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A Witness Seminar

14th July 2023

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Introduction

Towards an 'Ordinary Life'

In 1980 more than 50,000 people with learning disabilities in Britain still lived in a long-stay hospital, a model of care first developed in the 19th century for people seen as unfit to be a part of mainstream society or unable to care for themselves.

Responding to successive scandals and inquiries that exposed the cruelty and neglect of many people living in these institutions, activists developed and promoted an alternative vision and innovative model of care. The term 'An Ordinary Life' was taken from a pamphlet published by The King's Fund (1980) that promoted supporting people with learning disabilities to live in ordinary housing as a radical alternative to hospital care. Over subsequent years this vision influenced the work of numerous agencies, public and third sector, involved in providing support to people with learning disabilities. The work of local and national campaigners led to its eventual acceptance as a national policy in the White Paper Valuing People (Department of Health, 2001).

Witness Seminars

Historical perspectives are vitally important to effective policymaking and the development of services for the public. A failure to learn from the past often leads to bold claims about 'new' ideas and 'radical' reforms which invariably just reinvent the wheel and fail to avoid past mistakes. Over recent years 'witness seminars' have provided an important means to try to improve our understanding of key events or a particular period of policy development within the bounds of living memory. Witness seminars typically bring together researchers, policymakers, people undertaking or affected by policies and other key individuals that have studied or played a more direct role in the development of particular policies, new social movements or service innovations. Contributors address a particular subject from their own perspective, drawing on their memories or records of the time.

The Supporting Innovation in Adult Social Care (SASCI) Project

Innovation or doing things differently is often seen as a solution to problems. Adult social care might seem to be an area where new approaches will naturally flourish (with competition between providers, different people paying, choice over types of care and provider and so on). Yet, while there are many innovations and good evidence that some benefit people using care services, they do not always spread rapidly and often do not become mainstream.

Compared to other parts of society, little is known about innovation in social care and why good ideas spread or otherwise. Many organisations and people offer to help with innovation but not much is known about what they do and how they do it, or what works. The SASCI research programme is drawing together experiences of innovating or changing things in adult social care to let others know what might help.

As part of the programme this webinar considered the key themes of:

- The importance of evidence and values.
- The roles played by campaigners and other key influencers.
- How and why innovations spread and are sustained.

Acknowledgments

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Participants

SASCI Team Members

Gerald Wistow (Chair)

Chair of this event was Gerald Wistow, Visiting Professor at the Care Policy and Evaluation Centre (CPEC) at the London School of Economics (LSE). He has researched and published extensively on a wide range of health and social care services including those for people with learning disabilities. Gerald has also served in a variety of advisory roles supporting national policy and practice developments.

Carl Purcell (Organiser)

Carl is a Research Fellow in the NIHR Policy Research Unit in Health and Social Care Workforce, having previously worked in local government. His research interests include the development and implementation of health and social care policy across Children's and Adults' services. He is a committee member of the Social Work History Network. Carl leads the King's College London work in the SASCI project.

Witnesses

To begin with we heard from four people with lived experience who told us about their 'ordinary lives'.

Ajay Choksi

Ajay Choksi is a trainer and co-researcher at RIX Inclusive Research, University of East London (UEL). He joined UEL in 2007 as a technical assistant. Ajay has a strong interest in technology and enjoys exploring how new technologies can help people who have learning disabilities.

Baljit Kaur

Baljit Kaur is a co-researcher at RIX Inclusive Research, UEL. Baljit joined RIX during the pandemic and has been studying how technology has helped people stay connected with others during this time. Baljit is passionate about helping and supporting others, particularly those who speak different languages. They are interested in finding ways that technology can assist people from diverse backgrounds.

Roselyn Weinberg

Roselyn Weinberg is a co-researcher at RIX Inclusive Research, UEL. She began working with RIX on various projects in 2006. Roselyn has been involved in numerous training and research initiatives. She is a strong advocate who actively represents the rights of individuals with learning disabilities in different committees and boards. Roselyn is passionate about promoting inclusion and creating easy to read and easy to understand information.

Satvinder Kaur Dhillon (also known as Kiran)

Kiran is a highly skilled co-researcher at RIX Inclusive Research, UEL. With a passion for graphic design, she has made significant contributions to projects, including the Digital Champion Network. Her expertise in designing visually appealing and accessible websites has played a vital role in creating inclusive experiences for individuals with disabilities. Her commitment to promoting accessibility and inclusion showcases the powerful impact design can have on enhancing digital experiences and reducing inequality.

Ajay, Baljit, Roselyn and Kiran were supported by Gosia Kwiatkowska, an experienced researcher and co-director of RIX Inclusive Research at UEL.

Ann Shearer

Ann was a journalist on The Guardian when she first learned of the often appalling conditions in what were then still called 'mental subnormality' hospitals. This led in 1971 to her co-founding the Campaign for the Mentally Handicapped, later called Values into Action (VIA). This worked for the replacement of hospitals with community-based services based on principle not pragmatism and disseminated international examples of good practice. It was also the first organisation in the UK to consult people with learning difficulties and publicise their views. While VIA in England closed in 2012, VIA Scotland is still going strong.

Derek Thomas

Derek was a psychologist based at Northgate Hospital in Northumberland who played a pivotal role in helping to provide a coherent philosophical foundation for a new model of caring for people with learning disabilities, including through his membership of the Jay Committee (Committee of Inquiry into Mental Handicap Nursing and Care, 1979) and his authorship of the influential paper 'ENCOR: A Way Ahead' published in 1978. He also chaired the working group that informed the An Ordinary Life publication (The King's Fund, 1980). Derek later became Director of the National Development Team.

Bob Tindall

Bob has worked with people with people with learning disabilities and their families since 1976. Originally based in a long stay institution, Bob has, over the decades, been engaged in the development, maintenance and furtherance of opportunities for people to live an ordinary life, with support where needed, irrespective of disability. Bob's professional background was in senior leadership roles for several not for profit/ charitable organisations focused on learning disability and autism.

David Towell

David was born into a family where his sister, Patricia (Pat), had acquired profound impairments through childhood illness. His arrival was the occasion for her admission to institutional care. Much of his adult life, especially for 20 years as a leader at The King's Fund's 'Ordinary Life' programme, was addressed to changing this situation for Pat and everyone else excluded from equal citizenship. He now directs the London-based Centre for Inclusive Futures. David has written recently about the Ordinary Life initiative (see <u>Towell</u>, 2022)

Jan Walmsley

Jan is a historian of learning disabilities based at the Open University. She founded the Social History of Learning Disability Research Group in 1994. This Group pioneers history by, with, and for people with learning disabilities, their families and those who work and support them. Her particular interest in the Ordinary Life movement is on how it was spread and sustained to make it one of the most significant social movements of the late twentieth century.

Seminar Transcript

Towards an 'Ordinary Life'

King's College London and online, 14th July 2023 (11am-1pm)

Gerald:

This webinar is looking at historical innovations in social care. We're exploring a particular one which is further from the present day than <u>our other previous two</u>. In that sense it has the longest span of time to have been sustained and for its results to have been demonstrated or not. I think many of us will feel that its results have been demonstrated in a wide range of different circumstances.

I'm Gerald Wistow. I'm chairing this event. I'm a Visiting Professor at the LSE and I am part of the <u>SASCI</u> research team. We have a panel of people today as witnesses, a large number of whom were in at the beginning of the Ordinary Life initiative. This initiative was shaped by information about the kinds of services that were being provided for people with learning disabilities in the 1960s and 1970s and who created what became a social movement to secure very substantial change.

From the point of view of our SASCI research project this was an innovation which deliberately aimed not just to repair something that was wrong or make it a bit better but to actually transform it and replace it with something that was substantially different from what had gone before. In that sense it's a kind of innovation that maybe people talk about but such examples of transformation which are sustained over a long period of time are not always easy to find. So that's why we were interested in this innovation, and that's why we've invited the people here because of their involvement in initiating it, in developing it and getting it established on the floor, making it real if you like.

Just a note for everybody that there is an opportunity for you to add questions in the chat and we will be seeing those questions as they come in. We will not be able to answer all but we will choose some of them to address in the final session and so I hope you will put in your questions. They will also be very useful for us as researchers in terms of getting a wide range of responses to points that are made during this webinar because we will be analysing your questions and comments afterwards.

Without more ado I'd like to introduce the first members of our panel who are a group of co-researchers from the University of East London (UEL). They are going to start us off by showing what it means to live an ordinary life in England today and to set that as a starting point for us to then work backwards and see where we have come from in the last 50 years and what lessons we can learn in terms of embedding innovations as a result of the work of the Ordinary Lives initiative. So Gosia, can I ask you to introduce your session and your colleagues?

Gosia: Thank you very much. So yes, we are a team of researchers from the

University of East London and I'm here today with Ros (Roselyn), Baljit, Kiran and Ajay. Thank you very much for inviting us to do this presentation. We're very honoured. In preparations for this event we started thinking what is ordinary life and ordinary, what does it mean? What does it mean to us, ordinary?

Kiran: Just a simple life.

Gosia: A simple life, yeah.

Ajay: And boring and similar.

Gosia: What were some of the words that you sort of...?

Baljit: Same.

Gosia: It's same. It's similar. It's boring.

Roselyn: And being able to do the same things as everybody else can do.

Gosia: Being able to do the same thing as everybody else. So even though it sounds a

little bit boring and simple we actually felt okay, it's about having a life like everybody else. So we then thought about okay, so what are the aspects of our everyday life? And so if you go to the next slide please? Thank you. What

were some of aspects? (See Appendix 1).

Ajay: 'Simple moments'. It's about what we do.

Kiran: Being present with everyone.

Gosia: Being present, yeah, with everyone and everywhere.

Baljit: Finding joy in many small things.

Gosia: Finding joy in small things. And what else?

Roselyn: Relationships.

Gosia: It's about different relationships but it's also about?

Ajay: Personal growth.

Gosia: Personal growth and our learning and participating and moving forward all

the time. So then we looked at our daily lives and we collected different images for our 'simple moments', so we can have a look at those 'simple moments'. So Ajay what did you select here for your 'simple moment'?

Ajay: Right. At the moment I selected a 'simple moment' I chose, I went to the

work placement in university, the Rix Centre, I work in the office now and I

work at home remotely now, both of them to date and today now.

Gosia: So the picture you selected shows this?

Ajay: Yeah.

Gosia: And next please, and what about you Ros? What were your 'simple

moments'?

Roselyn: Well for me I work from home, which is the one thing I had to get used to

during lockdown. And the other thing is learning how to use an air fryer.

Gosia: 'Simple moments' in pictures that you had from your home.

Roselyn: And that is just some of the stuff that I've learnt how to cook in my air fryer.

Gosia: Yeah, okay. Next slide please?

Baljit: So this is me learning. I like watching films as well. Yeah. I like to watch

movies and just chilling out, so yeah.

Gosia: Thank you. And Ajay can you tell us what is Multi Me?

Ajay: Yes. Thank you. The Multi Me it's a similar easy thing to use, it's online for

learning disability and disability.

Roselyn: I do have a Facebook account and I see what people put up and not

appropriate.

Gosia: So you have this online safe Multi Me, okay, and you learn how to use it as

well. Kiran, what about you?

