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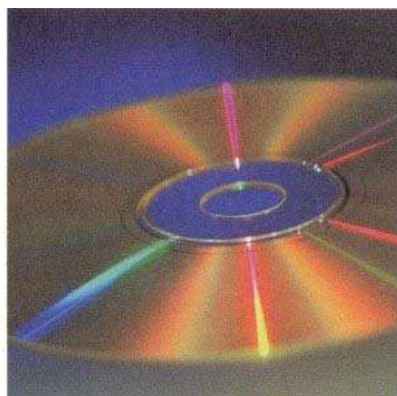
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Empowering older people through
technology: Academic Review of the
iContact Project conducted by Acting Up
and funded by Big Lottery,

1st January 2005 - 31st December 2007



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The Centre for Health Services Studies (CHSS) is one of three research units in the University of Kent's School of Social Policy, Sociology and Social Research. It contributed to the school's Research Assessment Exercise 6* rating. This put the school in the top three in the UK. CHSS is an applied research unit where research is informed by and ultimately influences practice. The centre has a long history of working with public health practitioners, both as members of staff and as honorary members of staff who are active as consultants to the centre and as practitioners in the field.

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1. Executive Summary

Multimedia work provides a way for vulnerable individuals to express their desires, wants and interests and so influence the services which they receive and the development of such services. It combines:

- *multimedia technology* video recording, digital storage and editing and playback facilities;
- *human systems* project workers to facilitate the use of the technology, by:
 - engaging with individuals and groups
 - demonstrating how the equipment can be used and where necessary use it
 - editing or helping with editing
 - organising viewing and discussions of viewings.

Partnerships and networks Some of Acting Up's initial partnerships have thrived, especially with Kingsgate, others have either not developed, WASSR and TLC or developed more slowly, UKOL Camden and new ones have developed, KOVE and INTERGEN. Acting Up has invested time and energy in nurturing all partnerships but participating in the project requires both confidence in its methods and objectives and resources to match the Acting Up investment. There seem to be a number of factors that differentiate between those partnerships which thrive and those that have not.

- *Size and resources* Smaller organisations, especially those with resource constraints or needing to meet external targets found it difficult to provide the resources to match the Acting Up input.
- *Perceptions of the benefits of multimedia to service users* Organisations that did not perceive the benefits of user involvement in multimedia profiling were unlikely to actively engage with Acting Up.
- *Willingness to take the risk* Multimedia involves the development of social relations as well as the use of technology. It is also a developmental process making it difficult at the start of the process to definitively identify likely longer term benefits and outputs. It requires an act of faith on behalf of all the participants. Some organisations, especially those that were established, relatively stable and self-confident, were more willing to take such risks.

Multimedia outputs/outcomes develop over time (For main public products see Appendix). As individuals learn to work with and develop confidence in the technology and each other so the outputs can develop from individual profiles to broader interactions. In communication terms it is possible to identify a progression in the complexity of communication:

- *One-to-one* e.g. communicating a profile to a specific person
- *One-to many* e.g. using profile material in a blog
- *Many-to-many* e.g. producing and using campaigning or training materials.

One-to-one and to-many has a major impact on those individuals who are actively engaged. As individuals developed familiarity and skills so their confidence developed. Different people used the technology in different ways. For example:

- Delia increased her engagement with her family;
- Mitch reduced his social exclusion;
- Reg used multimedia to make statements about decisions which affected his life;
- Gerald used multimedia to communicate to others about his life.

Multimedia also has indirect benefits and can affect those who do not directly or formally participate. For example at the Kingsgate Centre multimedia:

- provided an *additional activity and resource* within the Centre and increased the awareness of the value of new technology amongst users and centre staff;
- supported *engagement and interaction*;
- enabled participants to *engage in activity in a positive way*;
- *increased interaction between individuals*;
- helped individuals *increase their confidence*;
- had a *visual impact* on the Centre.

Many-to-many Multimedia can also be used by groups to create campaign or training materials. The various group products include:

- films on access and mobility issues (Kingsgate)
- an On-line magazine provides space online for participants to report on personal activities and campaigns (Kingsgate)
- 10 key things which support workers should do round a specific house (KOVE)

- Talking heads video, training material based on user and carer personal experiences (KOVE).

Overall The multimedia project involves the use of sophisticated technology to enable individuals and groups to express themselves. This approach has a number of important advantages. It is:

- *flexible*, can be used in a variety of ways;
- *person centred*, responsive to personal interests, skills and enabling individuals to thrive i.e. learn new skills, express themselves, influence others, enhance communication/memory outcomes;
- *empowering*, building individual and group confidence. It can be used one-to-one communication but provides the opportunity for group development; and one-to-many or many-to-many communication;
- *effective* producing high quality material which effectively gives voice to and empowers those who created it. It created excellent teaching material as it has a strong sense of authenticity and emotional impact increasing the likelihood that it will affect the feelings and behaviour of viewers.

