

# Evaluating the Participation in Occupations Service User and Carer Mini-Conferences: A Research Informed Teaching Project

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*of their individual journey*

When I reflect on what I witness  
Having the opportunity to listen objectively to a family's experience,  
To face up to the fact that I had probably been influenced by this culture at the time.  
It got a bit much.

A developing professional -  
WHY THE HELL AM I HERE!  
I felt moved, often to tears  
At times I felt over whelmed with my programme.

Oppression and disempowerment,  
This distressed me as I had never realised  
That they are not abnormal.  
(one thing that will definitely stay with me)

One speaker in particular,  
He had to paint an egg shell (I seem to recall),  
She described negative and positive experiences  
(This stayed with me)

I still remember the stories we met on those days,  
A human being before a patient or a person -  
Opened my eyes,  
How to look at that life.

I think that listening  
is very powerful.  
The richness of listening people first hand,  
Telling us about things they really knew about.

I don't feel afraid to ask questions and seek to understand,  
Understand the fears and concerns.  
It also made me reflect,  
I still have that desire now I am qualified.

I think that if I hold on to the thought,  
that they know more about their lives than I ever will,  
I will be able to ensure that I keep on learning,  
of spirituality of human beings.

*Poem constructed by Tricia Smith from direct quotes from student responses*

## INTRODUCTION

Student occupational therapists are entering a profession which prides itself in being client-centred, collaborative and sensitive to the meaning and purpose of every unique human life. 'Occupation' as understood by occupational therapists, encompasses the rich diversity of human activity from the smallest task such as washing one's hands, to being able to carry out a complex job at work. The human relationship to occupation starts at birth and ends at death. Occupational therapists believe that the health and well being of all people is intricately linked with the things they do on a daily basis, and the way that their personal, interpersonal and wider contexts support or hinder their ability to do the things they want and need to do.

Occupational therapists help people of all ages develop, maintain or change the way they carry out their occupations so that they can regain their place in their everyday life, undertaking the tasks which make up their roles and responsibilities. Doing this requires an ability to listen to what people want and to be sensitive to each person's unique desires and concerns. It is only when an occupational therapist is able to see a person as an expert in their own life that they can genuinely work with them to provide workable and lasting solutions to living.

In 2003, to aid the development of this important attitude, the occupational therapy degree programme at CCCU decided to invite service users and carers in to the classroom early on in their students' education. This fitted in with the wider move to include service users and carers in the design and delivery of services (GB Department of Health 2002). It was clear that the involvement of service users and carers in the education of Health and Social Care professionals would subsequently become a required element.

In considering the best way to do this, it was noted that service users and carers were sometimes wary of attempts to include them. They dislike being placed into classroom situations to simply tell their story without understanding the learning context, viewing this as 'tokenistic' (Harrison 2002). Many institutions have dealt with this by instituting training programmes for service users and carers in teaching and presentation skills (Leckey, Walters & Holt). However, not all service users and carers want to undertake such training and for the institution this is impossible to achieve without adequate time and funding.

In order to address these two concerns, the occupational therapy pathway of the Allied Health department developed an innovative approach based on a conference format. Embedded within a module called Participation in Occupations were two 'mini-conferences', one called 'Barriers to Participation' and the other, 'Enabling Occupation'. The mini-conference format is similar to that of a professional conference with an initial keynote speaker who sets the theme of the conference which is linked to the module learning outcomes. Following this, the service users and carers, who form a panel of 'experts by experience' give a 10-15 minute account of their life experiences framed by the conference theme of either barriers or enablers. After a break, there is then an hour for the panel to respond to questions from the students. Following lunch the students attend workshops designed to help them draw out the learning outcomes from the narratives they have heard. Finally, there is a plenary where students can feed back what they have learned during the day.

The mini-conferences have been evaluated highly through the end of module evaluation process, being consistently rated as the most valuable aspect of the course. The impact on student learning has also been demonstrated through a reflective element within the module assessment and this has shown a shift in attitude in a majority of students. Informal feedback from the service users and carers has indicated a high level of approval for this model of involvement.

In June 2009 a Research Informed Teaching project was carried out to determine the impact of the mini-conferences upon the development of student occupational therapists. The aim of this study was to investigate:

1. The impact on students' learning
2. The experience of service users and carers of being involved in the mini conferences

## METHODOLOGY

The research was carried out in two parts. The first part involved employing one of the service user/carer expert panel members, Dr. Diana Crampton, as a researcher to carry out interviews with 5 other panel members. In discussion with Dr. Crampton it was decided that she would produce a series of short journalistic interviews providing some narrative information about the person's life and an impression of being involved in the mini-conferences. Rayya Ghul explained purpose of the research to Dr. Crampton but it was felt important to give as much freedom as possible to Dr. Crampton to develop the interview question so as to reduce bias or any sense that we were 'leading' a response.

Meanwhile Rayya Ghul recruited 3 students at the end of the second year occupational therapy cohort as researchers. It had already been decided to use a one-question online survey to collect data from all cohorts who had participated in the mini-conferences (n=+\_220). The students were involved as much as possible in all parts of the research process. To prepare for participating in the research, the students were invited to read an article (Finlay 2006) and information on qualitative methodologies and data interpretation (Requallo no date). They were sent the proposed question and asked to comment on it. One student responded with a suggestion to reduce bias and this was then agreed upon:

*"In what way, if any, has participating in the service user and carer mini-conferences in the Participation in Occupations module affected your development as a student occupational therapist?"*

The students participated in a half-day training in data interpretation and then spent two whole days carrying out the data analysis and presentation of the results in the form of a letter to the service users and carers expert panel members. The 'letter' was chosen as a more accessible method of presenting findings.

## TRAINING PROCESS

It had already been decided to carry out a 4-stage interpretative process of data analysis (Braun & Clark 2006) so the student were asked to identify the potential responses and how they might begin to interpret the results. Drawing on issues raised in the Finlay article (2006) the students considered how they would or could be confident that the results were valid in the absence of quantitative analysis. Finlay suggests the five C's provide a useful guide: *Clarity*: the degree to which the research makes sense; *Credibility*: the extent to which the findings match standards of evidence and rigour; *Contribution*: the extent to which the research adds to knowledge and debate; *Communicative resonance*: the extent to which the findings engage the attention and interest of the reader, and *Caring*: the extent to which the researchers have shown ethical integrity (2006).

Students reflected on their dual role as a researcher and previous mini-conference participant suggesting this provided a 'double layer of subjectivity' as they would be able to draw from their perspectives to determine the credibility of the responses while being interested in what other students valued and picked out from the experience. The students also considered bias and suggested that the people who would contribute might constitute the 'keen' students who were still in university at the end of term and who had had a positive

experience which they wanted to share. Possible emerging themes were also discussed such as getting to know service users as people, confidence to interact with service users on placement and better understanding of what service users and carers want from occupational therapy.

Students were then shown a 4-stage analysis (Braun & Clark 2006) carried out by a staff member as part of another research project. The students considered the first 'coding' stage, theming the codes, arranging codes under major themes and finally presentation of results with original quotes. Then the students were given a page of raw data from another research project and invited to try out the process, which they did and discussed the process.

## RESULTS AND DATA ANALYSIS

31 students (just over 10%) responded. Initially the students were disappointed with what was perceived to be few responses, but once the process was complete they could see that it was more than enough because it was clear that there was saturation of ideas and also that the time to read and theme and review data was considerably more than they first anticipated on seeing the responses. Students were sent the results and came to the first analysis day with their codes. These were shared and typed into a laptop and printed and possible themes discussed. Each researcher wrote their themes on a 'sticky' and these were shared and compared. These included the challenge to assumptions and prior beliefs, the meaning and importance of occupational therapy, raising awareness, the importance of listening to narratives and the useful learning style. The student researchers were interested in the fact that I was the only person who had 'seen' education themes and this led to a useful discussion on bias and reflexivity. 19 initial themes were identified, the coded text was printed and cut out and then distributed among the themes (Appendix 1).