Kiran: Basically I go to centre with another colleague in the morning, in the

afternoon I do my nails, which I love doing, keep neat and clean, and actually now I've donated my hair to people, you know, to kids with cancer and yeah.

Gosia: So that is a 'simple moment' sort of picture, can we go to the next slide

please? And then we talked about other parts which is being present in the community and see those 'being present' sort of moments that we've selected.

So Ajay?

Ajay: So 'being present' I was doing a workshop to train other people, talk about

my work with technology, digital skills.

Gosia: Thank you. And next please? So here we have Ros. What about your 'being

present' in the community?

Roselyn: Basically... I also I'm a member of a group that does an awful lot around

sensory objects and that is a picture of me, the bottom picture is of me actually having afternoon tea on our patio where I live and that is... help me.

Jan: A workshop about the history of intelligence.

Roselyn: Thank you Jan. A workshop with Jan and Gosha and Kiran about

intelligence.

Gosia: Thank you. Next please? Kiran?

Kiran: This is me. Basically on Tuesdays I go cycling in Queen Elizabeth Park,

which is so good, really fun. And in the afternoons I go bowling and I always win. [Laughter]. And I love going trips with Ros to do things like learning what happened years ago about, you know, how they got tortured and everything. And working with Rix team is so good because you get paid.

Gosia: Brilliant. Next please? What about you Baljit? What were your 'being

present' moments?

Baljit: I would probably say I was doing Multi Me and doing the thing about the

managing, ...

Gosia: The Digital Financial Inclusion Project isn't it at the university?

Baljit: Which one?

Gosia: The one, the big one.

Baljit: Ah yeah... So I've been in quite a few projects we've been doing, so that

keeps me busy.

Gosia: Okay. Shall we go to the next one? So the next one was 'finding joy in small

things', so what were some of the joys?

Ajay: So what I found 'joy in the small thing', I was enjoyed with my colleague

doing Christmas celebration. I went to the gym and health dietician and I using a technology, digital jigsaw puzzle activity, which is very enjoyable.

Gosia: Okay.

Baljit: Having to see my flowers grew so fast, grew probably months ago. It was nice

to be able to see that grow so fast and ... very short and with, uh, yeah, ...

disaster having it done and a new shirt.

Gosia: Yeah. So that's the 'simple moments of joy' for you. Next one please? Oh

that's (slide showing) moments of joy, yours?

Kiran: This is me in Australia. That's a bloody long flight. [Laughter] It was very

good and it's very good. And this Pandora (shop) is very good there, I prefer it there than here, and basically that picture shows you basically the receipt, we spent so much money, \$500 just on charms and bracelets, and I was like "how much money did you guys spend? Oh my God!" So yeah, and these tattoos I got was when my brother died. And yeah, and I love cooking. I love

cooking my lamb curry.

Gosia: Fantastic. Okay. So we go next one, so your 'moment of joy'?

Roselyn: And this basically is me working from home but that is a more recent picture

that was took last Sunday because we had a party in our communal lounge

and oh yes favourite colour was pink and that is my flat.

Gosia: And so the next one was 'relationships', so our life relationships are really

important so we have lots of pictures of different sort of relationships. So

Ajay?

Ajay: Yeah. So I had quite stronger with my family now in the relationship and with

those involved with me, but unfortunately my father is passed away since two months ago, it was quite sad and quite upset now, I think he's serving the God now, rest in peace now, and I miss him so much and I just think about with

him now. So that is, um, yeah, moment, yeah.

Gosia: Family and relationship?

Ajay: Relationship, yeah.

Gosia: Next please? Baljit?

Baljit: Where do I start from? we build a nice relationship together and we get along

good.

Gosia: Next please?

Kiran: This is my granddad or my dad's dad and my mum's dad in the blue picture

and like they're my family and I love them and if anything happens to them I

will die, I'll kill them, I'll kill the person.

Gosia: Hopefully that won't happen.

Kiran: Because I'm really like emotional. And that's my best friend, on the top and

that's my little nephew, he's going to be 3 years old soon and I'm very, I support him a lot and I spoil him a lot. I'm auntie, so course got to spoil him.

Gosia: Of course. Next please?

Roselyn: Again that is, well the first picture is, the first picture was took when I was

doing all the work for the Museum of London. That is me with my carer, Lee, and all this is just some of the stuff. That is a recent one because on the Tuesday which I find so brilliant is that I peer support with the Multi Me

group in another day centre.

Gosia: Yeah. Okay. If we move on, so the last one is about 'personal growth'. I think

we can just go through the slides without speaking so people can see because we're running out of time. Some people can just click and have a look... Yeah.

And that's what we'd like to finish on.

Roselyn: All that it really leaves us to do is just thank you for letting us do this

presentation.

Gerald: Thank you so much all of you for your contributions and for just making real

what it is we're talking about. What strikes me immediately from those slides are two things. 1) You're out in public, you are sharing in the ordinary life that all of us do, and 2) you've also got incredibly full lives, almost exhausting to

look at, right, really enjoying yourselves.

David: Didn't look boring to us. [Laughter]

Gerald: I was just going to say that. I don't know where the idea of boring came from.

we're going back to. We're now going back to the 1960s, we're going back to Ann Shearer who's sitting next to me who wrote the first article that was ever published about life in what we then called mental handicap hospitals (Shearer, 1968). That kind of lit a spark I think it's fair to say which other

Thanks so much because that sets the backcloth or the foreground to where

people turned into a burning fire but you had a continuing role in it. You were a journalist who wrote an article for The Guardian (in 1968) and you then had a role in developing a campaigning pressure group which made a major contribution to closing the old hospitals and developing new patterns of

living, a sample of which we've just had today. So Ann, welcome.

Ann:

Thank you very much. I must say it was wonderful to see your presentation, thank you, because I'm going to take us back to something very, very different. In 1968 I was what was called Welfare Correspondent for The Guardian and there'd just been a big fire in a mental hospital in Shropshire and forty old ladies had died because their beds were in the corridors and they couldn't get out. Of course there was an outcry. In response, the aunt of a little boy called Alexander who was living in Harperbury Hospital in Hertfordshire, wrote to The Guardian's editor, describing conditions in his ward and asking why there was never similar concern about the state of 'mental subnormality' hospitals. So I contacted her and asked "Can I come and visit Alexander with you?" and she said "of course you can, good". And it was just as bad as she had indicated, in fact worse, because these were real children, very many of them, banged up in a single ward, half of them with no clothes, or dirty clothes, dirt everywhere, and one poor young nurse who didn't seem to have a word of English, trying to clean the table with a dirty dishcloth.

And I returned to the office I remember in a complete state of shock and I told the news editor and he just said "Are you sure?" and everybody who heard the story said "Are you sure?" because nobody knew what these places were like, they were entirely closed institutions. So my article took a while to get published, I had to go back to the hospital, of course, and get their side of the story; then the article had to go to and fro to the lawyers. "Are you sure? Are you sure?" Eventually it was published, 'Dirty children in a locked room: A mental hospital on a bad day' (Shearer, 1968). And after all that it was a bit of a damp squib. The only people who wrote to the paper in response were people you'd expect to do so: the director of Mencap saying "Yes, yes, we need some more money for these hospitals"; a famous sociologist, Professor Kathleen Jones, who was working in this field, said "I'm astonished to read this, I've never seen this in all the course of my research"; relatives of people in hospital either supporting or deploring what I'd reported.

But then the hospital took The Guardian to the Press Council, which is the regulation body to make sure newspapers tell the truth, claiming that the article was irresponsible, it was untrue. Eventually the Press Council agreed with the hospital and The Guardian printed the judgement as we were bound to do. But, God bless the editor, he very unusually reprinted the article. And that opened the story again. Then people started being interested because it was a nice scandal and so people wrote in either for or against, evoking freedom of the press arguing whether such articles were or weren't in the public interest.

But personally I got a lot of letters either vilifying me or praising me; nurses would phone from hospitals' phone boxes saying "I can't, I daren't give my name but do come and see our hospital, it's even worse" and then people from

Social Services phoned up and said "Do come and see what we're trying to do to support families, we're very much better". And however unwillingly I felt, "Well I'm in it now, I can't get out of it", so I kept on trying to raise the issue one way and another. But I think it would have just been a little bee in my bonnet had not two other things happened. One was the report on Ely Hospital (Department of Health and Social Security, 1969) followed then immediately by a great number of others which showed that we weren't talking about one dirty ward, we were talking about a complete systemic failure, which involved 65,000 of our fellow citizens. This seemed to me just an abuse of basic human rights and how can you turn your back on that? And the other decisive thing was the government felt obliged to act, it was shamed into acting, and Dick Crossman who was 'my Minister' in that he was in charge of the health and welfare areas I covered, made this something of a personal crusade and took on his reluctant civil servants and pushed. And, I'm probably running out of time, am I?

Gerald: One minute.

Ann:

Well one thing led to another and eventually a group of us got together and started the Campaign for the Mentally Handicapped (CMH). And I just want to quickly state the principles on which we were based right from the beginning: people with learning difficulties have a complete human right to share in the ordinary life of their community; to this end the hospitals should be closed, we never deviated from that, and replaced by comprehensive community services which should be integrated for ordinary provision local to where people and their families live; there should be no separate services for the most severely handicapped and then, importantly, people with learning difficulties and their families should participate in the planning and running of services. And the thing I'm proudest of I think, is that in 1972, just a year after we started CMH, we held the first conference ever in the United Kingdom for people with learning difficulties to talk about what their lives were like. Some of their stories were very sad, and what they disliked and hoped for was just so ordinary. I was lucky in that I had no connections with any other special interest group: I had no family member with a learning difficulty and so what I reported could not be seen as special pleading. I think that was enormously important, because how could the readers of The Guardian or wherever I was writing deny such utter simplicity? 'All I want is my own place, my own kitchen, with the food I like to eat.' How could you deny that, because it was so modest? Thank you.

Gerald:

No. Thank you very, very much. That's great. I'm really interested in you saying that it might have stopped had there not been the reports on Ely and the other hospitals because is there not the contrary argument that those reports might not have had any impact without the media beginning to get across the conditions in long-stay hospitals to a bigger audience?

Ann:

Interesting isn't it? I think perhaps, you know, each was feeding the other in a way. The Civil Servants did sit on the Ely report for a year. So if there hadn't been a bit of outside push perhaps the politicians wouldn't have felt compelled to publish.

Gerald:

David?

David:

Well that's really powerful, especially contrasted with the stories the group was telling us about your lives now and it tells us a bit about why we thought things had to change. I think I did communicate this wasn't easy. Ann was very unpopular for a while.

Ann:

Yeah.

David:

People were abusive to her and to The Guardian actually.

Ann:

And people were abusive to CMH and the director of Mencap wouldn't acknowledge me on the street.

David:

There was quite a lot of denial around. We didn't want to know that places called hospitals were actually damaging people and so there was a period in which through the inquiries and for other reasons the public started to discover that all wasn't as they imagined it should be in a hospital system. It was journalists like Ann and people who were prepared to blow the whistle that led to these inquiries and made this public knowledge. I think it was really good we started with Ann because that was a critical turning point in raising awareness that we couldn't carry on as things were.

Gerald:

And we might move along into the discussion that you and Derek Thomas are going to have. Derek, you were working in a long-stay hospital at that point?