2. Context

The Centre for Health Services Studies agreed to provide an academic review of Acting Up's iContact project. Given the developmental nature of the project and the limited funding, CHSS could not provide a full evaluation of the project. The team:

- provided advice and guidance to John Ladle and other members of the project team on the type of evidence which they should collect to demonstrate the impact of the project;
- visited the main sites in which the project was based, meeting the main participants;
- interviewed a small number of key participants;
- read key documents on the project

This report is based on these visits, meetings, interviews and documents. It starts with a short discussion of the nature of multimedia profiling, then discusses the development of multimedia profiling within Kingsgate Resource Centre and with KOVE and considers why Acting Up successfully developed in these contexts and not in others. It concludes with a discussion of the outputs of profiling and their impacts.

3. Multimedia profiling

The project builds on and develops Acting Up's use of and expertise in multimedia. Acting Up is committed to using such technology to enable vulnerable individuals to express their desires, wants and interests and so influence the services which they receive and the development of such services. Acting Up started working with individuals with severe learning disabilities and communication problems using multimedia to help individuals develop personal profiles which could be used as a record of individual needs and as a basis for improving their care and support. The iContact project extends this approach to older people who experienced a variety of health and social challenges including physical disabilities and communication difficulties. The starting point of the iContact project was the development of individual profiles which show people with communication difficulties how to use multimedia to build personal profiles on a computer-based catalogue. These profiles contain information about the person's needs, history, routine, points of view and any other information the person wishes to include in them. (Camden, n.d., p. 30)

Such profiles remain an important part of the project and of the overall process of extending participants engagement and involvement in the project and beyond. While Acting Up has always been committed to giving participants a voice by using multimedia technology, video-recording, computer-editing and film-making, to capture the reality of everyday life and experiences, the iContact project is based on an evolving and developing partnership between Acting Up, those using the services and those providing them. As individuals engaged in iContact have become familiar with the technology, learnt how to use it and seen its products so they have shaped its use and outputs. Through iterative cycles of filming, production, viewing and discussion, the Project has expanded from individual and personal products such as personal films or profile, through community development projects such as films documenting access problems or use of public transport to products designed to change organisational responses such as the 'talking head' films. The day care officer who had an interest in IT at Kingsgate noted the ways all aspects iContact project had developed. For example in the Centre there was strong interest in the production of Life Folders and they had 'really taken off'. The content of these folders were becoming increasing biographical, more like documents of life (Plummer, 2001) than restricted communications about service wants and needs.

Such biographical materials and associated documentary films have an authenticity and directness that is difficult to achieve by any other means. They are designed to and do speak for themselves and provide an insight into the ways in which the lives of older people with disabilities have developed, how they experience the world and the service they interact with. As a manager involved in project put it:

Multimedia... [is] the human face on all the paperwork. I feel, as a social worker, that I don't lose sight of the people. Multimedia Profiling slaps you in the face with the reality of people and real needs (Opaaluk, 2007, p. 18)

4. Project partners

The initial application to the Big Lottery for funding identified three possible sites and partners for the iContact project, Kingsgate Resource Centre, funded by Camden Council to provide a community centre and resource for older people, TLC which provided support services for stroke survivors and Westminster Advocacy Service for Senior Residents (WASSR). Following extensive discussions and consultation TLC and WASSR decided not to pursue their initial interest and Kingsgate Centre became the main site and through work at Kingsgate other partnerships developed with UK on line (UKOL), Kilburn Older Voices Exchange (KOVE) and INTERGEN, which provides intergenerational work experience for school students. We will briefly consider why Kingsgate proved such as fruitful partners then consider why TLC and WASSR did not pursue their initial interest and comment on the expanding network of partners and activities.

Kingsgate Resource Centre is a large well established resource service that acts as a day centre and community resource for older people in the London Borough of Camden. Prior to the iContact project the Centre already had IT facilities and expertise. The Centre provided a base for the Camden branch of UK On-line with two computer rooms. It also employed an IT worker who had successfully helped people in the centre use new technology and was also sympathetic to the Acting Up project and willing to support its development within the Centre. This IT project worker had also developed a communication space within the centre. The project also had high-level support within the Centre. The Centre manager was aware of the pressure on her facilities:

When you lose staff and you have posts cut and you have an influx of new service users as well it actually makes it quite... quite difficult and we've had an up and down year this year

Despite the pressure on resources the manager was committed to innovation and willing to take risks if she could see the potential for benefiting people using the Centre.

I don't think we've ever been frightened of starting new projects here, I mean it's quite a standing joke that, you know, what pilot or project are you going to start this month? You know, not this year, this month. We're quite renowned here for delving into things and saying 'oh yeah let's give it a whirl and see how it goes'. And most of them benefit service

users I think in one way or another. I think it's made us take on more partners and invest in that, invest time in that when we have time.

When asked why multimedia had thrived at Kingsgate and not in other settings she commented that:

I would hazard a guess that we're quite flexible here. Given the set up that we are you would expect us to be quite rigid but we're not.