The students were invited to consider the results in light of the reliability and validity with reference to Finlay (2006) and felt that while there was certain clarity and credibility to their analysis, the contribution to knowledge was missing. They could see that the results did not really answer the original question and they would struggle to present the results as agreed, in the form of a letter. The suggestion was made to look again at the coded text and consider an alternative way to interpret the data in light of this insight and it was decided to focus on the actual verbs being used by the students and use these to re-categorise the codes. The new themes included: questioned, reinforced, learned, challenged and increased. Two further themes were added, What and How (Appendix 2).

The codes were redistributed and then typed up into a table (Table 1)

Reinforced	Decision to study occupational therapy Beliefs about importance of choice [for service users]
Developed	Confidence to face placement challenges Respect for service user's own resources
Challenged	Negative stereotypes Perceptions of occupational therapy

Table 1: third stage thematic analysis (sample)

The students' homework was to see if there were any sub-categories in each data set and to distribute the 'What's' (the data without clear verbs) through the rest of the table.

When the researchers re-met, the possible subcategories were agreed upon (Table 2) and this yielded a much richer set of themes which the students felt provided a more 'authentic' voice for them to draw on (Appendix 3).

<p><b>Service User and Carer experience</b></p> <ul style="list-style-type: none"> <li>• <i>Awareness of the Service User's lived experience</i></li> <li>• <i>Service User Strengths</i></li> </ul>	<p>Power imbalances in mental health Fears and concerns of service users</p> <p>How service users contribute to their own solutions Service user is expert of their own life</p>
<p><b>Professional Development</b></p> <ul style="list-style-type: none"> <li>• <i>Professional Skills</i></li> <li>• <i>Professional Knowledge</i></li> <li>• <i>Professional Attitudes</i></li> </ul>	<p>Prepared for placement challenges Connection between occupation and health Valuing the person not the illness</p>
<p><b>The Experience of Learning</b></p> <ul style="list-style-type: none"> <li>• <i>Lasting Impact</i></li> <li>• <i>Meaningfulness of OT Education so far</i></li> </ul>	<p>Never forget the people Complemented theoretical work</p>

Table 2: Examples of fourth stage analysis

The coded statements for the 'How' section were themed (Appendix 4) to produce information on how the mini-conferences affected learning (table 3)

<p><i>Enhanced other forms of teaching</i></p>	<p>More real than case studies Listening to narratives enhance academic content</p>
<p><i>Different learning style</i></p>	<p>Fitted own learning style better – avoided demotivation Overwhelmed by more academic parts of the programme</p>
<p><i>Learning from the stories of Service Users and Carers</i></p>	<p>Learning from negative and positive experiences of care Good to hear service users express dissatisfaction</p>

Table 3: Examples of themes from 'How'

Full versions of these tables are available in the Appendices.

Drawing on these results the students completed the project by writing a 'letter' to the service users and carers. Each sentence of the letter can be linked to an illustrative quote from the original data.

## INTERVIEWS WITH MINI-CONFERENCE EXPERT PANEL MEMBERS

### A BRIEF OVERVIEW OF THE INTERVIEWS

#### Dr. Diana Crampton

By way of introducing some comments on the interviews undertaken, I would like to start with an anecdote.

Explaining to a friend what was involved in this project he said, “What do *you* know about care services?” I replied, “Well, I have a diagnosis of schizophrenia, I have a teenage son with Fragile X chromosome which causes cognitive delays, and I take care of a demented mother of 86 years”. He was a bit taken aback, as he knew all of these things, but had not put them together, nor had he, until I explained to him, perceived what a fight there is to attempt to ensure the best possible outcomes for the people you care for or for yourself. This is indicative of a general common-sense attitude to disability, which is that the person has to be almost dead on their feet, or visibly disabled before being considered a care user.

In fact, one of the strengths of the mini-conferences is that each individual is presented with a strong, logical, rational voice and the Occupational Therapy students are therefore confronted with people who have come to terms with their situations. A further factor in the mini-conferences has been to show that each of the people on the panels has had to fight to be able to access services for themselves or for the person they care for. (This obviously has implications for the policy of allowing users to access their own services with grants provided by government, the sort of policy which would be ludicrous for people like my son. I enclose my own mini-conference presentation as an addendum.)

All the interviewees were strongly committed to participating in the mini-conferences and perceived these as being both beneficial to themselves, as in this way they were able to depict a story about their lives, and also as beneficial to the Occupational Therapy students. In particular one interviewee was pleased that his own story had been used in an essay by a student. The experience delineates the service-users and carers as in some sense experts in a situation where previously it has been possible for certain people in authority to “speak over” them.

The interviewees have been most impressed (perhaps even slightly flattered, my term) by the interest and attention paid to them by the students. In addition, the students themselves have been most appreciative and in some cases sent a thankyou card signed by the entire class. A couple of interviewees expressed that the questions from the students had been useful and had prompted them to reflect further on their own situations. One interviewee had noted a certain surprise in the students.

No interviewee had seen a downside in the experience. The format of the conferences is viewed as good, with just 20 minutes to speak. Being on a panel with people with different conditions, service users and carers, and with different experiences but curiously similar in some ways was interesting. As one interviewee commented “It’s interesting to hear the strategies for staying well.”

All the interviewees stated that they would talk again, if asked. Some commented on the payment, which was seen as useful and helpful, not just in a pecuniary sense, but also in validating their input.

Overall this experience has been fruitful and useful for both students and service-users and carers. I would strongly recommend that this continues as it offers the new Occupational Therapists an insight into the lives of people they will be helping.



## INTERVIEW WITH CRAIG POTTER

11th June 09

*"I was born with cerebral palsy and have had five corrective eye operations, three operations on my legs and two convulsions not related to impairments. Everything that happens, you have a label and a diagnosis and you are medicalised, you are seen through via the spectrum of this is a person with an impairment.*

*"I've experienced how surgeons behave, and the whole raft of caring and nursing and I've also experienced in terms of care, as parents, Mum becomes carer, recognised by the state and you get benefits accordingly.*

*"I've had some contact with Occupational Therapists but before meeting the students, the idea was you go to be fitted for a wheelchair or a rail and the OT makes sure you get it 18 months later. The OT has also the job of enabling the individual to negotiate the world they live in.*

*"I went to a mainstream school but part of the specialist unit. I went into mainstream at 10 years old. Before it was exclusively the "physically handicapped class", before 1988, not formalized education but jam making and basket weaving. With Ken Baker's reforms and the advent of GCSEs, even disabled children were required to have some formalized education. Even Lady Warnock said there should be inclusive education. When I finished I went to secondary, then to college, then to University and did a Diploma in Business and then on to a degree in Business Studies and Applied Social Science at Christ Church."*

I asked Craig how he felt about sharing the information on his experiences with a group of people he did not know.

*"I loved it and I still love it and they keep inviting me. It's fine. It's really rewarding because every time you do it your life has moved on and the challenge is you are talking to a new group of students. So it's a balance between keeping it fresh for yourself and giving students something that they can apply from your experience. I think the real value is that you take ordinary people, we're a group of survivors, we have overcome barriers to be there. That's a slight irony because everybody has been enabled in order to articulate to the students.*

*"It is a benefit to the students because they can apply what they learn from a textbook but for us it's beneficial because we get challenged by the students and analyse life in a different way. One time a student said it didn't sound as if I'd faced many barriers. I stopped and said that what you won't realise is it still took me 45 minutes to get dressed. You get frustrated because things take so long.*

*"Another student said what is the difference between the difficulties you face and others face because if you define a barrier as economic or social, such as a student may come from a broken home and have had to overcome barriers/ there are all these things. I love the spontaneity and they love it."*

On the format of the session, Craig comments *"I think it is designed really well because everybody who is there gets to tell their story as an individual and after the break you come back and the students ask questions which can be answered by anyone on the panel. So for example, they may ask about inclusion and I will say it served me really well but a parent of a child who could not cope in mainstream might not agree. It's really good. The answer is that before inclusive education all disabled children regardless of aptitude would be put in special schools. Mainstream education has allowed children to be seen in terms of their individual aspirations but there has to be a balance. You had to have a one-size-fits-all to change things but some children were left behind and for them the barrier became mainstream education. Education is now tailored to the needs of the child"*.