Derek:

Yes.

Gerald:

You were a Psychologist?

Derek:

I'd just become a Psychologist. The people in my university decided I should stop trying to learn and read Ancient History and that I might go on to a Psychology course, so thank you Professor Brittain for steering me in that direction.

Gerald:

What I want to ask you is when you were working in a context where there'd been a lot of public exposure of poor conditions, what was the impact of that on people working in the hospitals?

Derek:

Well the hospital had gone through some transformation in terms of buildings so the centre's response to some of these things was to approve new buildings and some changes had taken place, for example in terms of schools being established in these long-stay hospitals and a new profession, teachers, were now also looking at what we were doing for and with children in school and representing children if the staff working with them were not up to scratch. It was kind of bumping along this place but I, as I say the professor really, really helped to direct me, decided I wouldn't make a good librarian and that there was something else beyond me. So I went on a placement to this hospital which is in Northumberland and one of the first people whom I met was a young man with learning disability from an adjacent hospital. I was meeting people before I took up my appointment and this young man whom I spent a whole afternoon with was very clear about what he wanted and what he needed. What he wanted was to continue with his education and he wanted to live as part of the community and he wanted a life, and his final point, it was a long conversation we had, he said "please can you do something about this? I know it's difficult and I don't expect these things to happen overnight". So that was a really powerful experience for me.

Gerald:

Can I just pause on that moment? Just for a minute just to make a point and then I want to introduce David Towell so you two can have a conversation about a number of issues. The really important point you made there, which many people actually are not aware of, is that at least one and I think perhaps both of the first two hospitals built by the National Health Service (NHS) in the 1950s were what we now say were learning disability hospitals but were mental handicap hospitals, we were still building such hospitals then. So it wasn't just that the conditions of the existing hospitals were poor and needed remedying, so we had to change the whole model of care because people were still thinking: hospital, renovate, improve, build new and perhaps build smaller, but the hospital model was still at the heart of what we were talking about in the years after Ann wrote the exposé that she did. I'm now going to ask David Towell and Derek Thomas to discuss in particular Derek's contribution to beginning to put a framework around what he learned from that person he met in the hospital right at the beginning and how in many ways that set the foundations for the kind of lifestyle that we began this conversation with. So I've introduced Derek. Can I introduce David Towell now? David was at The King's Fund and at the centre of the Ordinary Lives initiative.

David:

Well, there wasn't a centre but there were lots of component parts and I was one of those. Derek and I have known each other nearly 50 years. You can see we're the older members of this group today. Of course, you don't remember everything 50 years ago so we thought by having a conversation together we might get more right than doing it singly.

There was a critical period after Ann's work and the inquiries where people were struggling to see what should we do. CMH came up with these principles but they were a pressure group on the outside. I can't say too many people had signed up to that in the early years, but there was a change in

thinking and in my opinion Derek was one person who was critical to this. Three or four things I was talking to Derek about before we started were really important I think to what then started to happen. One was that Derek managed to get money to go off to the United States (US).

This was in 1974 and to a service in <u>Eastern Nebraska (ENCOR)</u> which was the first or one of the first in which people who had lived in just an institution were invited back to the community they came from and found housing in ordinary streets, ordinary places. They returned to their community, including people with the most complex disabilities. These were the pioneers and Derek took the trouble to go off and visit (See Thomas et al, 1978).

Very soon after, partly in response to all these scandals, the (UK) government established a Committee of Inquiry (Committee of Inquiry into Mental Handicap Nursing and Care, 1979) to look at the future of caring in learning disability. Indeed, it was this government report, chaired by a woman called Peggy Jay, which recommended that we give up nursing and start a new caring profession in this field, a recommendation the government never accepted, as it was resisted by the trade unions. But I think partly through Derek's efforts the Jay Committee did say something about their image of a better future. There's a whole long chapter about a model of care. I don't think we like the language much now but at least that was the starting point and Derek, I think based on his US experience, managed to persuade the Committee to set out some principles on which this model should be based of which living like others in the community was the first. So that was very powerful, at least it was for those reading it, not so powerful in the world of policy as it turned out. Derek's already said he was working in this large hospital or institution on the North East and he and his colleagues were able to start getting some children who lived in the hospital out into ordinary housing, into Council housing in the town of Ashington where I think the local Council saw people as their responsibility and offered free houses for the kids to move into, so we actually had a demonstration of doing what we started to say we should be doing in this small town in the North East. And this in turn led to our effort to think how can we make this more widely available across the country? And that led to The King's Fund, where I worked, trying to produce some guidance about how to do this for everybody, which we'll talk about a bit more in a moment. But Derek I've gone through 10 years of your life very quickly there. What was it that was kind of driving you? What inspired you to get involved in this, start coming up with this?

Derek:

Well, for a Psychologist this might sound surprising but it was an encounter with a psychiatrist and given the fact that psychiatrists working in services for children and adults weren't actually doing a lot of the innovation but I had the good luck when I arrived for my first meeting that is was with a guy called <u>Peter Sykes</u>. Here was a guy who, so I thought we and some of the other people that I was hiring and the psychology people, we all thought was

really motoring. This guy was very clear, he totally dismissed the idea that improving the buildings and this sort of thing and continuing to admit people to this hospital, the hospital looked okay whilst the new buildings were being built but nothing had really changed. Peter was insistent that we had to stop admissions, we had to stop bringing people into institutional care full stop. He was absolutely clear about that and that was really a powerful message. And again, there was good luck, the whole of my life's been a whole series of good luck moments and what we had was a nurse manager, Vince Gorman, who'd actually been one of the people instrumental in getting the Jay Committee set up through his conversations with his mate, I can't remember his first name.

David: Nicolas.

Derek:

Nicholas Bosanguet. So we'd managed to get that, he'd managed to get that going as well. But I then, so I said to myself "I agree with you Peter and I'm bloody well gonna try and do it" and I immediately had allies, I had a nurse manager who'd worked in that institution for years and years and years who became a close friend [Malcolm Johnson]. He was a guy who didn't have lots of education and this sort of thing but had commitment to human rights and when things were messed up in the hospital, when the nurses were drinking at night and this sort of thing, he was doing it, so we'd got an alliance, we'd got Vince, we'd got Malcolm, we'd got Peter Sykes behind us, although soon after he'd given us this amazing instruction he moved back to the West of England, but we carried on. I was determined to get allies in this situation, so it wasn't enough just Malcolm, it wasn't enough for me, so within a fairly short space of time I'd got myself back onto the Board of the Managers of the hospital and they were giving me money to buy more psychologists and it was at that stage that I brought Peter Allen in. He wasn't a clinical psychologist, I don't know what Peter Allen's background was but he was brilliant. Oh I know why I brought him in, because he trained with the Wings (Lorna and <u>John Wing</u>) in the Midlands and it was a bit of a shock to the other psychologists that I was hiring somebody who wasn't a clinical psychologist but he was a guy who was brilliant. And the other strengthening of the team to make a difference was when I first met Frances Brown, who was a Social Worker. So now we'd got people with backgrounds in training with the Wings, we had a brilliant Social Worker and she's still alive and well fortunately, and we were just, there was no stopping us then. As you know David we didn't just stay in the hospital, we went down the A1 Road and sometimes we got into London as well and got mixed up with you guys and this sort of thing. And it was just an amazing experience and it was innovation that wasn't costly, this was an innovation of people who got it, worked together to get it for people with learning disability and their families.

David:

Yeah. And I think having some ideas on paper, you might say a vision, that they'd actually see the factors and see how people in Northumberland were doing it, that started to make the different future much more possible.

Derek:

Yes.

David:

And I thought about this before but I think Derek's key point is it was people that made change but you had to build a coalition of people who had enough purchase on the system, including people and families, to make it possible and move things forward and I think Derek was really good at that.

Derek:

Yes. And I just want to put one thing we didn't sort of say when we were prepping a bit earlier, just a short time ago my daughter, our daughter has spent a lot of her life in hospital, but the thing that she, she was talking to another person who'd been in hospital as well and the conversation was something like this and it was that person A was saying "they're going to close Calderstones Hospital and that's a bit of a pity" and my daughter had said "why is it a pity?" and she said "well because it's actually worse than closing it, they're going to open it up on the Mersey Care site" and what actually was in some really, a nice location for people that were going to have to be in hospital and the managers that are still in the present systems are still doing this, so CEOs in Mersey Care wanted to now take over the responsibility of the long-stay hospital and what this young other woman had said was "and it's such a shame because at least we could go for walks, we could go down to the village" etc, etc. The CEO when challenged, not by the person with learning disability, had said "well we need to have proximity for psychiatrists to be able to move around the site" etc, etc, so how crazy is that? So we're making progress and now we've got CEOs in various parts of the country who are still arguing for large institutions. We have to do something about that as well.

David:

This may come up in discussion at the end but sometimes things go forward, sometimes they go back, so how we sustain progress remains the challenge, especially for the younger generation.

Gerald:

Okay. Well thank you very much for that. Shall we then move on to the next session with Bob Tindall? Because what you David have very well explained is the advantages of beginning to have not just a clear set of values on which services might be built but also beginnings of services on the ground that you can take people to. And you I know have that sort of experience by going out to America and seeing services on the ground in Nebraska; and in Northumberland you started to put services on the ground in Ashington. I thought a really interesting part of that story, which I hadn't thought of before, was when you said the local authority or Council began to say "this is our responsibility" because these were children who came from their area and they saw it as their responsibility to provide the opportunities for them to live within that area rather than be put away and they also saw responsibilities in terms of presumably ensuring that they not just got good accommodation but they also had better education.

Derek:

That's right. And the local authority closed one of the children's wards completely and children now had their own houses in Ashington. The local authority in due course then took over the responsibility for providing the staff support to those youngsters, so there was a natural change. There's one other bit that I want to squeeze in.

Gerald:

Okay, go on?

Derek:

Which is that the other person that I have so much admiration for - the nursing officer Malcolm Johnson who did everything right, who'd fought against the system all these years, in his retirement years what happened is a lot of the medics saw this as a place that they could practice, so new hospitals started to be built on the site which are again a complete nonsense, not saying that people with learning disabilities don't maybe or certainly need to access the psychiatrist and this sort of thing but not out in the hills. And so Malcolm in retirement and his continued commitment to these citizens set up an organisation called the Coquet Trust and he then, not with lots of money and this sort of thing, created housing right up into the depths of Northumberland and so there was a smooth change to the independent sector in terms of people, the people who are now working in good housing etc, etc. So all these models were coming together because of these people, Vince Gorman, the psychiatrist, etc, etc, and there are lots more of those people aren't there?

Gerald:

This is also a superb segue into our next presentation which is from Bob Tindall who was also in Northumberland and who was also beginning to put services on the ground and then played a major role in developing service provision for people with learning disabilities subsequently. So could we ask Bob to talk about your contributions a bit?

Bob:

I was in Northumberland, not in the same place as you Derek, but I knew Derek and I knew the other guys that Derek talked about, and that was actually very important to me. But I want to present a sort of patchwork of sort of opportunities and developments that might have been haphazard at the time but nevertheless pushed things in the right direction. They broadly formed three different elements, although they are very much interrelated, and they're also in two bits, one is actually about getting people out and the other thing is once you get people out is actually making sure that those new services actually give people the opportunity to have an ordinary life and don't duplicate some of the practices that were in the hospitals.