She felt the project fitted with the overall ethos and mission of the Centre to provide a voice for and enhance the independence of its users and was willing to make available resources such as space and staff time. This flexibility and the matching resources meant that Acting Up had the time and space to establish contact and build rapport with a group of older people using the centre. It was a two way process. Acting Up has made an important contribution to the work of the Centre, for example helping some users who were in danger of becoming isolated to play a more active role and enabling the Centre to document some of its activities, e.g. by producing a documentary film on Camden over 50s festival which Kingsgate supported. Following the closure of their Centre, an African Caribbean Elders group, moved to Kingsgate and several members of the group took an interest in multimedia. The Community Development Consultant noted the ways in which the flexibility of the Kingsgate Centre contributed to the success of the iContact project:

I think Kingsgate have been a very adaptable, adaptive host if you like. So yes it's a bureaucracy but it's managed in a dynamic way and... it's open to the community. I mean the very fact that it hosts Kilburn Older Voices Exchange without controlling it.. is a considerable skill in itself. So I think that's enabled Acting Up to play a much fuller role there than a more nervous objectives [or] target driven facility.

Some of the staff were concerned about the potential intrusiveness of the iContact project and the ways in which it might invade privacy but such fears were rapidly allayed when it became evident that the project was essentially responsive to individual and group requests:

My assistant manager was quite cynical about multimedia I have to say and was very worried about the privacy angle about somebody always having a camera put in their face, he didn't like that very much, has suddenly got very hooked on an inter-generational project. Now this was by the by from Acting Up and we're working quite closely with

Beckford School now on the inter-generational project. But of course they came on a Tuesday so straightaway the two projects dovetailed. (Kingsgate Manager)

Westminster Advocacy Service for Senior Residents Initial meetings with WASSR did not develop into a partnership. WASSR was a relatively small group which, at the time of initial discussions, had successfully applied for Comic Relief funding to set up a national advocacy network. With the increased workload WASSR's Director did not feel able to provide staff time to support Acting Up. As a relatively small organisation WASSR needed to meet external targets to survive. Without additional funding it did not have the capacity to participate. One possible explanation for the success of the project at Kingsgate was that in Camden the social service department recognised the linkage between user empowerment and IT development and was willing to fund and resource such developments. The Community Development Consultant contrasted the approach in the two areas in the following way:

Westminster is the only one that I have any knowledge because [I know the Director] [She] has kind of been sceptical about [the Camden approach]... she's also involved with the Old Peoples Advocacy so she's been sort of quite challenging about the decisions I'm making. I think the... Camden is an incredibly well resourced place. The fact that there was somebody with a job like mine for 5 years that's been playing around trying to get imaginative new uses of the Internet most boroughs don't have things like that and nor do most voluntary sector organisations. People need to be... prepared for the kind of ongoing evolving, quite challenging negotiations that John brings with him... John's always putting you on the spot and making you think.

TLC is a Hackney based support group for people who have had a stroke. Although initial discussions with both the manager and support workers were very positive, there were a number of major changes in the service. The managers of Kingsgate discontinued the TLC group running in the centre and the two workers running the Goal Attainment Programme resigned placing the programme in some doubt. TLC reduced the scope of their work with stroke survivors concentrating on work with groups rather than individuals. TLC appointed a new manager who wanted to use the expertise of Acting Up to produce training and promotional videos. Such work did not fall within the scope of Big Lottery funding and therefore Acting Up decided to concentrate on work that did. Acting Up maintained a relationship with TLC providing support for a report on their work with stroke survivors which TLC made for one of their funders. Acting Up worked with the TLC worker writing the report to produce material demonstrating the effectiveness of multimedia work especially in one-to-one and goal setting with stroke survivors. The source material for this is derived from Acting Up work at Kingsgate.

UK on line (UKOL) is a national network sponsored by the Department for Education and Skills and funded by the Department and local authorities. UKOL focuses on helping individuals access IT and various on-line resources. It also provides facilities and training in a variety of community settings and supports a unit at Kingsgate to help centre users develop their skills and increase their inclusion in on-line communities. The UKOL facility includes two rooms equipped with PCs with Microsoft software and internet access and there is a worker in the Centre with IT expertise who supports the facility.

Acting Up established a relationship with UKOL but this did not develop into a full and effective partnership. The main stumbling block was the different computers platforms and ways in which these platforms were used. UKOL uses Microsoft software and the service is essentially that of a free Internet Café; as the Community Development Consultant put it a '*sending e-mails to your grandchildren culture*'. Individual used the facility mainly to email or access the World Wide Web. In contrast Acting Up uses Apple MacOS software to enable participants individually or in groups to create their own records or films. Acting Up worked with an IT support worker in the Centre who was interested in and had the skills to edit video recordings and other materials. Acting Up has requested the purchase of two Mac computers for the resource room to enable users to do their own editing and to provide for the long term viability of the project. None of the organisations supporting IT in the Centre were willing to fund or support this:

I mean we've had some resource issues around, not necessarily money, things like we would have very much liked to have purchased 2 Apple Macs here which would have helped the project I think. And it wasn't a money issue because I actually had the resources to buy them but it was an issue within Camden because they don't like using Macs and they won't support them. (Centre Manager)

Although Acting Up has not been able to create a formal partnership with UKOL there has and continues to be informal relations. John Ladle has met with senior managers, and they have been very sympathetic to Acting Up's use of IT. UKOL Camden explicitly endorsed the Acting Up approach in its bid for additional funding in 2006.