Craig assents that it was probably better to be one of a group of carers and service users talking.

Of his impression of the students, Craig says: *“on the whole they weren’t knowledgeable because I think that most of them/ everybody’s experience is their own experience so you can’t know how people will react. What I found is that the students are really open to what people have to say.”*

*“For the most part the students won’t have experienced what it’s like to be in [a psychiatric] Hospital or to have operations or to have vision impairment.”*

*“Sometimes we are able to challenge some of the social constructs that they are part of, e.g. as a child the fairy story has the bad person as always disfigured and you make them think how the body and the person are very interrelated to each other.”*

Craig was given the opportunity to repeat some ideas to the students. *“There are bits that I’d repeat when I saw them. I think that for me the very fact that we’re asked to speak to the students is a sign of how far we’ve come and it’s really positive and that’s the value for somebody like Mark, who is a man but also a person with mental health difficulties, that challenges the stereotype and I like to think that I challenge too – I take pictures of my two girls and talk about my career, it’s more than a diagnosis, a client: you’re a whole person.”*

*“A few years ago you wouldn’t have been asked: we’ve gone from jam-making to careers and marriage. The biggest barrier is that people are able to take and share their experience: it will overcome barriers. I hope that in 20 years’ time a grey haired OT will say, I remember Craig.”*

Craig found the experience useful and commented *“I love it and I’ll carry on doing it for as long as possible. The experience has all been positive and I hope that the university carries on funding service user participation. It’s been really good to talk.”*

## IAN MACLAREN

2nd June 09

*“My first contact with Occupational Therapists was at the Buckland hospital doing neuro-physiotherapy and I was with a group of OTs. I didn’t have the foggiest clue what occupational therapy was. I have a form of MS called Primary Progressive. My daughter is 19 so it must have struck about 20 years ago. It’s not a terminal condition: it’s just a dreadful nuisance: I can’t drive anymore. I get dropped at University and this is my greatest place” (The interview is taking place in his carrel at the Templeman Library, University of Kent.) OT seems to be essentially related to life experiences and how it can be fitted in with life.”*

Ian’s experiences with the care services are as follows. He is ostensibly under the Health Service, his Professor of Neurology is based in Queen’s Square in London. Of the NHS he says *“when it works, it works beautifully, with hospital transport to pick me up and take me there.”*

How did Ian feel about sharing his experiences? *“I am fully open and I like to converse with people and share my ideas. I hope that I’m making life for their course more easy in terms of responses. Some people clam up and become recessive in a way and I like to be with people because if I can be of any positive use in the educational process, I like that a lot.”*

*“I’m a conversational type of person and I’m firstly relaxed in general terms in the mini-conference. As long as there are not any devious questions” (Ian chuckles). “People are quite understanding.”*

When asked if it felt better to be part of a group of service users talking, Ian avers *"I can do it in a singular fashion or a group fashion. When we went to Dover Christ Church, they have a base there too, bigger, my biggest problem was getting around. But I have my stick and I can get pretty much anywhere with that."*

On the questions of the students, Ian says *"I was surprised that they were interested in me. I don't think that people have any interest in me and it was great. It put me in different situations with other students and I felt valuable instead of being a sort of useless chump."*

*"It was quite a nice experience to be thrown in with the other students and also to be rotated with the other students: I would say 'can you come to the other table'. Again, I felt quite useful rather than useless."*

Ian was asked about his impressions of the students. *"They were surprised and interested. Most people when they see someone with a stick they think 'have I had a dreadful accident.'. The reason I like using a stick, when I was working in London people would say, 'how awful this young man is drunk so early in the morning'. So the stick is almost a kind of validation."*

*"People are surprised and interested as well. Some of the other students: there was a lady who had dreadful problems with her son and she couldn't bring him into the caring process. I think he was resistant, but I think she weaned him around to her direction."*

Ian's message to the students is that he had no problem talking, or relating his experiences. *"I think that people ought to try to understand one's experiences. It's not... It's useful, I think, for other staff and students to try to understand one's method of getting through. So, yes, I think if people are open and they can converse with everyone, then I've a feeling it ought to be made positive and caring, in a sense."*

Ian has participated twice in the mini-conferences and would do it again. *"OT, the therapy side, is actually so useful, that is part of the therapy, talking is part of the therapy. One of my nightmares was I wasn't able to speak anymore."*

*"If people are tolerant and understand it, it's as beneficial for your alter-ego to become ensconced with that."*

For Ian, the only downside of the mini-conference was getting there. Ian still walks. *"My mobility is compromised because of inability to drive. Despite that if people are considerate and they know what my limitations are then it can be accommodated and I'm very happy to do that."*

Finally, did Ian have any other comments?

*"I actually did benefit a lot from my understanding of OT from my first experience of it at the Buckland Hospital, probably about 7 or 8 years ago, and I don't know whether the Buckland is still operational. I was an in-patient (I don't like being hospitalized at all) but I understand that the neuro-rehab is now based at the Kent and Canterbury. I was hospitalized for a period of about fifteen days."*

*"The staff at the Buckland were excellent. They had a great gymnasium there and a useful set of therapies. I can't use my bike but there was one of the static bikes. Nurse said to me to put up the pressure. The nurses were good."*

*"Another difficulty is feeding: not a very nice thing. My wife has to do it."*

*"At present the neurologist is putting me on to Cambridge, where they have a genetic manipulation possibility."*

19th May 09

Mark Kilbey is an active member of a number of organisations dealing with people with mental health problems.

He is Director of an independent charity, the Canterbury and District Mental Health Forum, where he works 35 hours a week. He is South East Regional Coordinator of the National Survivor User Network, a service user led organisation, where he works seven hours a week. This second organisation has been running for about two years and has now been awarded £30,000 to deliver to the network, aiming to recruit more people. Mark is a member of the South Kent Council of Service User Forums, which includes 6 user forums in Kent and deal with all the commissioned groups, funded by Kent County Council (KCC) and the National Health Service (NHS). There is also a voluntarily run bi-polar disorder group for East Kent which meets in Canterbury with up to 20 people each time and this will find Mark there too. He also runs the Media Action Network South East, an anti-stigma and discrimination group with 35 members at present, supported by Time to Change (Comic Relief).

Mark has presented his story at the Participation in Occupations mini-conferences about five or six times. He is a sufferer of Bi-Polar disorder I, and has been variously unwell and well for some 20 years. He lost two jobs, with the police and with KCC through mental illness. He was a detective for 18 years.

With respect to sharing his life-story with the students of Occupational Therapy at Canterbury Christ Church University, Mark's policy is *"to be totally open about (my own) mental illness, because if I'd known where to get advice outside the statutory services, I wouldn't have had to endure further problems."* He feels the mini-conferences are important because he is sharing information with *"potential professionals who will be dealing with people like me"*.

Although you can enlist help as a service user, it does not mean people will listen, Mark avers and says, *"this forum was a place to say that not all things are great"*.

Mark has spent three weeks in intensive care after a suicide attempt and is aware of what suicide can mean for not just the person attempting this, but also for generations of people related to the sufferer.

Not many people want to admit to having some mental illness and these talks are about the possibility of leading a normal life, although his attitude is that mental health is with one forever, given certain circumstances. He feels it necessary, he says, *"to live in the grey"*, avoid the depression and the tremendous highs.

Mark was asked his opinion about the format of the mini-conference. He felt that *"it's long enough: 20 minutes. Also you have various disabilities – really interesting because although I've never spoken to them, and our illnesses are very different, all the experiences are identical. That's interesting, it shows you that you're discriminated against, and the general thing that society does. It's interesting to hear the strategies for staying well."*

Mark felt that being in the company of other service users and carers was possibly better (than being alone) because of the broad range of people's experience. *"They are a bunch of talented people and it was incredibly useful to me and enriching for the students because they are listening to people who could have sunk without trace and you as professional people can have a part in this recovery, assuming you have the right attitude."*

Mark told me that he is *“always pleasantly surprised that the students seem very interested and you can see that from their questions. The best questions are when people say something out of their own experience or something about a person who is close to them, this shows they are interested”*.