So the three elements I've called one structural, one legislative and policy change, the third one thought leadership, these are all things that I think helped either me personally and thousands of people like me, things that have helped and pushed in the right direction. Derek's already made reference to one of them which is actually if you're doing something which is damaging people the best thing you could do is to stop doing it, so the stopping of people being admitted into long-stay institutions I think is very important,

because it limits the damage, but also it creates an urgency to develop community-based services that actually need to be developed if there isn't the easy option of just placing somebody in hospital. So that was important. Also as things moved on the linking of funding with individual people that was largely transferred to the local authorities was obviously a powerful incentive because my experience of working at Prudhoe Hospital, which is also in Northumberland, and trying to get people out was you had to have a very moderate disability indeed to have a chance of getting out of hospital, very moderate, and that was partially because the local authorities had crises of their own of people living in that local authority and therefore didn't have a lot of sort of energy I guess to also try and bring people out at the same time, so the whole idea of funding linked to individuals that actually might begin to create good opportunities for people was also I think very important.

Then looking at the whole area of different policy change, I mean there was a whole range of things, and I'll mention a few but not necessarily in chronological order. There was the focus on closure of some of the long-stay hospitals for various reasons, Ely being the one that's already been mentioned, <u>Darenth Park</u> was one of the early sites as well (see Korman and Glennerster, 1990). There was the influence of the work of CMH and people who had the same sort of ideas and enthusiasms and energy to do something different. There was an initiative to get children out of the hospital in the early '80s which led to some really interesting innovative work I think over time (see Alaszewski and Ong, 1990). There was a Welsh Government, I think it was a Welsh Office at the time, thing called the All Wales Strategy (Welsh Office, 1983) which I worked on for 3 years down in South Wales which top-sliced health funding and gave that to develop services in the community, and there was also the Nimrod Project (see Davies et al 1991) which helped develop community-based services, that was subsumed in to the All Wales Strategy work. There was the NHS and Community Care Act 1990 and what that did was tilt funding towards the independent sector. I think what that did most of all was create a lot of capacity in fledging organisations to try and get in there and start making a difference or if you like create a certain amount of energy and a certain amount of capacity to respond to the scale of the challenge to get a lot of people out of hospital.

And more latterly there's been things like the protection from rent restriction rules which meant that people could access higher levels of rent which took into account the effects of their disability and also give people tenancies and give them some control over their living environment and also actually usually made people slightly richer than they were before because you're not very rich if you're living in residential care. Not very rich when you live generally, actually, but particularly not rich if you live in residential care.

So those were some of the things that were around and pushed in right direction that could be exploited, and I'll use that word quite deliberately, to create opportunities that might create better things for people. And the third area and certainly not the least area, is thought leadership and the work of CMH, the work Derek you did, the children's houses, the NDT, that's the National Development Team, all of those things I think helped. There was some good work done around programme analysis and service systems, PASS, which helped a lot of folks like me look at human services and try and work out how they reflected an ordinary life and usually came to the conclusion that they didn't very much really and they had to change quite a bit to enable that to happen (see Wolfensberger and Glenn 1975).

So those were the sorts of things that were around and then there was what I would call the bits that came afterwards, the bits that sort of tried to improve things generally when people were moving into the community at scale. There were Jim Mansell's two reports in 1993 and 2007 (Department of Health 1993; Mansell, 2007). Jim did two reports because the amount of energy and activity from the policy changes that he was outlining wasn't that great and therefore the government asked him to repeat it in 2007, but that was around trying to create capacity - community-based services to absorb and support whatever needs people living in the community actually had rather than push them towards some sort of institutional provision. It was the development of person-centred planning because it stands to reason doesn't it that if you are gonna try and help somebody achieve an ordinary life you have to know what they want and you have to get some people round the table who might actually be able to help to do that, so person-centred planning I think was important. For me running community-based services, there was the whole issue of making sure that staff knew how to engage people in ordinary life activities, particularly people with more severe disabilities because a lot of opportunities for engagement simply get, and still are actually, get missed on an everyday basis. So encouraging people to make sure that people are engaged because being engaged in real life because if you are, you know, it gives you control doesn't it? Gives you some control over your life, so that's really important. And I think the development of Personal Budgets as well, again if we're thinking about control, we think about power, we think about who's got the power here, then actually if you've got the money then actually you've got more power than you had before haven't you?

Derek: Was access to advocacy a part of some of that legislation that you're talking about?

Bob: Yeah. It's far from a comprehensive list though but you're right, with that as well, most certainly. And I think the other thing was there was a certain amount of coordination amongst provider organisations which had to work with each other. The NHS and Community Care Act 1990 was essentially something about creating a competitive environment but actually in reality some organisations who might compete with each other for contracts with local authorities actually do quite a lot of collaborative work and still do. I

think that was important, I think it's also immensely important for the future. So that's a sort of broad if you like sort of run through I think some of the things that actually helped get us to where we are.

Derek:

Gerald:

Ann:

One other thing that I think was really important and that was once we'd got it round into our heads that people, children shouldn't come into hospital and so where should they be? Well, if at all possible, they should be with their families, but those families had lost some of their own kind of ordinary life because they're now having to look after their sons and daughters at the weekends and things like that. And a lot of the push that I recall is that people at the local authority were really important because right across the country we had some very leading-edge directors of Social Services, people like the guy John, his name's gone out of my head but...

David: <u>John Chant</u> – Somerset County Council.

Yes. Who'd been in care himself and people like <u>Brian Roycroft</u> (in Newcastle-upon-Tyne) etc, etc. So once, we didn't just have Social Workers but we had people at very senior levels in the local authority system and as we go forward we've got to have the local authority. Actually my personal view is that local authority should be probably in a leading role right across all the cities to make a real difference to ordinary citizens, to children and adults with learning disability.

Can I bring in Ann at this point? Because I just, you know, you were involved in the setting up of CMH and you continued...

Ann: We started it. [Laughter]

Gerald: Right. Founded!

Ann: I founded it.

Gerald: I'm very sorry. And I just wondered how you saw this set of developments, you know, there's a creation, I think what you're describing Bob is that the health and care system within it there are all kinds of opportunities, there's a supportive environment that you can latch onto, lots of opportunities. I mean

how did it look from a CMH vantage point?

Well we were thrilled, of course we were thrilled, because here were people saying 'It's possible.' One we might mention is one of our first CMH members, Alan Kendall (Director of North West division of Barnardo's) up in Lancashire, who was providing small homes for two or three very, very

severely handicapped children.

Derek: That was in parallel with what we were doing in Northumberland.

Ann:

In parallel with what you were doing in Ashington. I remember visiting Ashington, as I also visited Barnardo's, and it was just enormously heartening that movement from rhetoric to the beginnings of getting something in place. And then there was a cooperation with The King's Fund which I think was terribly important because Fund is so respectable and we were such non-respectable people with our little reports. A I did quite a lot of work personally with The King's Fund, which was great. In CMH, we carried on our work giving a voice to service users through The King's Fund which helped with a series of what we call 'participation events' where staff and people who use services came together and debated what was possible and what not, people spoke of their hopes and why they wanted this and that. It became a very sophisticated programme, I think because it was under the aegis of The King's Fund and service providers were willing to go to meetings there who wouldn't come to CMH meetings.

Gerald: Which is a superb cue for me to introduce David Towell again who...

David: We're the respectable ones we've just learnt.

Am I able to say you David led The King's Fund Programme on ordinary lives (see King's Fund 1980; Towell, 1988; Towell, 2022) and who provided my first personal encounter with the Ordinary Living Initiative as well? David, would you like to talk about your role and that of The King's Fund?

Sure. Just to say, building on from what Derek and Bob have said, yeah there were all these public organisational frameworks and some useful legislation and some not useful legislation. But what made the difference was people like Derek and Bob and lots of others that they've started to mention who picked up the ball and ran with it and tried to find ways round the difficulties to make a difference once we were inspired by a vision of how things could be better. So it required managers, therapists and families to think they could do something and that maybe a credible difference between then and now I think. We might come back to that later.

Okay, The King's Fund has had a lot of plugs already so I do need to tell you a bit about that. We've been presenting the story kind of historically but actually all the things we've talked about so far were kind of running in parallel and part of the job of The King's Fund I think was to try and bring these things together so as to build a national programme. So I need to tell you about what The King's Fund is, a bit about me, a bit about what we did, so maybe a couple of observations about what was useful. The King's Fund is a very old charity, founded in 1897 by the then Prince of Wales, who became King Edward VII, hence The King's Fund, so it has high status as people say, maybe not been very useful but it has high status, as the King's name is attached. The first half century it mainly raised money from people who donated to give to the voluntary hospitals from London but when the National Health Service came those hospitals were all nationalised so that

David:

Gerald:

role wasn't necessary anymore, so they turned instead to the idea they would use their resources to try and improve quality in health and related services and that's what they've done since then. The King's Fund currently has £200m in the bank so if it couldn't get money from the government or whatever, it could fund its own activities, which gives it a lot of freedom. It could use that freedom in very 'establishment' ways, to maintain the status quo, however some people saw the fact that we had the King's name and a lot of money to mean that we took on challenges that other people couldn't and that's how we got into the hospital institution's and learning disability. What's more, with those resources, if they were doing something they could stick at it. The one I'm going to tell you about is at least a 20-year programme of support to folk like these in making a difference where they were.

I joined part of The King's Fund in 1978. It was then partly a conference centre, a library, providing resources before the internet and WhatsApp and so on, and also a publishing house. So it was very well placed to be a kind of independent centre where people could meet, share and we could spread their stories, and essentially that's what we did for a long time. Before my ENCOR work with CMH and others, that started by trying to bring from elsewhere a clear idea about what is a life based in living your life to the full and living like everybody else in your community, what that would look like, and good people including Derek and indeed Ann came together to produce this first pamphlet and print that in 1980 (King's Fund 1980). This says: "Our goal is to see people with learning disabilities in the mainstream of life living in ordinary houses in ordinary streets with the same range of choices as any citizen and mixing as equals with the other and mostly not disabled members of their own community". Actually, Ann wrote that sentence. She's a very good writer. None of us could write a sentence that long and still make sense [laughter]... And that's where we got the Ordinary Life slogan from. We could then squeeze the 45 words into an 'ordinary life' and that became the kind of symbol of our efforts.

Just for interest, there's a picture on the front of the first pamphlet; it's ordinary streets with trees and ordinary houses, nothing very sophisticated. Two years later the government produced design guidance for what they called health service residential accommodation for people with severe disabilities, edge up the roofs of these places on the front and if you turn to the middle it tells you how to produce a 24 bed unit made up of three x eights or two x twelves or whatever. So there was definitely a parting of ways here and the government still is in the past and apparently Merseyside still is, whereas we were saying "no you don't need to build anything, there's all those places out there called houses or flats or houseboats, why don't we use them?" And that was really the radical change. This pamphlet (King's Fund 1980) didn't tell you how you might do this in detail, of course we hadn't done it then, so this was theory.