Through the work that our partner agency, Acting Up has done at Kingsgate Resource Centre, as well as colleagues in other work, we see how valuable it is to give people a voice where they did not have one because of disabilities or lack of knowledge/skills. In this way computers become a natural part of people's lives and it is easy to extend their computer skills and refer onto other courses and into work, as appropriate. They gain the

confidence in using IT, self-expression and being in learning situations. As far as we know there has not been any widespread work done with either groups in this area (UKOL Camden, 2006, Section 4).

Informal relations with the UKOL tutor at the centre have been good and she is keen on and supportive of multimedia profiling. As a result one of the two rooms allocated to UKOL has effectively become a multimedia room. There has been an increased use of the facility but there has also been a shift from individuals to group use, i.e. a shift from an Internet café which as the Community Development Consultant noted had a limited market to a creative working environment with a broader appeal as participants can produce their own profiles and also interact and collaborate to produce and reflect on films. Members of the multimedia group use the walls of the room to display blown up images of themselves creating a sense of ownership.

Kilburn Older Voices Exchange (KOVE) is a Camden based community group that uses Kingsgate as its base. The group is active in representing the interests of older people especially users of social care within the Kilburn area of Camden and receives funding from Camden Borough. There is an overlap between KOVE members and individuals who use the Kingsgate Centre and to some extent the development of the relationship with KOVE has been a natural development of working relations in Kingsgate. However there has also been some brokerage. The Community Development Consultant who was a formerly manager of day services in Camden and had a close relationship with both the Centre Manager and KOVE saw the opportunities for using multimedia technology in KOVE activities and facilitated collaboration. This consultant described KOVE as

a kind of community panel in which users would work quite a challenging... users and community reps would work in quite a challenging way with professionals and latch on to services where it was thought it was mutually agreed those would make some improvement.

The overall approach adopted by KOVE fits well with the approach and philosophy of Acting Up:

KOVE... has a person centred mission which sits very nicely with the Acting Up connected to disabled people's voices being at the centre of the programme (Community Development Consultant).

Acting Up has worked with KOVE since 2005. KOVE has received funding from Camden to develop a Home Care Services Partnership and as part of this work Acting Up helped KOVE use

multimedia to produce a DVD based on three interviews and designed to improve Home Care Services in Camden. The KOVE material represented user perspectives and was made available to the agencies providing services within Camden. John Miles (2007) in his evaluation of the Partnership noted the involvement of Acting Up:

Acting Up's director, John Ladle, is closely involved in the work of the HCSP's Sub Group on Care Standards & Good Practice. He has directly linked an input around the principles of user involvement to the design of the multimedia material and has offered advice on the training approaches that the providers could adopt. Acting Up have also enabled KOVE to keep a filmed record of the film-making itself and of the Sub Group at work. The KOVE members brought an extra dimension to deployment of the multimedia programme. They have learned skills in the use of the camera and in carrying out themed interviews but the Project Team's three volunteers have also brought an important element of 'peer support' to the work of the Partnership. This is felt by several observers within the Partnership to have contributed both to putting people at ease and to prompting disclosures that might not have been made otherwise. Members of the team have contributed in an advocacy role within debates at the Sub Group and in the main Partnership meetings. The service-user representatives both appreciate these contributions. One spoke of the team being perceived as 'neutral' by interviewees – i.e. trustworthy in not having a professional interest (KOVE, 2007, pp. 16-17)

Acting Up has supported KOVE with a number of projects including the development of training materials based on user experiences of services and a video about the access and transport problems in and around Camden. While KOVE has provided opportunities to develop multimedia work, the relationship with Acting Up has also stimulated KOVE:

Acting Up has really... has really kind of shaken up KOVE, you know, and enabled it to grow and exactly how that would... You know, how KOVE will evolve without it or with more limited input isn't sure. (Community Development Consultant)

The response to this work in Camden social service has been very positive and senior policy makers there are keen to use the materials to facilitate training for 30 homecare providers, care management teams and residential/respite providers providing services in Camden and are actively exploring the possibility of developing this type of work with other community groups in Camden.

New partnerships Acting Up is expanding its network of partners in and beyond Camden. The existing work and relationship with Kingsgate has been important in providing opportunities to develop new partnerships. For example Acting Up was keen to develop links with local schools but direct approaches to head teachers were unproductive. Acting Up has been able to contribute to the *INTERGEN* programme that provides intergenerational work experience at Kingsgate. The initiative came from Kingsgate staff who saw an opportunity to involve Acting Up and invited school students to come in and work alongside older people using multimedia. This initial work was very successful and drew in and engaged with some children who had been disruptive in school.

Comment Some of Acting Up's initial partnerships have thrived, others have not developed and have been replaced with new ones. Acting Up has invested time and engaging in nurturing all partnerships. There seem to be a number of factors that differentiate between those partnerships which thrive and those that have not.