The first time Mark attended a mini-conference, students subsequently used his story for the essay that formed part of their coursework and came to see him. He was impressed that the students were very good and ‘got it’. *“You could see the students wanted to get information in more detail.”*

Mark has always found people ask questions and it is very good to have a mixture of backgrounds amongst the people presenting their stories, which are very different although the experiences are quite similar. The good professional is not the egotist who says they have all the answers but the one who says there’s a self-help group for instance.

Mark has always been impressed with the attention the students give and also the quality of the questions asked and always comes away feeling that they will be better at their job. *“I always feel it is 100% positive, it’s always been that I’m pleased that I’m involved with this.”*

Mark was critical of Occupational Therapy because it seemed a waste of time sitting around and making egg cups, when you’re not allowed to boil an egg. A most positive experience for him was when he was allowed to cook a meal. *“You’ve got to get the individual back to their reality. It’s necessary to give people choice.”*

Mark found the experience with the students useful and would do it again. He comments: *“In a way, after years of being secret, it is nice to sit and be totally open and it is useful to me. I didn’t feel like a pet, or in a beauty pageant, where you’re wheeled out by an agency. This is not like that, you are enlisted as part of a team and you are remunerated.”*

Downsides to the experience? *“From my perspective I haven’t had any bad experiences. My only comment would be that a broader base pool of service users could be engaged in this work and no training of health professionals should be undertaken without such involvement. This will be of mutual benefit to trainers and trainees. I sometimes don’t feel CCCU hierarchy seems to grasp the basic fact, that Rayya certainly does, that first hand experiences inform students better and enhance the training experience.”*

Most service users and carers hope to make some changes after the appalling experiences they have had. *“I don’t think health professional training should be delivered without reference to people who are service users. Some psychology students, for instance, didn’t ever meet a mental health sufferer. It’s a sort of arrogance.”*

## JANET HATTON

3rd June 09

Janet Hatton is a carer for her son A\*\*\*, who is now 28 and who was born with complex heart problems, subsequently suffering brain damage after surgery at the age of four months. He has cerebral palsy, epilepsy and a bad heart. He is one of four children. Janet’s experiences of the health services include meeting the health visitor, occupational therapist, going to the hospital. Also nurses come out and she has experience with the wheelchair services. A\*\*\* went to Chailey Heritage, a boarding school, one of the leading schools for severely complex disabilities.

Janet felt that it was possibly easier talking to strangers about her experiences. In her mini-conference she steered away from more emotional points, like whether the hospital was to blame at the birth of her son. She also steered away from negative aspects like declining wheelchair services, because she felt she didn't want to paint a poor picture of a service which might improve. Nor did she tell the OTs that her son, her husband and herself have become Catholic converts. She felt that religion might upset people. Nor did she touch on family relationships. She states that still to this day her oldest son resents the time spent on A\*\*\*. He seems to have a problem with imperfection, and also has a niece with disability.

Janet felt that the situation had changed her, but that she would no longer wish to be the person she previously was.

Janet did not talk about the financial aspects at the mini-conference. She says *"When I had A\*\*\* you couldn't work if you had a disabled child. Carers don't like to be talked over anymore than the disabled. Sometimes in a group thing, if you are with your disabled person and you can find yourself being discussed. A\*\*\* doesn't want to be talked about. He speaks well but his understanding is not as good as his speech. He has no concept of abstract things, like feelings or pain. He can't express some things."*

*"It is important to let carers feel part of the team if they want to be: some might not want to know."*

For Janet, the format of the session could have been improved by having a longer Q/A session. However, she mentions that she did not take part in the workshops and there might have been a good opportunity for more questions.

Janet definitely felt it was better to be part of a group of service users and carers. *"I would have said it was easier. If you had been one on your own ...it was interesting as a carer to hear what the others had to say. I did bear in mind that the others had disabilities so I bore in mind and took care of what I said."*

On the subject of the questions from the OT students, Janet said *"Some of the questions were quite searching. One question was difficult to answer, but I can't recall what it was. The whole thing was therapeutic, having to stand back from my situation and talk about what was appropriate and it made me review what I had to say and it seems to have been an unintended consequence that it was therapeutic."*

For Janet *"the students were very attentive and interested but it was difficult to gauge as a speaker how knowledgeable they were. However, the more searching and deeper questions were from the more mature. In my life I found that the best therapists were those with the widest experience of life, either those who had another career, or had a disabled sibling or some other problem. I have also found that those with a sense of humour are better."*

*"Many people may have gone in at 18 and won't get experience, so it backs up how work experience is important."*

Further comments from Janet: *"One of the most frustrating things is that there is lack of choice, although there are some carers who actually adopt and knew what they were taking on. The Catholic Church would say that God only gives disabled children to people who can cope."*

Janet would be willing to present at a mini-conference again. She has presented just the once. *"I was put in for Carer of the Year on TV and got through to the quarter final and they did four or five hours filming."*

Janet also takes care of a granddaughter with disabilities. She has been doing this for seven years. There seems to be a genetic component to the heart difficulties, she tells me.

I asked Janet if there was a downside to her experience of giving the mini-conference. *"No I don't think so. Sometimes it's not good to drag up the past. If I had been a different sort of person it might have been difficult."*

Janet stated that it was good to receive payment as she is now 60 and a pensioner. Her GP tells her she knows more about hearts than he does, but, she says ruefully *"I can do nothing with it."*

*"What was useful from the mini-conference point of view was that with A\*\*\* at home for 20 years and S\*\*\* for 9, when I did the talk that gave a more rounded view although some things have not changed at all, some things are different. There are more disabled children around than years ago and there are strains on the services, there seem to be more financial constraints than when my son was young. Although the medical services have moved on, hospitals seem strained and stretched to the limit."*

*"Finally I would say that it is extremely important for therapists to have good communication skills, both written and spoken, to present the case. It is important also for therapists to give the full picture. Carers need to shout loudly."*

## LAURA DREW

20<sup>th</sup> June 09

Laura Drew is visually impaired, registered partially sighted. She is dyslexic and has learning disabilities. She has problems with her ears, with a slight hearing loss and had operations when she was younger. She has scoliosis, curvature of the spine and a congenital malfunction of the knee joint. She has had six operations on the right knee, so walking and standing for long periods are both difficult.

Of the mini-conference, Laura says *"it was a bit nerve-wracking, but I didn't mind it. It wasn't a problem, although I couldn't see the students very well."*

*I liked being part of a group with Craig and some of the others. I liked being part of a panel. I didn't mind doing the talk: I quite enjoyed it and have done it twice."*

Asked whether any of the students' questions had any impact, Laura replies *"I remember the first time, one of the students asked me about my school life and how it affected me and that was quite a good question. I answered it well."*

Laura felt that the students were surprised by her situation. *"When I particularly talked about my knee problem and my knee dislocated quite a lot, my right knee had dislocated 200 times, since I was 8 and they were quite surprised. I was only 8 when it first happened and the medical authorities thought I would grow out of it. They wouldn't do anything till I was 16"*.

*"When I talk to the students, I include everything so they remember me. I am also on Rayya's wheel."*

Asked if Laura found the experience useful, Laura unhesitatingly replied that she did and that she would definitely do it again.

Laura didn't think there were any downsides to this experience of the mini-conference and had no further comments.

## LETTER TO THE SERVICE USERS AND CARERS

Anahita Hashemi-Ahmady, Carol Jarvis and Patricia Smith (Year 2 Occupational Therapy students)

This letter was written as a way of presenting the results of the Research Informed Teaching project in a clear and accessible way. Every sentence of this letter is based on statements made by students who responded to the research question: *In what way, if any, has participating in the Participation in Occupations service user and carer mini-conferences influenced your development as an occupational therapist?*

Dear Service Users and Carers

You may not realise how much of a difference you have made, not just to us as individuals but through our work to the lives of other people. Although we all thought we knew what being "person centred" was all about, suddenly we realised how much more we have to learn – a humbling experience, and sometimes even an uncomfortable one.

