top, there is a header with the text "Nulife St Barts team" and a "login" link. Below the header is a navigation menu with seven items: "Home", "What we do", "Support", "Gallery", "Stories", "Money", and "Health and Safety". Each item has a small icon representing it. Below the navigation menu, there is a breadcrumb trail: "You are here: [Home](#) > [Stories](#)". The main content area is titled "Stories" and contains a video player. The video player shows a woman (Debbie) speaking, with a play button in the center. Below the video player, the text "Debbie's story" is displayed.

Fig 28. Video clips of Debbie on the Nulife St Barts team website web.thebigtree.org/stbarts/page.php?pid=654

Case Study: Firstline Supported Employment Service

Firstline is an employment service for people with learning disabilities and is governed by Newham Social Services. This service provides supported employment and help people with learning disabilities to find and get into paid work.

The screenshot shows the homepage of the First Line Supported Employment Service website. The header is purple and contains the logo and name of the service. A navigation bar below the header has seven icons representing different sections: Home, About Us, The Service, What is a job?, What Can I be?, Job Searching, and Employed!!. Below the navigation bar, a breadcrumb trail indicates the user is on the Home page. The main content area features a large 'Listen' button and a welcome message. The footer contains several accessibility icons, including W3C XHTML 1.0, W3C CSS, W3C WAI-AAA WCAG 1.0, and the BIGtree logo.

Fig 29. First Line Supported Employment Service website web.thebigtree.org/firstline

The web editors for this website are two service users with learning disabilities who are supported by a member of staff from firstline. The information is created and uploaded by the two service users themselves but other peers have also been involved. The two web editors are very able and computer literate. The group meet on a weekly basis with the supporter, who ensures that the information they write about is relevant to the topic - finding work and information about jobs. She helps them to make the information accessible.

This group attended a one day workshop at the UEL; they initially came with two service users and two members of staff. The workshop provided them with the basic knowledge of how to use the website template and they managed to cover every aspect of the template in the workshop. The group seemed to pick up the instructions quickly and without much support, when interviewed they said **“All of it was easy, it was straight forward to use”** and **“I found it quite simple to use, to add pictures, sound and text”** The group have not yet added video and they feel that they may need further support to do so.

One of our concerns with this group was that one of the supporters who attended the workshop appeared to want to be in charge and not allow the service users to say and write what they wanted. He seemed to think that it was acceptable to re-word things so it sounded professional. This, clearly, took the ownership away from the service users and was contrary to the aim of the exercise and of the project in general. This aspect of the workshop was discussed as a group and the Rix team trainers explained that the information should be presented in a way that is a good representation of first hand experiences and that the best way to do this would be from the service users themselves.

Despite this initial setback, Firstline's website became a good example of how people with learning disabilities can share their own experiences and skills to inform and help others who are in the same situation and who are looking for work. The website is very informative and touches on many areas to do with finding work such as interview tips, job searching, telephone skills and the different types of jobs. The information is presented in a form of a step by step guide using all of the key factors for accessible information such as pictures, text and audio. The group have expressed an interest in adding video to the website. This website is ongoing and continues to grow with exciting and valuable first hand information.



Fig 30. First Line's website links to six pages of information about looking for a job. web.thebigtree.org/firstline/page.php?pid=478

Case Study: Dan and Laura

Dan and Laura both work for the Learning Disabilities Social Work Team. Dan is a social worker who works closely to transition and supports people who are going through transition. Laura is a service user who works as a part-time administrator for the team. Dan and Laura were both put forward by managers from the Learning Disabilities Transition Team to attend the Champions course.

It was thought that Dan would make a website as an introduction to transition and what transition is. The idea was that he would look at the processes through transition and show a couple of examples of people who have or are going through transition. Dan was also the supporter for Laura who has made a personal website. Laura attended the course on her own and was supported by Dan and the Rix Centre team to build her website.

The two websites are very different both contain interesting information and are both accessible and informative.

Looking to the Future: Transition

This website has really useful information but is lacking in pictures, Dan has managed to explain transition without using too much text and he has already added most of the audio. Whilst Dan attended the course we had many conversations about what types of pictures he could use. He felt that it was difficult to take pictures that represented all of the information in his website. He had ideas to follow a couple of stories about one or two of his clients who have been through the stages of transition, but this proved to be difficult because he didn't have access to equipment ***"I would like to make stories/case studies especially about one of my clients who has just moved to independent living, but the camera wasn't available when I went to see him. Finding time is also a problem"***. Dan would like to carry on with the building of his website but it seems like he doesn't have the time to do so. This website would be a crucial part of the portal as it explains what transition is.