- *Size and resources* Smaller organisations, especially those with resource constraints or needing to meet external targets found it difficult to provide the resources to match the input from Acting Up.
- *Perceptions of the benefits of multimedia to service users* Organisations that did not perceive the benefits of user involvement in multimedia profiling were unlikely to actively engage with Acting Up.
- *Willingness to take the risk* Multimedia is a social process as well as a technology and it is difficult at the start of the process to clearly identify its outputs. It requires an act of faith on behalf of all the participants. Some organisations, especially those that were established, relatively stable and self-confident, were more willing to take such risks.

5. Multimedia outputs/outcomes (also see Appendix)

In the iContact project multimedia has been used in a number of different ways, initially to develop individual profiles but as individuals developed confidence and as the partnerships and networks expanded groups have started to use it to influence service development in various ways.

On-to-one and one-to-many communication

Acting Up has worked with individuals in Kingsgate to develop personal material or profiles. Multimedia Profiling is a computer-based catalogue of a service-user's daily activities and personal history. Using a collection of images, video clips with sound, the user and service provider together compiled and presented multimedia reports that powerfully convey individual issues and support needs. These profiles provided individuals with an opportunity to express their own views and communicate them to others who were important in their lives whether these be friends and family, other service users or workers providing them with support in their own homes or elsewhere. The centre manager indicated that she had been impressed with the ways in which Acting Up profiles of young adults with severe learning disabilities had shown her how effective profiles could be:

even if you're in the care profession for older people there's something about young adults with learning difficulties that's quite... it sort of tugs on your heart strings a bit. And the fact that you could see these kids, and they were kids, they were 18 or 19 year olds, you know, were making themselves really understood by the use of multimedia.

Since the profiles were essentially personal communications their form and structure varied and developed out of work with each individual and their level of engagement with the project. The Acting Up worker played a key role in the production of the profiles by helping the subject of the profile record material and editing the recorded material into a profile. While IT support staff in the Centre and several of the participants in the project have developed skills in editing they do not have the expertise and experience of the Acting Up team so the both the availability of the support provided by Acting Up has been important in enabling participants produce high quality materials:

*I mean you do see the difference in the editing, not so much in the filming, but [IT support worker] will edit in one way and there's a couple of service users within the group that also do some editing. They're not quite as brutal as John. John's very good at just leaving in the very succinct bits that whack you, you know, and cutting out all the drivel really around it.
(Centre Manager)*

Thus Acting Up provided visible support for individuals make video-records of their everyday lives but it also provided less visible background support in either editing or helping individuals to edit the recordings into profiles and films. The project worker needed to be sensitive to what participants want to say and communicate and this sensitivity played an important role in empowering participants:

Nick [iContact project worker]... at Kingsgate since the beginning has such a curiosity about other people's lives and an affinity with getting them to engage with unfamiliar senses means that there's always something fairly dynamic going on. So Nick is in himself, his kind of adaptiveness, his willingness to turn to a complete stranger and get working with them within 5 minutes totally suits the kind of... the culture of people who come in on a minibus to a busy centre full of their own needs and concerns... the facility that Nick brings to engaging people and empowering them actually... the speed with which people will take to using a camera and his readiness to advise, the fact that it doesn't feel technical or mystifying. (Community Development Consultant)

Individual profiling had a major impact on those individuals who actively engaged. As individuals developed familiarity and skills so their confidence developed. Different people used the technology in different ways. For example:

- *Delia increased her engagement with her family.* Delia was experiencing memory loss and at the start of project she was keen to talk about her grandchildren but could not remember their names. The iContact project helped Delia build up a personal folder initially scanning in photos of her grandchildren and the biographical material. Delia then found her children's email addresses and initiated an email correspondence with an exchange of family photos and information so helping her retain her identity, participate actively in her family and reinforcing her memory;
- *Mitch reduced his social exclusion* At the start of the project Mitch had been an 'outsider' and was considered by many as 'out of control'. His involvement in the project provided him with skills and activities. He has set up his own website, is blogging and has learnt to use the camcorder, for example to document the access difficulties on his journey to the Centre. He talks to others and is considered to be part of the group;
- *Reg used multimedia to make statements about decisions which affected his life* Reg has a progressive muscular condition and used multimedia to make statements about his life and treatments. He made a film of a journey into London using public transport to show it could be done. He also recorded improvements he experienced after treatments and participating in the stroke group;
- *Gerald used multimedia to communicate to others about his life* Gerald is a stroke survivor who cannot use one side of his body and who has severe aphasia. The IT worker in the Centre created a way for Gerald to control a video camera and Gerald, in collaboration with his partner, Vanessa, produced a video of his holiday in Liverpool that changed people's perceptions of him.

The Centre manager described the impact of multimedia on Mitch in the following way:

Mitch ... has got quite severe mental health problems, challenging behaviour and I think this is the only place he hasn't been banned from in Camden really but we're quite accepting of challenging behaviour... Well Nick's given him a lot of one-to-one time... He's learnt an awful lot around multimedia and UK Online and contacting people that he had lost contact for like 20 or 25 years, some with some unfortunate stuff because he's learnt about deaths of people... so it has its...emotional downside if you like but I just think he's found a bit of self importance, self worth if you like. I think too many years of people telling him he couldn't do things.