Listening to you talk about your experiences provoked insights and reflections that were often challenging but which had a positive impact on our development. Hearing about negative experiences made us realise the importance of collaborating and building relationships in future practice. At the beginning of the course there are always some students who are wavering in their vocation and your contribution reinforced that they had made the right choice.

This experience gave us a new perspective on the people we will be working with. We gained an awareness of the lived experience of others and this gave us a new understanding of issues such as power imbalance and stereotyping. The opportunity to hear the carers' perspective was unique and highly valued. To look at ourselves from your perspective challenged us to rethink what we will be doing as occupational therapists. We learned to ask people what's important to them and to always recognise the strengths of those we work with.

We took what we learnt from you into our placements and it changed the way we practised. We questioned the reality of what's on offer, and went out determined to offer more as a result. We are developing professionals, and listening to you influenced that development in a positive way. The value of skills that we had learned about, like building relationships, became real to us, and our determination to do better for service users grew.

One of the biggest changes was to our attitudes, respecting you as experts in your own lives and your experience of healthcare. We became aware that you care about what we do and that it matters to you that we are authentic. We learned the importance of looking at people as individuals, and valuing the person not the illness.

The experience did not only develop us as occupational therapists but as individuals. It made us explore our thinking which led to greater open mindedness and self awareness. Our perceptions changed and triggered new thinking, which increased our confidence. It clarified our beliefs and values and steered us into areas of practice which we had not considered before.

This was a different kind of learning experience which added depth to our understanding. The opportunity to listen and ask questions was priceless and one of the most helpful aspects of our education. It will stay with us forever, and we would like to thank you.



## LETTER TO SERVICE USERS AND CARERS WITH ILLUSTRATIVE QUOTES

You may not realise how much of a difference you have made, not just to us as individuals (letter)

*“Made me aware of my own values and beliefs”* (direct quote from data)

but through our work to the lives of other people.

*“when interacting with service users on placement, I don't feel afraid to ask questions and seek to understand their perspective and individual circumstances.”*

Although we all thought we knew what being “person centred” was all about,

*“The meaning of person-centred care became more prominent and raised for me just how important it is to put the patient first in all treatments.”*

suddenly we realised how much more we have to learn – a humbling experience,

*“It doesn't matter how good we look in our SOAP notes, if our treatment of service-users doesn't stand up to their scrutiny, it isn't good enough.”*

and sometimes even an uncomfortable one.

*“This distressed me, as I had never realised that there were so many environmental barriers to participation in occupations.”*

Listening to you talk about your experiences provoked insights and reflections that were often challenging

*“It is this experience which has really made me consider that as a student OT I have to question practice and consider the 'cultures' in the work place,”*

but which had a positive impact on our development.

*“it has helped to [...] identify areas that I need to focus on when in practice and also prepare me for future challenges.”*

Hearing about negative experiences made us realise the importance of collaborating and building relationships in future practice.

*“The way that it has affected my development most significantly is in regards to demonstrating how important being client-centred is. This mainly stems from one service user's experience with some professionals in health and social care who had a negative impact upon them through not listening to them or responding to their needs.”*

At the beginning of the course there are always some students who are wavering in their vocation

*“at times I felt over whelmed with my programme, and that not a lot was sinking in and making sense.”*

and your contribution reinforced that they had made the right choice.

*“It also provided a new sense of encouragement and motivation to want to become an OT so that I can enable a person to overcome their barriers.”*

This experience gave us a new perspective on the people we will be working with.

***“Participating in the conferences really opened my eyes, gave me awareness of the client's perspectives”***

We gained an awareness of the lived experience of others

***“The conferences give you an opportunity to hear what it is like to have an illness or disability.”***

and this gave us a new understanding of issues such as power imbalance and stereotyping.

***“This enabled me to understand that individuals with disabilities are denied many opportunities to engage in daily occupations [...] I recognise that they are not abnormal and enjoy participating in similar occupations to me.”***

The opportunity to hear the carers' perspective was unique and highly valued.

***“I had never considered the issues of client consent from the carer's perspective.”***

To look at ourselves from your perspective challenged us to rethink what we will be doing as occupational therapists.

***“[The conferences] also enabled me to further my skills in understanding patients' needs and the many ways in which occupational therapy can help [services users] in a person centred way.”***

We learned to ask people what's important to them and to always recognise the strengths of those we work with.

***“I have learned the importance of taking peoples view and feelings on board and how they contribute to finding solution to their problems.”***

We took what we learnt from you into our placements and it changed the way we practised.

***“when interacting with service users on placement, I don't feel afraid to ask questions and seek to understand their perspective and individual circumstances.”***

We questioned the reality of what's on offer,

***“It then dawned on me that there is limited resources to actualise my goals in meeting the needs of the clients.”***

and went out determined to offer more as a result.

***“It has helped me on how to improve upon my standards”***

We are developing professionals, and listening to you influenced that development in a positive way.

***“This has allowed me to hear their opinions and experiences, and use these to develop my own beliefs, values and attitudes around the service I would want to provide as a professional.”***

The value of skills that we had learned about, like building relationships, became real to us,

***“I found that actually meeting and listening to the narrative of real service users and carers gave a greater depth to the academic stuff we are taught.”***

and our determination to do better for service users grew.

***“I have taken a mental note from the experience that LISTENING to the service user and/or carer enhances the therapeutic relationship.”***

One of the biggest changes was to our attitudes,

***“I also questioned my own feelings, thoughts, values, beliefs.”***

respecting you as experts in your own lives

***“I think that if I hold on to the thought that they know more about their lives than I ever will, I will be able to ensure that I keep on learning and don't become complacent.”***

and your experience of healthcare.

***“I think one of the most valuable things I got from the mini-conferences was how the service users felt about their experiences of the services and treatments they had experienced.”***

We became aware that you care about what we do

***“We need to remember that service-users are our equals - that they see what we do - and they make judgements, whether they say so or not”***

and that it matters to you that we are authentic.

***“I remember one carer saying how obvious it is when someone doesn't really care about what they're doing”***

We learned the importance of looking at people as individuals, and valuing the person not the illness.

***“enabling me to get a real understanding about how the service user feels, and the importance of not labelling people with their condition, and understanding that each individual is different.”***

The experience did not only develop us as occupational therapists

***“these conferences will enhance my training in becoming an Occupational Therapist as I will now view things from the service users perspective, making sure I do not patronise the user or in any way ignore their human rights.”***

but as individuals.

***“My participation in the service user/carers mini conferences in [...] has had a significant impact on the way that I now view real people in the real world, with real issues.”***

It made us explore our thinking which led to greater open mindedness and self awareness.

***“enabled my thinking and attitudes to move to a more healthy place”***

Our perceptions changed and triggered new thinking, which increased our confidence.

***“it was great to hear them express their dissatisfaction - because that's how some of our service-users might be feeling when we meet them, e.g., in hospital, but don't feel able to say so. So I'll always try to remember that.”***

It clarified our beliefs and values

***“It was useful in that it complemented the theoretical work covered on the importance of spirituality of human beings, in overcoming new situations and adapting to them”***

and steered us into areas of practice which we had not considered before.

***“It was at the first of these conferences that I knew I wanted to be a mental health OT”***

This was a different kind of learning experience

***“having the opportunity to listen and engage with service users and carers at the conference is a far more profound and effective learning experience”***

which added depth to our understanding.

***“I found that actually meeting and listening to the narrative of real service users and carers gave a greater depth to the academic stuff we are taught.”***

The opportunity to listen and ask questions was priceless

***“these conferences were priceless as they provided a unique opportunity to understand our services users perspective of their individual journey through the care system [...] as they gave us the scope to explore, debate and ask direct questions.”***

and one of the most helpful aspects of our education.

***“The opportunity to participate in the mini conference in the first year was one of the best experiences of this course to date.”***

It will stay with us forever,

***“I will never forget some of the people I was fortunate enough to meet at the mini conferences.”***

and we would like to thank you.