You are here: [Home](#)

Home

This website is about transition

Listen

It will tell you what transition means

Listen

Fig 31. Looking to the Future: Transition website was developed by Dan, a social worker. web.thebigtree.org/transition

Laura's Links

Laura attended the course independently after the first two sessions of being shown how to get to the university. At first Laura seemed a bit anxious about attending the course but then seemed to have gained confidence after a few weeks. Laura would always arrive promptly for 9.30 every week and she would set herself up by login in to her website and waiting for guidance. At the beginning of the course Laura needed a lot of prompting and guidance from Dan and from the RIX team. We spent quite a bit of time planning with Laura, to make sure she understood what she needed to do and to encourage her to come up with her own ideas to add to her website. By the final week Laura really clasped this way of working and she managed to create a whole page without any help or input from anyone else. She decided to do a page on love, she managed to plan the page on paper first and then added this to the website by typing the text and picking the relevant pictures, she did not get round to adding the audio because of time but I am sure that she would have managed to do the audio with minimal support. The page was a great achievement for Laura but the actual content was very random and not very informative, with a bit of support this page could be made better.

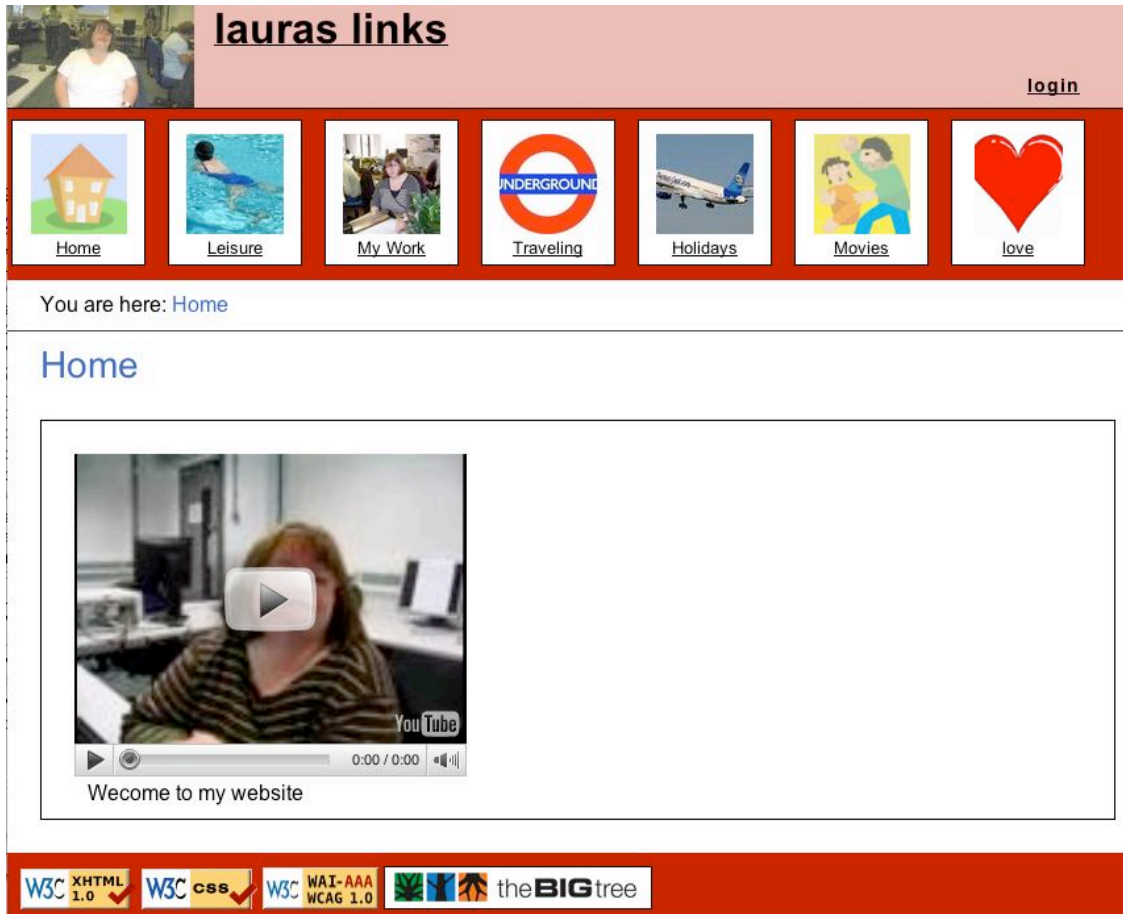


Fig 32. Laura's Links was developed by Laura, a service user. web.thebigtree.org/lauraslinks

Laura really benefited from the Champions Course and when the Rix team asked her what she liked about making her website she said **“All of it”** and **“Typing and talking into the microphone was easy”**. Laura did seem to think that she done all of the website herself without much help but she did need a lot of support and help throughout the course. It is possible that if she were to build the website development into her daily work she could do most of it herself but would probably need guidance in the type of content to be added.