Over the next 10 years I produced a lot more of these pamphlets, this time saying we're happy to actually do it with you. So people in Harlow liked this so they did their own Ordinary Life in Harlow (Harlow Campaign for Mentally Handicapped People, 1981), and that's local people picking up the ball saying "we could do this and that's what we need around here". Ann wrote this on children coming home from hospital (Shearer, 1981) and there were about ten more in this series in that period. This is obviously all pulled off my shelves recently. In 1985 we had a meeting of some of the people who were providing leadership around the country, we put a big flipchart up with a map of England on it and then people filled in what was going on and you started to see the density of efforts of the kind that Bob and Derek are describing. We then sent Ann on the road with a photographer to collect these stories and write them up with photos, this very nice book Building Community (Shearer, 1986). Ann's work showed people in our country we can do it, so we were busy reinforcing the idea that everything was possible. This is my book from 1988, Ordinary Life in Practice (Towell, 1988), no longer theory, this is what we're doing. That's the story.

Incidentally the first pamphlet cost £1. Can't get much for a pound these days can you? A few things about this. There were some opportunities and some barriers and some people with motivation, it needed something to bring those efforts together to make real change and not just in a few places but everywhere. What The King's Fund tried to do was to use these resources, the conference centre, the library, the publicists, to make this story widely distributed and in fact we reprinted the first pamphlet four times in the following two years, a lot of people were interested. And what we used to do with others was to ensure that people who were being innovative in one place, were testing out their experience with other people so we were gradually building a network for change which over time, over a decade this became nationwide, and probably the critical shift in this was shifting perception and seeing people with learning disabilities as people like everybody else who just want to get on with their lives in a way that's simply for them, as opposed to some other group that need to be diagnosed, classified and put away. So that was the real radical change, thinking differently about people.

Some other mutual places like the <u>Tizard Centre</u>, the <u>Norah Fry Centre</u> and the Northwest Training and Development Team were all kind of supportive nodes in these national networks of people learning from each other and encouraging each other and that's why we said together we were building a social movement for change which started on people's lives. And I think my final point is that the fact all this was going on meant that lots of people felt, as President Obama said in his first election, "yes we can". There was a "we can do this" bias and what's more we can reinforce each other's efforts to do so.

Gerald: Thanks very much. Reflections from other members of the panel?

Derek:

Well I'd like to strengthen the reference to research communities because I think we were very pleased, those of us who were trying to do things on a day-to-day basis as opposed to researching, we had some magnificent researchers in the UK and we also had some mini plans in Wales and I can't remember where else there was sort of research ...

Ann:

Wells Road was one, in Bristol.

Gerald:

Yes, Bristol's Norah Fry Centre and before that Wessex.

Derek:

Right. And then if I was drinking I'd raise a glass to Linda Ward and <u>The Joseph Rowntree Foundation</u>, not just the fact that I was a part of that. It was really enjoyable the way that Trust handled its money and the way that Linda shared it out to us in various ways, so we were able to do stuff that we couldn't otherwise do.

David:

The Joseph Rowntree Foundation made this a major focus of its work for about 8 or 9 years and funded research and development, not research in purely academic forms but applied research that demonstrated what could be different and that was a huge asset.

Jan:

One of the things we haven't mentioned though are the family initiatives because there were things like MacIntyre and Home Farm Trust in the 1960s, they're all coming up now to their 50th anniversary or just beyond it and they too were pioneering different ways or ways of not having their children go into institutions. I don't think that's been woven into the story because I'm not sure how much they are part of it.

Roselyn:

I was born in the 1970s and I was sent away to a boarding school and I came home, it must have been when I was 18, no, 19, and London Borough of Redbridge paid for me to go away. What they didn't realise is what a bad person I'd come back as! [Laughter]

Bob:

Can I say something about the power of that paragraph that you wrote Ann? Because you do need somebody to just give a bit of coherence and for me that personally that created a bit of steel because at the time people were still saying "oh, you know, they couldn't possibly live out in the community that's a ridiculous idea". You have to have things that you can hang onto, so if we look at this in communications terms that is incredibly important.

Ann:

Thank you for that. I think that's something CMH could do: because actually we had no service responsibility, we could always ask "Is this a principled thing?" And we were very lucky that we had very good international contacts right from the start, so the network was very wide, people like Gunner Dybwad at Brandeis University opened doors to very many good things: that's how we met ENCOR of course. So I think that became a role of CMH, which then renamed itself Values into Action, to keep

recalling people to principles, because of not having responsibility for service delivery.

Gerald:

Well I think we should now explore more about how the notion of an ordinary life took hold and Jan Walmsley is going to lead on this, and would you like to kick it off please?

Jan:

Well I first encountered what was going on in 1985 when I accidentally got a job at the Open University, which was producing a course called Patterns for Living, which is a continuing professional development course. I read it and I thought if this is university standard this is very poor because to me it was so obvious. What it was saying was so obvious, who needs a university to tell you this? That people should have an ordinary life, they should be part of a community, because I was new to it, I had no idea of the history, I had no idea, you know, I just arrived as an administrator. So that was my first encounter with an ordinary life.

I think what is really interesting and I don't think we should forget what an achievement it was to change the thinking. In the 1950s they had to prove that children could live somewhere other than a hospital. Can you believe that? It actually had to set up an experiment and research it and say "oh yes, children did a bit better than they did in the hospital", they were still in a big house, they were away from their families but they were out of the hospital and they got a lot more attention and they did better, how amazing. People had to do research to prove that people with learning disabilities could earn a living, could do some work, they had to prove it, indeed Jack <u>Tizard</u> had set up experiments in the 1950s to do that.

Roselyn: I have got a whole list of work placements that I've done over the years.

Jan:

I think I read about them actually, yeah. But what I'm saying is that people's thinking was so limited and what was the great achievement I think of an ordinary life and other things like normalisation was actually to create a framework where people like you could do what you had to do. And I think that was, that's such an important thing which we need to remember if we want to change things. And it was a nice, as you said a lovely, simple, memorable, ordinary lives, ordinary streets, lives alongside other people, that's pretty easy to remember, isn't it? Don't need a PhD to remember. I think it's kind of this mental framework and I think what was achieved and with the help, I went to some of The King's Fund meetings, I was very new to it, was actually saying this is the only way to think, there is no defence of the other way of thinking, you've got, this is just logic, this is common sense, hegemonic thinking. So I think the research was important but without energetic people to draw attention to the research it wouldn't have gone anywhere. I think that's the problem with research, we do more and more and more research but unless people take notice of it nothing happens. One of the things that really changed things was that professionals got on-board with

changing things, the CMH and there was this Association of Professions for the Mentally Handicapped that existed. Does anything like that exist now? Can we see professionals leading change? I can't.

Roselyn: Unless it has disbanded we've got People First.

Jan: I'm very pleased we have got People First, but what we need as well is

professionals standing with People First saying "we need to change things" and that's what we had I think in the Ordinary Life Movement, a large number of professionals. I think that the PASS stuff that you mentioned, you know, I rarely met anybody working in mental handicap, sorry about the

language, in the 1980s who didn't go on one of those courses.

Ann: Yes, that's true.

Jan: And you were told what to think. You weren't really allowed to say "I don't

agree with this".

Roselyn: Consultation.

Jan: No. It was more than consultation. It was actually this is the way to do things

and this is what you've got to go away and do.

Roselyn: You did a consultation in the day centre where I go to and the first thing I

said is "well why are you asking us now? You didn't ask us in the beginning".

[Laughter]

Jan: I think it was nice, you know, there wasn't any self-doubt around about it, it

wasn't full of caveats, this is what we've got to do and this is how we've got to

do it, a very, very good message. And I made a little contribution, this

Patterns for Living course that I worked on, we sold 30,000 packs of this and they were for people to study, they weren't for, they were often organised by professionals, but it was unqualified people, parents and other people to study together, to build up a kind of picture, energy, commitment, so that was at the kind of level of non-professionals but family members and more than 30,000 people actually used it. It was extraordinary. I spent a year marketing it because I didn't have anything else to do but because we didn't have any

money to do another course I was sent off on the road, but it was very exciting to see people coming together in all parts of the country learning and I suppose learning that simple message, it's an ordinary life, we need that, we need that. I think we worked with Mencap, now you said how Mencap was

really hateful to you Ann, but Mencap helped raise the money for that course

and was very much behind it.

Ann: Mencap changed.

Jan:

And it was a powerful voice for change and it had the voice, the ear of government as well. And I think governments were attracted by the idea that it would be cheaper, I think they were embarrassed by endless scandals of what was going on in these hospitals, there were about ten I think, ten serious scandals from 1967 to 1980, all had official reports and that was embarrassing. They couldn't recruit staff, low pay, it's a bit like social care now, low pay, they're out in the country, middle of nowhere, not exactly an attractive place to work so they couldn't attract staff. So governments, never led, they really didn't lead this but they didn't stand in the way as I see it anyway because there were endless research projects showing that community care was cheaper, whether that was correct I don't know, I mean I think they were just as often research projects set up by government. What you were saying about the finessing of financing, I mean we have this problem now don't we with the 2,000 people in assessment and treatment units? When they leave they're no longer NHS funded and the local authority has to pay and so they don't get out. Well that was sorted and the details escape me but in the 1980s as you said that was sorted, so that is actually what I think unblocked the pipeline in a major way for people to come out of hospital. And I think there was a lot of pushback, there was an amazing film came out called Silent Minority in 1981 about conditions in these hospitals. It's harrowing, you can see it YouTube if you want to, I don't think I'll recommend it unless you're in a very positive frame of mind, and people sort of denied it.

R: I would probably say the one thing that has made an impact was I think

Winterbourne View.

Jan: Yes. Winterbourne View was a bit like Ely in 1960 (see Hide, 2022).

That has made a large impact because I think we, all of us service users we had to do safeguarding training, like something that you wouldn't ask a

service user to do.

But I suppose the question I want to pose now is there are still 2,000 people in those units despite the fact government said they'd close them. What I don't think we've got is professionals, sort of spearheading like the CMH type professionals getting on-board and really pushing it. I don't think we've got it there. You can say I'm wrong but I think that pressure from people within the system is missing. So we've got People First and we've got pressure from outside but it feels like that is missing. Anyway there's my perspective and I think it's great credit to everybody that we did get as far as we did and we can hear about your ordinary lives and enjoy them.

I would just say to share with you guys, I know that what is a long-stay hospital, what it looks like, it's not like stay in a hospital, it's like a prison there. I just heard about years ago in a project is called a Living Archive Project and we just mention about the Mencap and when I was watching the

Ajay:

Roselyn:

Jan:

video on YouTube, when I was looking video online it was terrifying and shocking, that was a long time ago, I just felt like it's I've never seen this before in my life now. I wasn't born in 1980, when I look in the video YouTube it's terrifying for me and shocking. And then God forbid my parents are safe for me, I didn't go to boarding school, I didn't go stay in hospital, it was safe and sound. Thanks.

Derek:

Can I ask a question Gerald which is I've never really been in touch with Mencap but my impression, and I did some consultancy at one stage, my impression was that it wasn't in a leadership role Mencap, it wasn't taking a lead in relation to people with learning disability. So my question is because I'm not too in touch with it is: is there now a different kind of leadership? I mean first of all is there still a Mencap and is it any good? That's the first question.

Roselyn: I'm led to believe, unless I'm wrong, each Borough has got a Mencap.

Ann: It's got a local, yeah.

Derek: Right.

Roselyn: It's done locally.