***“Thank you for the opportunity”***

## PERSONAL REFLECTIONS

### PATRICIA SMITH, STUDENT RESEARCHER, S07 COHORT

Participating in this research project has been a powerful learning experience for me as an occupational therapy student and as a person. My understanding of the relationship between service users and therapists, and how this develops through mutual listening, has deepened. Participation in the process of research has changed how I understand qualitative research and strengthened my awareness of experiential learning, which has given me new insight into the experiential nature of the occupational therapy process.

On starting the project, I had a sceptical approach: what could we really learn from the respondents and how authentic would it be? I had limited understanding of the process of identifying themes, and I wondered about how 'objective' or accurate this could be. As the research progressed, however, I became fascinated by how the raw material of individual voices refused to be manipulated out of shape by the sorting and re-sorting of 'data'. I became aware that the subjectivity of the process, which I had initially seen as a weakness, also gave it a mysterious strength, as layers of data and interpretation seemed to develop a natural rhythm and authenticity. Service user's voices were reflected through students' perceptions, and the voices of students were subtly changed by the researchers' thinking. The subjective power of individual voices was striking, and I became interested in how alternative mediums such as poetry can be used to express the subjective quality of research in new ways. I wrote a poem, which combined phrases from a range of students into one 'story'. This gave me a new insight into the qualities which are unique to qualitative research.

Working collaboratively was an important aspect of the experience. As a team we had different qualities, approaches and attitudes, and our collaboration was strengthened as a result. The value of collaboration was also evident in the data; students talked of listening to service users and being changed as a result, of wanting to work more collaboratively because of their hearing of the mini-conference stories. Many individuals talked of one story making a difference, and the transformative power of narrative struck me. Again, there were layers – the students also had their stories of what they had heard, and how this had changed them, and we as researchers and practitioners were changed by reflecting on their experiences.

Having a background in education, I was struck by how the mini-conference functioned as a different kind of learning experience. So many students seemed to connect with this way of learning, often contrasting it with their negative experiences of traditional approaches. I became aware that experiential learning seems to have a special value for many people, and this led me to reflect on my past career as a teacher, and to make links with my future career as a therapist. Occupational therapy has always been concerned with experiential learning, with changing being through doing: an obvious insight, but one which became fresh for me through this experience.

### CAROL JARVIS, STUDENT RESEARCHER, S07 COHORT

I was invited by Rayya Ghul together with two other students, to participate in the Informed Teaching Research project, this was an opportunity to participate in an exciting project and learn more about the research process.

I had done some preliminary reading prior to the first meeting. Rayya explained the type of research method we would be using, a 4 stage thematic analysis and gave us an example of data from her research in which we practiced the first stage of the analysis, identifying important and pertinent themes.

A discussion around identifying issues regarding the interpretive process gave me insight into how the themes I identified could be influenced by my subjective experience, one such discussion was around reflexivity; how my involvement as a student may influence or inform the research findings.

Rayya emailed the results of the survey and asked us to identify themes and bring them to the second meeting. I identified statements and categorised them into emerging themes including direct quotes from the data. It soon became apparent that I should have only identified statements at this stage; Rayya explained the importance of following a systematic process in order to interpret the data as accurately as possible. This became apparent during the third meeting when we decided to reconstruct the statements under different headings, giving rise to the data in relation to the research question being investigated in an alternative way; better reflecting the participants' responses.

Whilst sorting the data much discussion ensued between the students and Rayya ensuring all statements and themes were considered.

Rayya asked myself and two fellow students to write a letter to the service users and carers using the final identified themes keeping the research question firmly in mind. This was the last stage we would be involved in and was the most exhausting part of the whole process. We spent time considering the identified themed statements and arranged them in a letter which we felt best reflected the thoughts and feelings of the student participants, occasionally being reminded to consider the research question by Rayya if we lost our way!

I was genuinely emotionally moved when Rayya read the letter back to us; firstly because I had attended one of the Participations in Occupation Mini Conferences and personally placed great learning value on the experience and secondly I felt it was a privilege to interpret the data on behalf of fellow students. Amongst other things their feeling of gratitude was heartfelt and it was a great honour to be able to convey this to the service users and carers.

As a result of participating in this piece of research I have a much better understanding of the process and feel more confident in deciphering research findings and would willingly volunteer to participate in future research.

#### ANA HASHEMI-AHMADY, STUDENT RESEARCHER, S07

Myself and two other students were invited by Rayya Ghul to participate in the RIT project in July 2009. This was an exciting opportunity, as I had no prior experience in research and had thoroughly enjoyed the Participation in Occupations (PiO) conference in year one of my occupational therapy (OT) studies.

Rayya asked if we could analyse the data received by the OT cohorts and identify any common themes. Prior to participating in the RIT project I had read around how to identify codes and themes and highlighted what I felt to be relevant. However, it was evident after our first meeting that I had rushed ahead and not fully appreciated the extent of how to analyse the data. We shared and explored other possibilities and approaches, which drew out a completely new set of data I had not observed when first reading the reflections. After recovering from my quiet embarrassment (!), I realised the grand scale of what we were researching, and how detailed and intricate the process was. I felt a new appreciation for articles I've read in journals and also how bias may occur in findings. For example, as I attended and personally enjoyed the conference, therefore I was hesitant to highlight any negative comments and more willing to focus on the positive.

One of the more important aspects for me, was being able to discuss how the conference impacted on my learning and development as an OT, and discover that a majority of other students had the same experience. i.e. one particular spokesperson discussed their difficulties in receiving person-centered care in an acute

mental health setting. Soon after this, I had a placement in such a setting and found that my opinions and previous conceptions of a mental health acute setting had changed, and I had formed new ideas and beliefs of what could be achieved in this setting.

In order to complete our sessions with Rayya, we were requested and honored to use the data we uncovered to compose a letter to the spokespeople at the previous conferences. This was one of the most rewarding exercises I have completed since studying, as I felt that the research came together and not only informed us of the benefits of the PiO conferences, but also the people who were willing and brave enough to share their stories with us. The end result was an honest compilation of reflections which I believe represents the data collected, and hope will encourage the speakers to return and contribute to other student OT's development. To me, this was the best piece of written work that I had developed since studying. It enabled me to reflect on how much I had learnt and how important it is as an OT to *listen* to our service users.

Overall, the experience of participating in the RIT project has informed me of the invaluable contribution of qualitative research in our profession. If the opportunity were to arise again, I would jump at the chance! Thanks Rayya.

#### RAYYA GHUL, PRIMARY RESEARCHER, SENIOR LECTURER

Participating in the Research Informed Teaching project has been one of the most rewarding activities I have carried out as an academic. Having the students as co-researchers was exciting because it was an opportunity to share with them the excitement and difficulties inherent in qualitative data analysis. It is fair to say that I worked the students very hard over an intense period of time but it allowed them to have firsthand experience of working with meaning and interpretation. It is one thing to talk about how meaning is a co-constructed phenomenon but quite another to participate in it.

The students were able to engage with the concepts in the Finlay article (2006) in a very real way, especially the idea that meaning 'emerges' and how validity is not just about numbers but also about a sense of authenticity and honesty. They realised the responsibility they felt towards the other students to represent their views fairly and in as coherent a way as possible and it is perhaps in this, above all else, that I could see the value of their undertaking research. They became clear about the ethical nature of qualitative research; that it is not simply about reporting the respondents' view, nor was it about *their* interpretation of others' views. Rather, they had to be able to be trusted to interpret messy and complex data in a way which provides an honest reflection of the contributors' views. They learned that a heuristic process infused with an ethical stance is what is required to be a researcher of ethical integrity (Finlay 2006).

The letter, therefore, is presented with confidence that it does indeed represent an authentic response of the students to the service users and carers, that it is not simply a polite 'thank you' letter, offered as a token, but represents the profound and lasting effect that students felt when listening to their stories.

In addition, reading the service users' and carers' narratives produced from the interviews by Dr. Diana Crampton provided evidence that our experts do enjoy and appreciate the conference format we have developed here at Canterbury Christ Church University. They confirmed our belief that the conference format privileges their stories and positions them as experts. Bringing these two strands together then, it can also be seen that the mini-conferences generate solidarity between service users and carers, future practitioners and educators.