She described the impact on Gerald in the following way:

The most startling for [was Gerald who] has very severe aphasia who normally would only say yes or no, the occasional word... and was quite isolated within the centre apart from with the staff. So the only forms of communication he got really was from staff members. All my staff have been trained in picture speak, which is communication talk for people with aphasia... We saw multimedia in a way as a bit of an extension on picture speak... But multimedia was almost like one step on from this so we did a lot of work with Gerald around... [The IT worker] managed to come up with some contraption where Gerald could strap the camera to the side of his wheelchair. Gerald is paralyzed on one side... but we were determined that he was going to actually shoot the film. Anyway he took the camera away on holiday with him for a week. He probably drove his partner insane but, you know, and then he came back and of course he was in the main dining room and he said to Keith and I, well indicated that he wanted to show us the... what he'd done on holiday and Nick sent up the Apple and of course within 3 or 4 minutes we had a crowd around us like nobody's business. And Keith made some silly remark about oh where is that Gerald then, you know. He said Whitby or whatever. No, he'd say. Sorry Gerald, you know, where are...? Liverpool. And everybody went... Liverpool. Right. But what it did, believe it or not, was not only was it good for Gerald because Gerald was like the star, you know, it's like I've done something in this centre that nobody else has done. You know, I may have had a stroke, I may be paralyzed, I may have no speech but they didn't take a camera off for a week. He got Vanessa to film him in the bath. It was the funniest thing ever.

While the actual profiles were important products, there were important benefits to the process. In some cases, involvement in profiling stimulated interest in related activities. For example one

participant rediscovered his interest in photography. For others the profiling process provided an interesting activity. The manager of the centre felt that even individuals who did not directly participate in the Project indirectly benefited:

It's benefited all service users in the respect that they see other people interested and involved. So even those that don't get involved I think if you see it going on it's quite a stimulating environment, even if you are the 97 year old that's sitting in a chair having a doze. I don't think that really matters. And what everybody accepts and even expects now is that on any given day there can be 3 or 4 people walking around with a camera... taking shots of this, this and this so... So yeah I think even if you spoke to people out there and said do you know anything about Acting Up? Even if they said no, if you said do you see people going around taking photos, oh yes they do that all the time. You know? So yes I think it has benefited even the people that haven't been involved in it.

She noted the ways in which project had changed the level of activity in the Centre particularly on Tuesdays, the day on which Nick the project worker came in provide support and assistance:

It's [Acting Up] changed Tuesdays beyond all recognition. I always get quite frightened of going out the door on a Tuesday because you never really know what you're going to go into. I suppose it's been a little bit of a launching pad for several projects and members of staff have got interested in totally different ways so... We're working quite closely with Beckford School now on the inter-generational project. But of course they came on a Tuesday so straightaway the 2 projects dovetailed. So with the children working with the adults that were working with multimedia we are also working with service users with aphasia that were using multimedia because they didn't have the power of speech de da, de da, de da and like all of a sudden Tuesdays is crazy. You know you've got that all morning, you've got KOVE in the afternoon and then multimedia's part of KOVE and so on and so forth. So I was feeling quite left out of all of this.

This activity has a positive benefit for the individuals involved and the Centre.

Multimedia:

- provided an *additional activity and resource* within the Centre and increased the awareness of the value of new technology amongst users and centre staff. For example one member of staff indicated that while he was initially very sceptical and swore he wouldn't appear on video or touch a camera he felt it had '*taken the fear out of the centre*' and was particularly valuable in changing attitudes to '*some awkward customers*';

- supported *engagement and interaction*. There were a number of participants whose levels of engagement rose and typical staff comment was 'so and so was always isolated and sat alone but now...' Many staff and participants felt that multimedia was 'fun' and enable them to come together in an enjoyable activity;
- enabled participants to *engage in activity in a positive way* – showing enthusiasm and developing a creative process. One participant we talked to said he had been homeless and in and out of institutions over twenty years and the project had 'changed his life around' as it expanded his life. He had learnt to use the computer, video camera and make films. He had collaborated with Acting Up on making a film about disabled people's access to the Underground called 'Down the Tube';
- *increased interaction between individuals*, for example two participants collaborated to make a film on wheelchair access to public transport by filming the ways in which they could get to the West End on a bus. In doing so they had collaborated on the filming and editing and told us that they were trying to get Channel Four and Michael Palin interested in their work. They were working on a video letter for Michael Palin to show him what they were doing;
- helped individuals *increase their confidence*. One of the participants we talked to indicated that he used to run his own company but his ill health had undermined his self confidence. He felt that participating in iContact was enabling him not only to express himself but was providing him with a 'handle' to bring back his confidence;
- had a *visual impact* on the Centre especially in the UKOL room which was transformed, its walls are covered with large photos of the group participants and its computers were actively used.