Derek: So is this a leadership at a local level expressed through it? Yes?

Roselyn: As far as I'm led to believe it's local.

Jan: It's a very difficult question to answer isn't it? There is a national Mencap and

there are local Mencaps and there doesn't seem to be that much connection

between the two as far as I can see, but I might be wrong.

Gerald: Well there are a lot of national organisations who are in tension with their

local roots, some of which are sort of federations and some of which are membership bodies. I think the respective sort of strengths and opportunities that local groups see changes over time as well, you know, because they're critically dependent on the people who join them at a particular time. I say this as somebody who's been a member of a local Mencap for a long time which had a service development role, the major reason it had that service development role was because there was a senior lecturer in the university where I also worked who had a very severely disabled son and who was unhappy with the way the health authority was treating him and was fed up of fighting battles with the health authority. He decided he would set up a service himself and I think some local Mencaps have that kind of dynamic to them. National Mencap, I would argue, obviously changed its national image

radically when Brian Rix became its head.

Roselyn: Can I just say one thing?

Gerald: Yeah, sure.

Roselyn: We've had strong links to Brian Rix because he opened the day centre that

we go to in Wanstead, and we've also got the, uh...

Jan: Rix Research Centre at the University of East London.

Roselyn: Yeah. Which is named after him.

Gerald: I think he played a big role for the wider public in understanding what

learning disabilities was, what the services were that we offered then. He also had access to leadership. But what I was going to go on to say is that more recently when <u>Jo Williams</u> took over as the leader of Mencap, I think Mencap was a critical influence not just in the field of learning disabilities but it also broadened out and it helped to establish and fund the <u>In Control</u> movement that was responsible for developing personal budgets. So, its role has changed at different times, it's had more public prominence at times than others but

it's worth asking the question where is it now?

Jan: It is a little distracted I think by its service providing role as well because it's

got the campaigning and the providing of residential and other services, which is I think quite a difficult 'two horses' to ride at the same time.

Ann: And certainly for families, you know, if they're dependent on what's already

provided they're not going to rock the boat too much and that was always a tension, it's bound to be a tension. This was certainly true in the early days and it was, I remember in CMH, when the first parent joined CMH we were

so pleased.

Jan: But there was a new organisation wasn't there? Rescare was set up to resist

the closure of the institutions, so Mencap can't have been unequivocal in its opposition and certainly by the time I was involved it was much more

positive but that was in the later 1980s.

Ann: But I think this confusion of roles is very important. For instance, I went to

New Zealand where the government had said plainly the Mencap equivalent could take over and develop the services and there were some great people working, great people, not only parents but involved citizens. I went to Australia where the same thing was a complete disaster because they didn't have the leadership. So, you know, it depends, and New Zealand, of course,

is a very small country.

Bob: One issue that's come up on the chat, which is about people with profound

and multiple learning disabilities. Certainly, in the early days in a long-stay hospital before they were closed, you didn't have a cat in hell's chance of living in a community if you were in there because you needed a lot of

support which probably didn't get moved from the hospital. Therefore, it was

only when the funding mechanism came in that this created the opportunity to develop some services and opportunities for people. Their families were often the biggest advocates for people in making that happen. But it does raise the other issues that once people with profound and multiple learning disabilities are in the community there's still quite a big job to do to ensure that there is engagement for people every day in a way that they can experience life as not just a series of random assistance here and there but actually something a bit more structured and a bit more helpful. And I think that's an ongoing issue, I think it's still with us. I think it's got better but I mean I think looking at the sweep of what we've covered I guess there's obviously major benefits for people to come out into ordinary community settings but I think we're still working on making support effective for people and making sure that they actually do things every day and not be passive observers of what's happening in their house at the time.

Jan:

One of the things that came up at a conference I've just been at this week, which was about community, was friendship and how important that is and how services don't support it, they don't see it as their job to help people make and keep friends. And we were thinking that was quite an important change in that if you look at John O'Brien's five accomplishments but building relationships isn't one of them. It's community presence, participation, contribution, but it's not building relationships, and maybe that's a bit to add to the ordinary life picture that we have here.

Gerald:

Can I turn to our audience and ask if there are questions that they would like to pose?

Carl:

Question from Juliette Malley.

Juliette:

This might be partly my ignorance, but I've just got the impression from today's discussion that the staffing of these long-stay units has changed quite a lot over time and I was interested in the observation that the staff you think are less involved now in trying to drive forward change. And so if my ignorance means that I'm taking the right assumptions away from today that there's been a change in the type of staff that are involved, do you think that that has anything to do with it? Because I mean care workers tend to have very low status, you know, and they're not that well organised and I just wonder whether that has anything to do with the lack of sort of staff involvement?

Gerald:

Right. Have a go at that, Jan?

Jan:

I think it is something that probably deserves a bit more investigation but if you think about it what professions are actually involved with people with learning disabilities there are some psychiatrists, a few learning disability nurses. These learning disability nurses are the only ones that are exclusively

part of that workforce, and there are very few social workers. There aren't many professionals...

Roselyn: No. Because you know why there aren't enough social workers? Because I

can vouch for these two, they come, they do the reviews and then they leave.

Kiran: Yes, very true.

Jan: I think that says it all actually, that there aren't many professionals, they're

not very committed for, some of them I'm sure are, and they're not organised as a group as was the case in the 1980s I think fostered by the initiatives you

discussed.

Bob: I think that the current generation of people providing support is just as

passionate, just as skilled and just as committed as our generation was. Obviously, times are tough and for all the reasons that we already know and I think that's made their jobs harder but I think there's the capacity for hope is

still very much there and there are willing people to take this whole

development further forward again. I think there are so many people who are described in that way that, you know, there is hope there, it just needs to be led and we haven't got as much policy change, we haven't got as much, there's no sort of stuff coming together which makes it easier for them now I

think.

Jan: No slogan like an Ordinary Life to rally round.

Bob: Just use the one we've already got.

Gerald: We've got another question from Jillian Pawlyn.

Jillian: Hello everyone. Good morning. I put a statement in the chat but I'm a

learning disability nurse and I think, having been a member of the National Network for Learning Disability Nurses many decades ago, that was a large collective of learning disability nurses from the whole of the UK who came together with a collective voice and we had the opportunity to speak out about lots of different things that were affecting our practice and connect us with other groups. Where we are now today is we don't have a group like that. We do have groups where learning disability nurses can come together

but they're few and far between.

We're actually at the point and I apologise if I have got this wrong, where the Nursing and Midwifery Council doesn't actually know where learning disability nurses are working in the formal sense. Yes we fill in our database every year but it only gives a geographical catch, it doesn't actually say where, so it's actually really difficult now to get learning disability nurses collectively together to actually be able to consult, to advice, so we do rely very heavily on the nurse consultant network and the nurse leaders to feed

things through and through that we rely entirely almost on social media as our spaces to connect because we no longer have email groups like we used to do in the past, we no longer have those national annual meetings where we can all get together and thrash things out. So yes, I agreed with Jan's comment earlier, I do think the voices of learning disability nurses are now so lost within individual organisations and often we are the lone worker as a learning disability nurse within an organisation particularly in the independent or private sectors. So it is sometimes difficult to actually make a formal response or really make a move to consult and change things if you don't feel you've got a body of people around you. The LIDNAN network for academics, as Jo's just put in the chat, is a powerful voice for academics but we're growing that, we need to grow that voice of people who are practitioners and we do seem to rely a lot on the unions bringing those voices together but it's certainly not as it was for the national network all those years ago. Thank you.

Gerald:

Thank you very much.

David:

A good point. I think to ask what was the innovation of Ordinary Life, there's not a simple answer to that question. Certainly, there was a kind of clarity of values, there was widespread demonstration, but more subtlety there was a national community of practice. [Chorus of yes's] So that was probably the key change vehicle, lots of good people thought there were others lots of good people doing similar things and would support each other and I would say the key investment of The King's Fund was being a kind of core to that learning network.

Ann:

This is a shadow side of an Ordinary Life and integrated local services: specialism disappears, which in a way it should, and yet that means there isn't a coherent body which actually knows something about it, instead it's a busy social worker who must also going work with children in care. I've never thought of that, it's a real downside of an Ordinary Life, not for people who are living it, I don't mean that, but in terms of planning services and initiatives.

Jan:

Was a question about social media I suppose?

Carl:

I think Elizabeth [Tilley] asked that question and she's got her hand up now, so Elizabeth do you want to put your question to the panel?

Elizabeth:

Thanks very much to the panel for a really terrific and thought-provoking session. I think, you know, things feel very difficult at the moment. I think a lot of people would agree that we need a new social movement to help really bring together allies to address some of the ongoing inequalities faced by people with learning disabilities and I think hearing about the social movement around an Ordinary Life is very inspiring and people need to know about how that works in practice. But my question is whether you feel you

could have done that and achieved that in today's context? And I guess I suppose with the sort of exposure that social media brings, on the one hand I think it can be an amazing tool for connection but I think it also serves to highlight people's differences and the fault lines perhaps in much more visible and public ways. So under the scrutiny of social media do you think you could have achieved what you achieved then now? That's my question. Thank you.

Gerald: Who'd like to kick off?

Roselyn: Probably say hello Liz.

Elizabeth: Hello Roz. Lovely to see you.

Roselyn: Probably say I didn't know about social media until probably about 10 years

ago and I have to say that there's too much negative press on social media

about everything, so I don't know.

Jan: Can you imagine social media at The King's Fund David? What would it

have done?

David: My fantasy is that we are much more effective with modern means of

communication than printing leaflets in Ann's back room and stuff, and expect people to buy them. We could certainly have spread the message and provided support much more effectively with WhatsApp groups and so on.

Gerald: However, the kinds of pressures that you experienced Ann could have been

much more threatening?

Ann: Could not have been much more.

Gerald: No, they could, they might be...

Ann: Couldn't to me, sorry.

Gerald: Sorry. In the world of social media, being exposed to that rather than, you

know, what you were exposed to, which was terrible as it was but would it not have been even more difficult for you to have sustained the work that you

did?

Ann: I'd have to be a bit tougher wouldn't I?

Gerald: You would.

Ann: But there's a simple answer which is don't have any of these silly accounts.

[Laughter] I mean I have never had one, I'm never going to have one, or need

to turn it off.

David: There is a danger of getting together people who were all born close to the

end of the Second World War and discussing the situation in 2023.

Jan: Yeah. We're probably not the best people to answer the question.

Ann: No.

Gerald:

Let's move on to a question that was posed for us by a group of people with lived experience who advise and support the research that we're doing. Carl met with them and they produced a number of questions but one that I'd like to focus on because we have begun to touch on it, is what about the people who are still in institutions today and why is it that they are still there? Does this reflect either an inability of the Ordinary Life initiative or does it, you know, at the time to establish models of care for all groups of people who were being cared for by the NHS traditionally, is it a reflection of the lack of continuing pressure for different models of care? I don't know whether you have any thoughts about why we still have the problems? Why we still have institutions?