## ACKNOWLEDGEMENTS

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## APPENDICES

### APPENDIX 1 INITIAL EMERGING THEMES

The impact of the mini-conference on student learning  
Enabling individuals to become reflective practitioners  
Enabling individuals to develop practice

Recognising enablers and barriers to participation in occupations  
A reinforced understanding of occupational barriers and enablers

Narratives  
One story making a difference

Increased confidence in the application of the therapeutic use of self

Useful learning style  
Conference as a valuable learning tool

Structure of conference

Carer experience

Raised awareness of relationships and person centred care  
Increased awareness of the importance of person-centred care

Meaning and importance of OT  
Value/meaning/purpose

How the experience of the conference was  
Emotional impact  
Lasting effects

Gaining insight and understanding from service user/carer perspective and integrating this into practice  
Raising awareness of service user and carers perspectives and experiences  
Service user perspective  
Enhanced insight into service users and carers experience of disability

Challenge to assumptions, thoughts, beliefs and values  
Questioning  
Giving students the opportunity to ask questions of self and others and integrate into practice

Importance of listening  
Opportunity interact/engage with service users

Reality

Understand service users as experts

Relationship to practice/placement services  
Changing practice  
Relating experience to practice placement

Learning about issues in the service context

APPENDIX 2 THIRD STAGE THEMATIC ANALYSIS

Changed	<p><i>Lasting Impact</i>                  Will stay with me                  Lasting impact                  Never forget the people                  Stuck in my mind                  Stayed with me                  Lasting impression                  Wanting to hold on to learning</p> <p><i>Practice</i>                  Practice                  More inclusive practice</p> <p><i>Perceptions</i>                  Perceptions of reality                  Beliefs for the future                  Perceptions</p>
Questioned	<p><i>Internal/Intrinsic/Self</i>                  Oneself                  Own practice                  Thinking</p> <p><i>External/Extrinsic/Others</i>                  Workplace cultures                  Role of health professionals</p>
Increased	<p><i>Personal Qualities</i>                  Confidence                  Confidence to ask questions on placement setting                  Self awareness                  Openmindedness</p> <p><i>Professional Qualities</i>                  Person centred care                  Desire to improve own standards of practice                  Awareness of how important OT is                  Need to treat people with compassion                  Clinical OT reasoning</p> <p><i>Awareness of the Service User's lived experience</i>                  Awareness of power imbalances                  Respect for service user's expertise                  Service user strengths                  Understanding of the effects of conditions                  Awareness of oppression</p>
Challenged	<p><i>Preconceptions</i>                  Negative stereotypes                  Assumptions                  Perceptions of OT                  Stereotypes</p>
Learned	<p><i>Service users' lived experience</i>                  Public perception of disability and how this affects service users</p>

	<p>Service users experiences  Power imbalances in mental health  Service users perspectives  Negative perceptions of care  Fears and concerns of service users</p> <p><i>Service users' perception of OT</i>  Understanding OT from client's perspective  Understanding influence of OT  Improved knowledge</p> <p><i>What's important to service users</i>  Person/human first  Understanding service users need</p>
Developed	<p><i>Professional Development:</i>  Professional development  Understanding of OT</p> <p><i>Professional Skills</i>  Prepared for placement challenges  Helped professionals give support to service users  Therapeutic skills/relationship</p> <p><i>Professional Knowledge</i>  Appreciation of importance of occupation  Connection between occupation and health</p> <p><i>Professional Attitudes</i>  Respect for the resources of service users  Understanding of service users experiences  Beliefs, values and attitudes  Thinking and attitudes  Determination to do better for service users in future</p>
Reinforced	<p><i>Identity as an Occupational Therapist</i></p> <p><i>Occupational therapy as a Vocation</i>  Personal vocation to be an OT  Decision to do OT  Personal inspiration to change lives as an OT  Motivated to become OT  Personal vocation – gained respect for OT as profession  Confidence that what I am learning will help people in the future  Aspiration to empower people</p> <p><i>Meaningfulness of OT Education so far</i>  Clarified what OT means  Importance of occupation at beginning of training  Relating experience to academic work  Complemented theoretical work  Reinforced beliefs about choice  Meaning and purpose of what taught on the OT course  Hope for the future  Clinical thinking</p>

Insight into	<p><i>Service User Realities</i> Service user and carer perspectives</p> <p><i>Service User's lived experience</i> Feelings of service users Personal experiences Spirituality of service users Into difficulties service users have in integrating into society</p> <p><i>Service User Strengths</i> How service users contribute to their own solutions</p> <p><i>Services users's experience of services</i> Idea that service users and carers know if a clinician really cares Power of therapists</p> <p><i>Effectiveness of Occupational Therapy</i> Power of OT to achieve change</p>
Reflection	<p><i>On the learning experience</i> Frustrations with the course put into perspective</p> <p><i>Self</i> On own practice Made me want to work in mental health On own beliefs and values</p> <p><i>Restrictions on practice (realities of practice)</i> On shortcomings in practice Consider improvements in care Relating experience to practice placement Lessons from negative care On placements On developing practice On shortcomings on funding and legislation</p>
How?	<p><i>Enhanced other forms of teaching</i> Made up for shortfall of practice hours on placement Added to a range of experience which are limited by type of placements Enhanced academic learning Good to have it early on in education Built on previous learning Brought training to life Complemented theoretical work More real than case studies Listening to narratives enhance academic content</p> <p><i>Different learning style</i> Overwhelmed by more academic parts of the programme Contrast with other forms of learning opportunity More effective than other forms of learning Fitted own learning style better – avoided demotivation Helping learning style – learning from experiences of others</p> <p><i>Format of the mini-conference</i> Diversity of speakers Hearing from real people</p>

	<p>Being able to ask questions of service users  Real lives and experiences  Compare reality and theory  Meet service users  Opportunity to listen to SU and carers  Opportunity for exploration and debate  Different context in which to meet service users and carers  Interacting with service users  Humanising service users</p> <p><i>Learning from the stories of Service Users and Carers</i>  Learning from negative and positive experiences of care  Good to hear service users express dissatisfaction  Listening to experiences of carers  Learning from hearing about negative experiences</p> <p><i>Meaningfulness to student experience</i>  Invaluable experience  Promotes reflection  Raising awareness  Able to see how OT can contribute  Felt moved to tears  Useful to hear that things can improve  Rewarding experience  Lovely experience  Interact with reality</p>
What?	<p>Equal rights  Person centred care  Service users are making judgements of us  Relationships  Carer's perspective  They're just like us – solidarity  Respect their privacy, dignity and integrity  Particular issues that are relevant to practice  Service involvement in practice  Importance of holding onto this perspective to avoid complacency  Therapeutic use of self  Client-centre care  Empowered by person centredness  Negative attitudes towards service users and carers  Therapeutic skills  New appreciation of the issue of consent  Importance of listening and therapeutic relationships  One experience in particular  Barriers and enablers – raised awareness  Distressing experience  Respect for service users  Person as human being  Impact of one story in particular  Service user scrutiny is important  Meaning and importance of occupation  Most helpful  Humbling experience  Expertise of the service users  Relating to service users as capable  Reality v idealism</p>

	<p>Understanding roles of service users Service user is expert of their own life Anticipate service users needs Being fortunate to have participated in mini-conference Service users experience of care Barriers and enablers Importance of collaboration Services as barriers or enablers Hearing about strategies that work Raise new issues Impact of one particular speaker One narrative in particular Narratives Impact of health and social care professionals Individuality of the service user Valuing the person not the illness Importance of listening to service users and carers Service user as ultimate arbiter of quality of practice Valuing disabled people Service limitations Valuing service user input into own treatment</p>
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**Impact on your development as an OT?**