Many-to-many communication

Many of the individuals who used the multimedia to develop their own outputs also worked as a group to produce various products designed to be broadly communicated. For example:

- films on mobility and access issues; a walk to the Kingsgate centre, using public transport and access to toilets on Kilburn High Road
- an On-line magazine provide space online for participants to report on personal activities and campaigns.

In the Kingsgate Centre, the Manager has used the resources provided by Acting Up to develop group work with a group of stroke survivors:

My stroke project had been used by the Home Care Partnership Project. We did a sort

of mini evaluation, monitoring the evaluation around the people in my stroke project and what they expected from Home Care... I asked John Ladle to come in and talk to the group to see how they would feel about multimedia. And I suppose they were a little confused as how we were going to use it and I said at the start that it had to be used how they wanted it to be used, not how I wanted it, not how John wanted it, it was how they wanted it to be used... We are having fun with it but we've had one session where it was very emotional, people relived the time of when they had the stroke, how it had left them, a lot of tears, a lot of group hugs, a lot of... But it was good... It was the right place to let go and feel that it was alright to let go. John thought those bits might need to be edited, that people wouldn't want them to be seen but when we actually played it back to them 2 weeks later they were happy for it to stay... to stay as is, you know?

The work with the stroke group developed out of work in the Kingsgate Centre and the overall nature and purpose of the multimedia work was negotiated with the group and developed as the group reflected on the material produced. Acting Up enabled KOVE to use multimedia as part of their group campaigning activities. KOVE had already had established experience of representing users' views and the initiative for using multimedia came from the KOVE coordinator:

When it became apparent that the iContact project could provide support to amateur film making, the KOVE coordinator found some people within the KOVE team who were prepared to take on the active role of interviewing and so on. They'd already broken some somewhat new ground walking up and down Kilburn High Road and either spying on toilets or actually, you know, interviewing shop keepers and managers and so on about what facilities they had. (Community Development Consultant)

KOVE used multimedia to express their collective views. The products include:

- *10 key things* which support workers should do round this house The group wanted to talk directly to camera and this was then edited by Acting Up and amplified with contextual materials;
- *Talking heads video* this is essentially training material based on the personal experiences of KOVE members.

The method of producing such material does not in practice differ substantially from the method of producing profiles. Both rely on individuals recording material, often narrating their experiences and this is then edited to produce a narrative. The main difference is in the purpose of and audience for that narrative. In the case of the profile the subject chooses both the basic

theme of the narrative, for example his or her life or his or her experiences of care and also chooses the audiences, i.e. they can show or send their profile to their friends or family or even chose to make it public by placing it on the web. In the case of campaigning or training material, the subjects make their experiences public. Their narratives are designed to challenge the attitudes and behaviours of others and to make the viewer aware of and change their perceptions of people with disabilities by helping the viewer to understand the complexity of their everyday lives and the type of help and assistance that is most effective to enable individuals to live as independently as possible. In such many-to-many communications an individual participant will inevitably lose control of part of the process. While they can exercise a veto and withdraw they do not fully control the selection and construction of the narrative nor can they decide which audiences see it. Thus the provision of consent has to be more formalised and there have to be clear decision points. An individual can add to or change their personal file. It is always a work in progress, a personal private document that its owner can chose to make public. In contrast a training video is a 'finished' product and a public statement.

The Community Development Consultant emphasised the importance of ownership and endorsement from those involved in such material. He described the involvement of one participant in the following way:

from the material I've seen where she's been filmed watching the film of herself she's got those real signs of both ownership of the material and the belief that it should be used elsewhere to talk to others. So she really is quite a strong protagonist.

The Community Development Consultant noted ways in which the material produced in this way is different from traditional promotional and training material that is often based on actors' role playing and how this is likely to have a strong impact on those who view it:

There is an interesting thing about how people react to material. So for example whenever we watch the Marion film, you know the original Marion film, very slow paced etc, lovely stuff, you can see that people are reacting very differently to it and have different things to say, you know? Some people get very angry because they think that she's being very badly treated. Other people are mesmerised by her composure and how she's dealing with life.

The production of such films has enable KOVE to influence the development of home care services in Camden. For example John Miles in his evaluation of KOVE's Home Care Service Partnership commented:

Through its film-making KOVE has empowered its members and volunteers and by establishing the Sub-Group has placed them at the centre of an exchange of trust and ideas. This role of the volunteers is recognised by providers and service-users alike. The films also assist the process of holding difficult issues at arms-length – ‘cool contact’: One of the agency managers explained to the evaluator how she has used the material not just to shift the thinking of care-workers but also that of their office colleagues. (Miles, 2007, p. 18).