David:

Got some thoughts, yes. We certainly, I think the third paper in our King's Fund series was called Facing the Challenge (King's Fund, 1987) as we argued that people should live in the community, people started saying "well what about X or what about Y?" and a favourite X was people with challenging behaviour, so we addressed that and for sure we knew what to do and people like Jim Mansell demonstrated it. So it's not a lack of knowledge if you've been given the values about what we would need to do. Of course it did start young is another point, we haven't talked about education today understandably but if we were starting again I think we'd start with education, everybody goes to a mainstream school, have friends who are nondisabled, grow-up in their community, make progress as they get older, that still doesn't happen very much. We can't go back and start again but we could start now on that. But it I'd like to say we turned the tide in the late 1970s, early 1980s. I think it's partly because the generation pushing it, people round this side of the table, actually are all the sons and daughters of the Second World War (1939-45), so started off optimistically and believed we could do stuff. I'm not sure people who are born 40 years later have that experience and they have good reason for thinking that things may be more difficult in some respects, even though we're supposed to be a much richer country now. But I think there's also a kind of turning the tide in reverse direction somewhere into the first part of this present century where the idea that we can do this started getting undermined by concerns about costs, about people who have not been part of this movement before getting positions of authority that no longer reinforce these messages and where you might expect leadership it's being reduced by the constraints of austerity to a much more kind of contained and rationing approach to what services do. So I think some of the conditions, I mean most Ordinary Life work was done during Margaret Thatcher's period so that wasn't ideal economically but

nevertheless we thought we could do stuff. I think there's been a change of culture now and the opposite is the view, it's all got too difficult.

Jan:

I'd endorse that and I think commissioning services is quite a difficult thing to do, commissioning the right services for people who need it and a lot of expertise was taken out of local authorities but local authorities have to do that commissioning. You have to be pretty good, you have to know what you're doing to find the right services to write the right specifications to get it to work. There was a woman called Sheila Taylor in Milton Keynes who was a social worker, she knew everybody and everything and when she retired there was a huge gap, nobody replaced Sheila Taylor as the person to go to in Milton Keynes when you wanted to talk about what was going on in services and I think that really is a big problem when you're looking at getting people out. They've got to have the right commissioned services for people.

Ann:

And, you know, when I hear terms like that I realise how far I'm out of the loop now. I just think about simplicity, you know, the things that were able to happen that Derek and David were talking about, they were very simple: you got a house and enabled people to live in it and enjoy it. And I think we've lost that simplicity, which was idealistic if you like. Now it's the awful question of how easy it is to be pioneers and how rewarding, and how difficult it is to sustain and generalise opportunity.

Roselyn:

Problem with that Jan is that not only do you pay to go to the day centre but you've also got to pay to go to do the activities as well.

Jan:

Have you?

Roselyn:

Oh yes.

Jan:

But you could choose not to go to the day centre could you and go somewhere else with what you're paying?

Roselyn:

I suppose you could stay at home and imprisoned in your flat until [laughter], until further notice.

Gerald:

Derek?

Derek:

Yes. Last night when I was worrying about what the hell I was going to say with David, I got this pack of ENCOR out again. Now often conversations that David and I have had was who was in ENCOR first and who typed it up and all that sort of thing, which it doesn't really matter because it was one of three people etc, etc, but when I started reading it I just like, it's amazing, it is absolutely amazing what happened in ENCOR and what it's still doing.

David:

Derek were you reading your own stuff there?

Derek:

No, it wasn't, it was the blue thing, I don't know who wrote it, I don't know if it was, whether it was, the various people whose thoughts fell out first, Valentine and the guy that we were talking about.

Ann:

Alan Kendall.

Derek:

Alan Kendall. And we were all, and Hugh Firth (see Firth, 1982) etc, etc, we were all absolutely blown away about it and that was just because it was happening. How could you close a place like that? You know, we were worrying about could we close these places down? Of course we bloody well could close these places down if we set our minds to it. This is brilliant and I think many people won't have read it and I'm gonna read it again and again and again until we establish some modelling along this kind in the UK and across the UK. And that's all I wanted to say really, I just got really excited about it. It's an amazing document but more important it's amazing what people did, what the families did, what the legislators did backed by the other academics across in the US with people like John O'Brien.

Ann:

O'Brien, yes, and Wolfensberger at ENCOR.

Derek:

Wolfensberger, etc, etc. It was that leadership and then some people in Eastern Nebraska did it.

Ann:

He was in Nebraska. He said "this is what we're going to do" and anybody who knew Wolfensberger, knew he was an extremely hard man to cross.

Ian:

Yes indeed.

Gerald:

We've got some people like that in the UK.

Ann:

I mean with that degree of obsessionality.

Derek:

But it wasn't just Wolfensberger. With the whole alliance of American people, you know, shouting out, applauding, giving help, and then passing some of these ideas across to the UK but they haven't taken and so we've got to make them grow.

Gerald:

There's a really interesting comment here which I think we might like to look at which Carl has put up and at the end of it it says that all this was very important at the time but we've really not got to rest on our laurels, the job isn't finished yet. I mean I think that's an important point about innovation, that innovation isn't an event, it is a continuing journey and it has to be constantly reinforced. And I'm gonna have to draw this to a close. One thing we haven't talked about is looking at this from the outside it seemed to me that some of you were incredibly effective in penetrating the Department of Health. I mean you got a full-time job in it Derek, or a largely full-time job as Head of the NDT. David was an Assistant Director of the NDT. You had

civil servants who really understood and were driven by those sorts of values, and of course you had people who then helped write <u>Valuing People</u> as a White Paper (Department of Health 2001) which set out a really formal vision completely at the centre of government policy at that time.

Roselyn:

Yeah. Which is now, all the partnership roles are now all based on the Valuing People principles.

Gerald:

I'm going to conclude by saying that towards the end we have raised this issue about whether the values and the initiatives that you got underway, I mean I think we're all beginning to say well perhaps there isn't the same force, it isn't being constantly reinforced now and that question whether therefore some of the pressure and supports for this way of life, because that's what it is, whether they are being diluted. Perhaps we need to revisit an Ordinary Life in the context of the kind of political economy in which we live today? And on that note I'm going to take chairman's liberty of just finishing there, not allowing anyone to come back of course, but to thank everybody, all of you [turning to Roselyn, Baljit, Gosia, Kiran and Ajay], thank you for kicking it off in such a great way and for joining in the conversation as we went along. We are really grateful to you all. People have talked today about how we began to have a service that existed, we could demonstrate it to people and you started us off by demonstrating the kind of lives that you are able to lead and we all have responsibility to ensure that you do that. And I want to thank everybody else on the panel, not just for the contributions they've made but for making my life possible by sticking to time.

We will get a transcript of this discussion and edit it into a report for our website. Thank you to everybody for joining in, listening in and for the questions and especially for the comments to which we will give a great deal of thought as we analyse the material that we've got. Many thanks to everybody.

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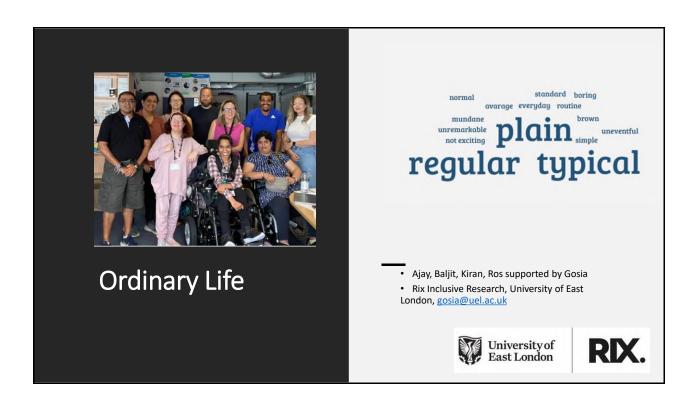
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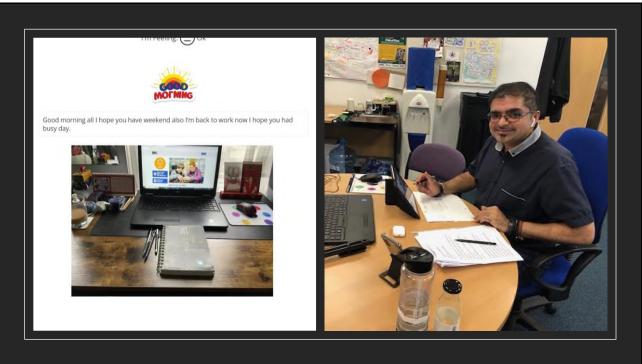
$\begin{array}{lll} \textbf{Appendix} & -\textbf{Slides} \ \textbf{used} \ \textbf{by} \ \textbf{researchers} \ \textbf{from} \ \textbf{RIX} \ \textbf{Inclusive} \ \textbf{Research}, \ \textbf{University} \\ \textbf{of} \ \textbf{East} \ \textbf{London} \end{array}$

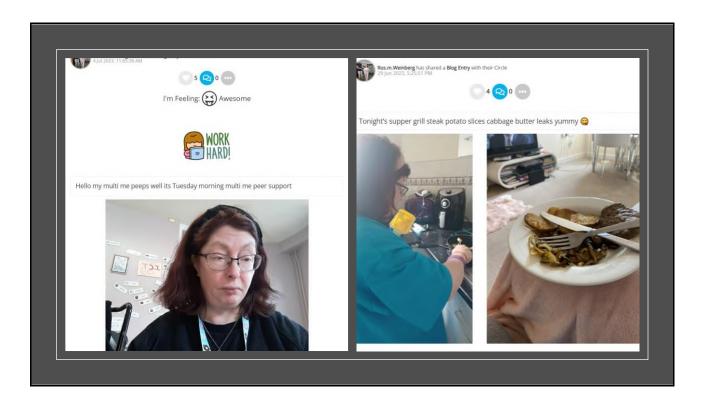


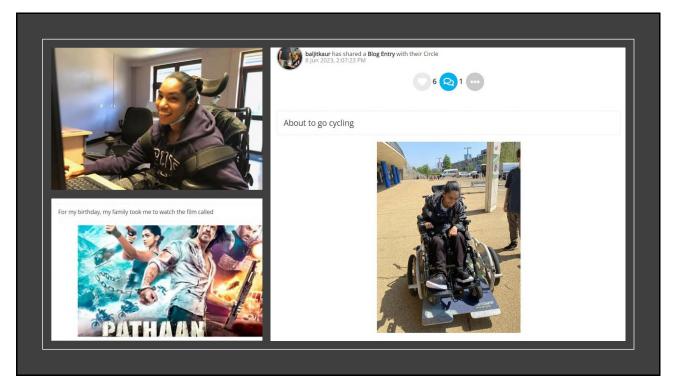


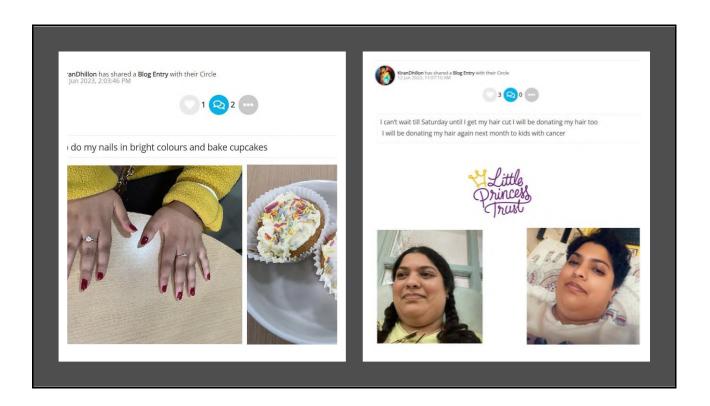
• Simple moments





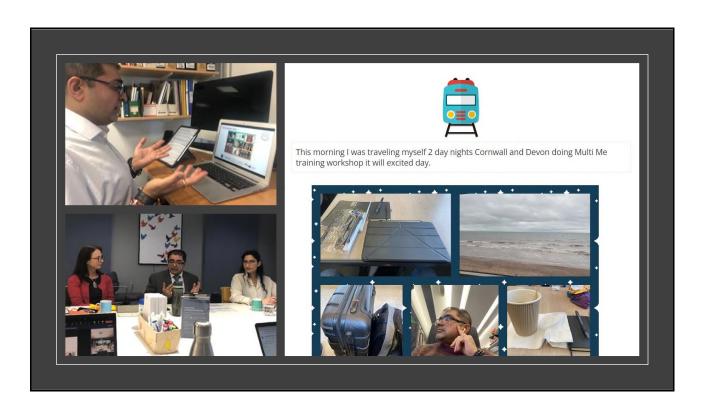


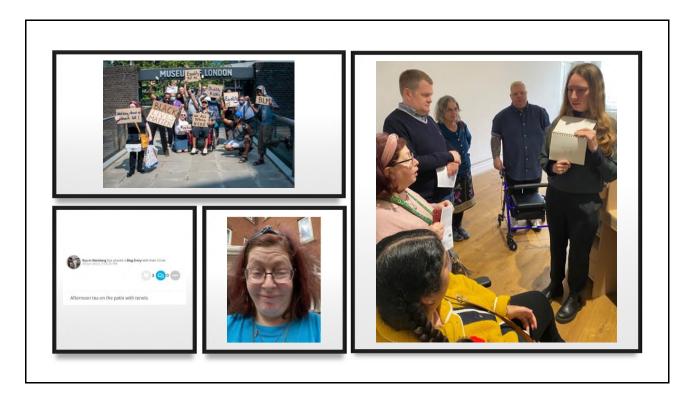


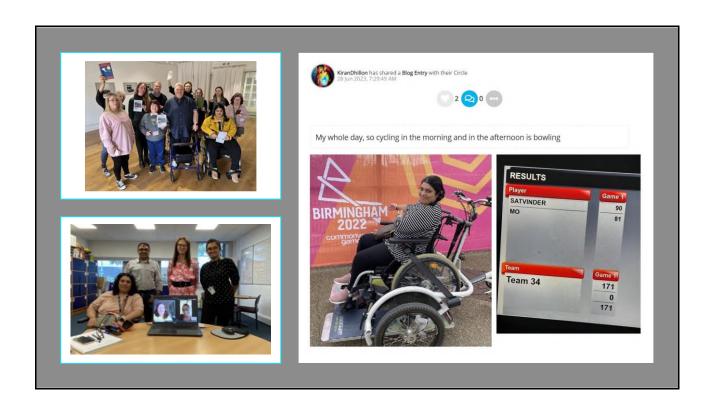


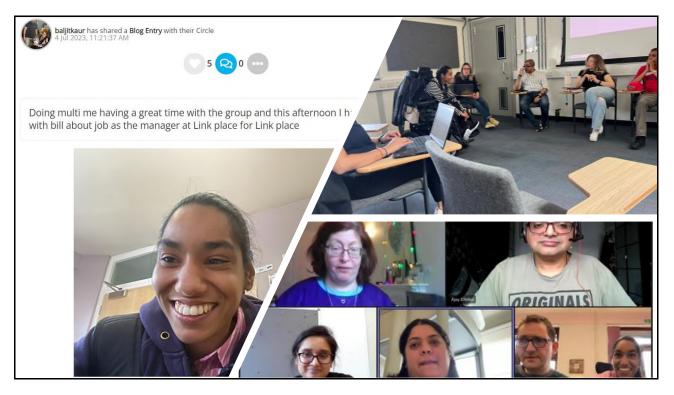
Being present



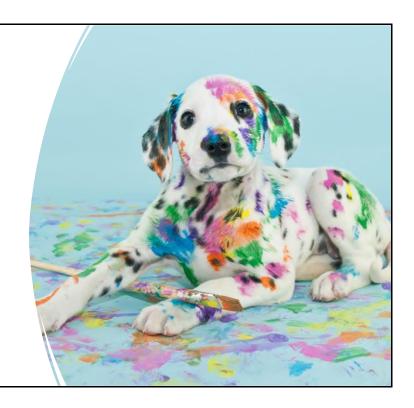




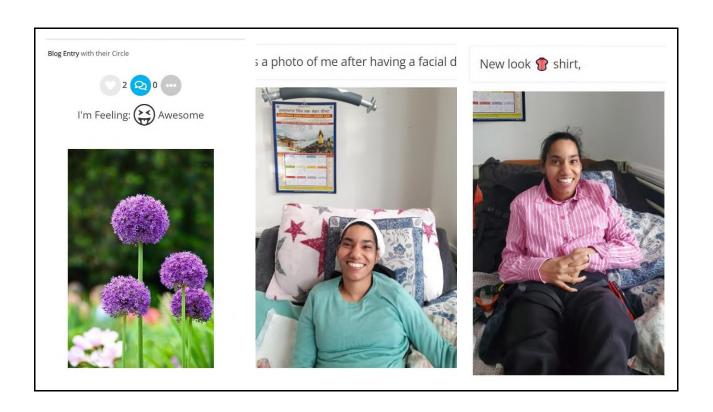




• Finding joy in small things







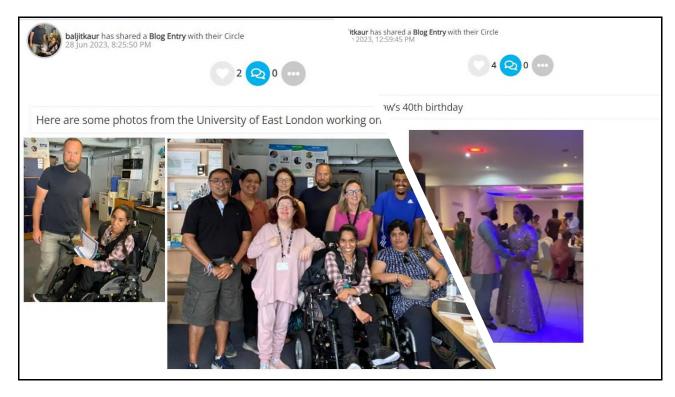




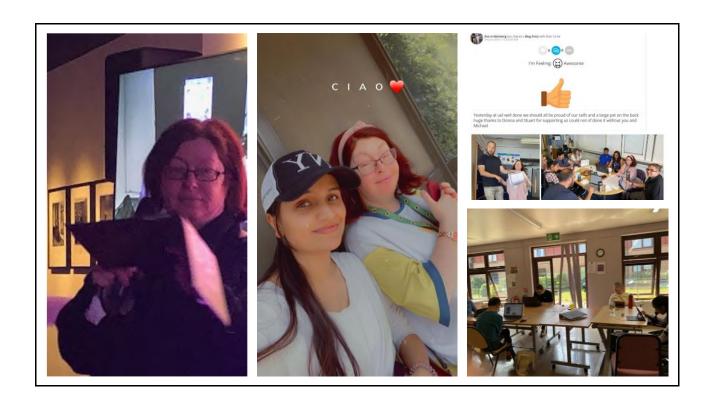
Relationships





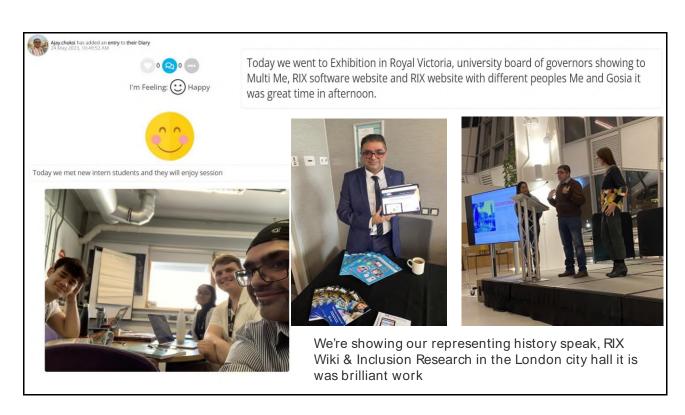


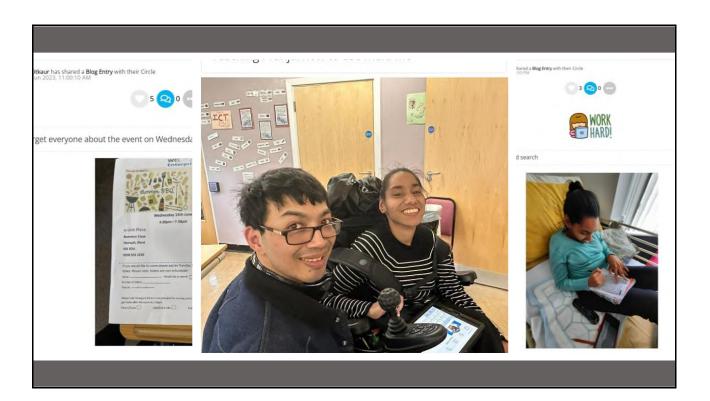


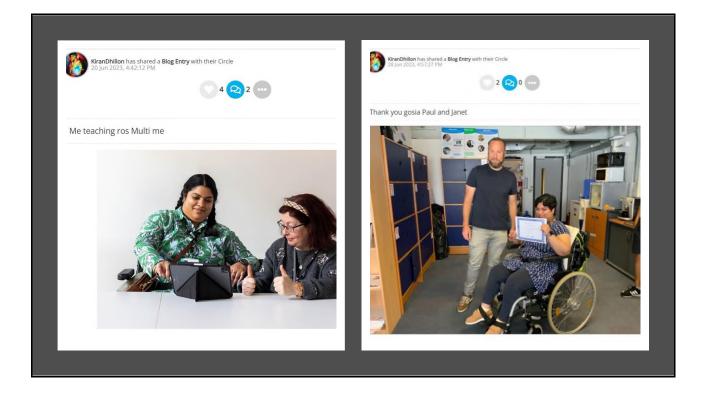


Personal growth



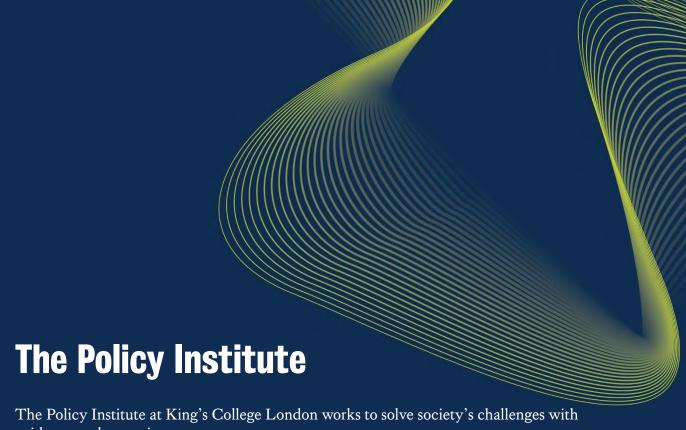












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