He also commented on the positive reaction of service providers to KOVE's material

Let's try to illustrate this. The Sub Group has watched one of the service-users making a contribution on film. In response one of the provider managers has spoken at length. She talks eloquently about the importance of ‘the little things’, and how much of the damage arises from the failure to attend to them. You can see the service-user present pulling a face – perhaps because, although the manager doesn't intend it to, the use of the phrase ‘little things’ (she means ‘crucial details’) appears to downgrade the users’ concerns (Miles, 2007, p. 18)

It is important to note that not only did the Project enable some participants to move from individual to group work, there were also opportunities for individuals who worked in groups to develop individual projects. For example the Community Development Consultant described the case of one KOVE activist who decided to concentrate on a personal project:

a founder member of KOVE who features quite strongly in the [film]... She's not part ... of ... the people who go out and make the films because she's not well enough but she's a founder member of KOVE and she participated a lot in giving her views about Home Care and in encouraging other service users. But towards the end of the process, I think it was a sort of mixture of pressure, self consciousness, etc, she decided that she no longer had the energy to do the campaigning... So she has actually in effect resigned from KOVE and committed herself to the new project of making a sort of online journal about life and users in the centre.

6. Final comment

The multimedia project involves the use of sophisticated technology to enable individuals and groups to express themselves. This approach has a number of important advantages. It is:

- *flexible*, can be used in a variety of ways, for example as a personal private work in progress or as a definitive public statement;
- *person centred*, responsive to personal interests, skills and enabling individuals to thrive i.e. learn new skills, express themselves, influence others, enhance communication/memory outcomes;
- *empowering* building individual and group confidence. It can be used one-to-one or many communication but provides opportunity for group development; many-to-many communication and are a key to building social solidarity and creating inclusion.
- *effective* producing high quality material which effectively gives voice to and empowers those who created it and has a strong sense of authenticity and emotional impact increasingly the likelihood that it will affect the feelings and behaviour of viewers.

7. References

Camden (n.d.) *Older people's recommendations to make participation easier: In our own words*, The London Borough of Camden, London.

Miles, J. (2007) Evaluation of the Home Care Service Partnership (HCSP) 2006 – 2007, Kilburn Older Voices Exchange (KOVE), May 3rd 2007

Opaaluk (2007) Members' newsletter, Older People's Advocacy Alliance, www.opaal.org.uk

Plummer, K. (2001) *Documents of life: an invitation to critical humanism*, Sage, London.

UKOLCamden (2006) Application for UK online Social Impact Demonstrators Grant Funding 2006/8, UKOLCamden.

Appendix

Key Outputs from the iContact project

1. Multimedia - DVDs

With KOVE (Kilburn Older Voices Exchange

Home Care Service Partnership Training Materials 1.

'Margery's World' and

'Main Points'

- First Meeting
- Care Plan
- Lifestyles
- Good Communication
- Working Together
- Time Keeping
- Good Care Skills

Home Care Service Partnership Training Materials 2.

'Diverse Voices in Homecare' (users, carers and home care providers from black and minority ethnic communities and family carers for people with dementia tell their stories)

Home Care Service Partnership (documentation showing the development of joint working in the making of the training DVDs).

'Crossings' (Older people talk about and demonstrate the difficulties of being a pedestrian on our busy streets).

With Kingsgate Resource Centre, Camden

'Access to Life' (DVD of transport and mobility issues featuring users of Kingsgate Centre). 2006

'Intergen' – (a record of two projects with users of Kingsgate Resource Centre and Beckford School, Camden). 2007

Individual multimedia profiles (The Kingsgate Multimedia Group – individual multimedia profiles produced with members of the group). 2005 - 2007

'Kingsgate Stroke Survivors' Group' (documentation of the group's activity) 2007/2008.

With the Hillwood Centre, Camden

'All Here Together 1'. (DVD sampler of the celebration of diverse cultures at the Age Concern Camden's Hillwood Centre in 2006)

'All Here Together 2' (Second year of celebration with commentary from centre manager in 2007).

With the London Borough of Camden

'Camden Over 50s Festival' (DVD to facilitate consultations with groups of older people during the Camden Over 50s Festival, 2007).

With OPAALUK (Older People's Advocacy Alliance)

'Three Voices' (2007)

(a DVD that presents the experience of three people using advocacy services and a range of comment from older advocacy activists and service providers).

For information on the availability of multimedia documentation from the iContact project, please contact John Ladle, Acting Up Director – john.ladle@acting-up.org.uk

2. Multimedia – online

iContact Online Magazine (featuring older people's profiles, stories and activities, and hosting video news from other organisations).

the iContact magazine can be accessed at www.acting-up.org.uk/icontact.htm

3. Reports and Articles

Alaszewski, A. & Alaszewski H. (2008) Empowering older people through technology: Academic Review of the i-contact Project conducted by Acting Up and funded by Big Lottery, 1st January 2005 – 31st December 2007, Centre for Health Services Studies, University of Kent, 2008

Camden (n.d.) *Older people's recommendations to make participation easier: In our own words.*

The London Borough of Camden, London. 2006

Opaaluk (2007) Members' newsletter, Older People's Advocacy Alliance, www.opaal.org.uk

Miles, J. (2007) Evaluation of the Home Care Service Partnership (HCSP) 2006 – 2007, Kilburn
Older Voices Exchange (KOVE), May 3rd 2007

Miles, J. (2008) '*Social networking in real company: multi-media, 'community hubs' and the
engagement of older, disabled, people'*

The articles and reports listed above can be downloaded from www.acting-up.org.uk