<b>Service User and Carer Experience</b>
<i>Awareness of the Service User's lived experience</i>
Awareness of power imbalances
Respect for service user's expertise
Service user strengths
Understanding of the effects of conditions
Awareness of oppression
Feelings of service users
Personal experiences
Understanding roles of service users
Into difficulties service users have in integrating into society
Negative attitudes towards service users and carers
Public perception of disability and how this affects service users
Service users experiences
Power imbalances in mental health
Service users perspectives
Negative perceptions of care
Fears and concerns of service users
<i>Carer's perspective</i>
<i>Service users' perception of OT</i>
Understanding OT from client's perspective
Understanding influence of OT
Improved knowledge
<i>What's important to service users</i>
Person/human first
Understanding service users need
Equal rights
<i>Service User Realities</i>
Service user and carer perspectives
<i>Service User Strengths</i>
How service users contribute to their own solutions
Expertise of the service users
Relating to service users as capable
Service user is expert of their own life
Spirituality of service users
<i>Services users's experience of services</i>
Idea that service users and carers know if a clinician really cares
Power of therapists
Service users are making judgements of us
Impact of health and social care professionals
<b>Reality of Services/Reality of Practice</b>
<i>Practice</i>
Practice
More inclusive practice
<i>External/Extrinsic/Others</i>

Workplace cultures
Role of health professionals
<i>Restrictions on practice (realities of practice)</i>
On shortcomings in practice
Consider improvements in care
Relating experience to practice placement
Lessons from negative care
On placements
On developing practice
On shortcomings on funding and legislation
Reality v idealism
Services as barriers or enablers
Service limitations
<b>Professional Development</b>
<i>Professional Development:</i>
Professional development
Understanding of OT
<i>Professional Skills</i>
Prepared for placement challenges
Helped professionals give support to service users
Therapeutic skills/relationship
Therapeutic use of self
Anticipate service users needs
Importance of collaboration
Valuing service user input into own treatment
<i>Professional Knowledge</i>
Appreciation of importance of occupation
Meaning and importance of occupation
Connection between occupation and health
Barriers and enablers – raised awareness
<i>Professional Attitudes</i>
Respect for the resources of service users
Understanding of service users experiences
Beliefs, values and attitudes
Thinking and attitudes
Determination to do better for service users in future
They're just like us – solidarity
Respect their privacy, dignity and integrity
Importance of service user involvement in practice
Importance of holding onto this perspective to avoid complacency
Empowered by person centredness
Respect for service users
Person as human being
Service user scrutiny is important
Individuality of the service user
Valuing the person not the illness
Importance of listening to service users and carers
Service user as ultimate arbiter of quality of practice
Valuing disabled people
<i>Occupational therapy as a Vocation</i>
Personal vocation to be an OT
Decision to do OT
Personal inspiration to change lives as an OT



Motivated to become OT
Personal vocation – gained respect for OT as profession
Confidence that what I am learning will help people in the future
Aspiration to empower people
<i>Professional Qualities</i>
Person centred care
Desire to improve own standards of practice
Need to treat people with compassion
Clinical OT reasoning
New appreciation of the issue of consent
<i>Effectiveness of Occupational Therapy</i>
Power of OT to achieve change
Awareness of how important OT is
<b>Personal Development</b>
<i>Internal/Intrinsic/Self</i>
Oneself
Own practice
Thinking
<i>Personal Qualities</i>
Confidence
Confidence to ask questions on placement setting
Self awareness
Openmindedness
<i>Perceptions</i>
Perceptions of reality
Beliefs for the future
Perceptions
<i>Challenging Preconceptions</i>
Negative stereotypes
Assumptions
Perceptions of OT
Stereotypes
<i>Self</i>
On own practice
Made me want to work in mental health
On own beliefs and values
<b>The Experience of Learning</b>
One narrative in particular
Narratives
<i>Lasting Impact</i>
Will stay with me
Lasting impact
Never forget the people
Stuck in my mind
Stayed with me

Lasting impression
Wanting to hold on to learning
Importance of holding onto this perspective to avoid complacency
<i>Meaningfulness of OT Education so far</i>
Clarified what OT means
Importance of occupation at beginning of training
Relating experience to academic work
Complemented theoretical work
Reinforced beliefs about choice
Meaning and purpose of what taught on the OT course
Hope for the future
Clinical thinking
<i>On the learning experience</i>
Frustrations with the course put into perspective
Listening to narratives enhance academic content
One experience in particular
Impact of one story in particular
Distressing experience
Humbling experience
Most helpful
<i>Quality of the learning experience</i>
Being fortunate to have participated in mini-conference

## APPENDIX 4 HOW

<p>How?</p>	<p><i>Enhanced other forms of teaching</i>          Made up for shortfall of practice hours on placement          Added to a range of experience which are limited by type of placements          Enhanced academic learning          Good to have it early on in education          Built on previous learning          Brought training to life          Complemented theoretical work          More real than case studies          Listening to narratives enhance academic content</p> <p><i>Different learning style</i>          Overwhelmed by more academic parts of the programme          Contrast with other forms of learning opportunity          More effective than other forms of learning          Fitted own learning style better – avoided demotivation          Helping learning style – learning from experiences of others</p> <p><i>Format of the mini-conference</i>          Diversity of speakers          Hearing from real people          Being able to ask questions of service users          Real lives and experiences          Compare reality and theory          Meet service users          Opportunity to listen to SU and carers          Opportunity for exploration and debate          Different context in which to meet service users and carers          Interacting with service users          Humanising service users</p> <p><i>Learning from the stories of Service Users and Carers</i>          Learning from negative and positive experiences of care          Good to hear service users express dissatisfaction          Listening to experiences of carers          Learning from hearing about negative experiences</p> <p><i>Meaningfulness to student experience</i>          Invaluable experience          Promotes reflection          Raising awareness          Able to see how OT can contribute          Felt moved to tears          Useful to hear that things can improve          Rewarding experience          Lovely experience          Interact with reality</p>
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## RAPHAEL

My 15 year old son is probably about 6'2" tall with size 12 feet. His hands are also big and when he gives you a playful slap he almost knocks you over. Generally speaking he is shy and does not invade others' space, but on the odd occasion he has to be warned not to put his hands around his brother's neck. He is also a little bit obsessed with guns. And Thomas the Tank Engine. A boy of contradictions then.

He was over 10 lbs when he was born. It was an emergency Caesarian. The consultant gynaecologist coyly apologised for not having noted that the foetus was so big as I was growing enormous. There was no problem with his birth, though, and his first feed more or less set the scene for his big appetite: he drank a whole bottle of baby's milk, when usually new-borns consume about a half.

He was slow in developing. He did not smile very quickly and it was 9 months before he could actually sit up. His older brother was sitting at 6 months. However the paediatrician was not concerned with this. As time passed, it was obvious that he wasn't learning to talk. In that period there was a lot of talk about the MMR vaccination causing autism, but I was living in Italy and society there is not so clued up on this. However, eventually my father-in-law insisted that the child be taken for a check-up with the town's paediatrician, who said that indeed my boy was not developing as he should. Would he go and pick up something from another room if I told him to? No, my boy took no notice of communication at all, although he was smiling and apparently cheerful.

By this time I had developed post-natal depression and came back to England. One of the first things I did was get the boy, Rafi, seen by the doctor and the process of assessment began. The consultant paediatrician in Folkestone looked at him and said to me "he is DEFINITELY not autistic, I can tell you that", however she, too, was concerned about his delay and he was allocated a place at the Children's Centre at Foxwood for a short period a week. While he was in nappies when he was there at the age of three, a summer in Italy meant that he managed to get out of them, with relative ease of potty training I would say. A bit of a surprise really. But he was still not talking, or taking much attention of being spoken too. He had a bit of a fierce temperament, but was never violent, never threw anything, just roared his head off. This didn't stop me taking him to mothers' and toddlers' groups, so I was able to get out of the house.

After the Children's Centre, Rafi was given a place in the special language unit at Hythe Infants, but after about a year, the teachers there felt he was demanding too much attention, was unable to keep up with the progress of his peers and was recommended a place at Highview, the school for children with Moderate Learning Difficulties, since redesignated, in Folkestone. He went there at about five years, I think, and has been there ever since.

By the time he was four, he started to put some words together. And by this time I was part of the National Autistic Society and had heard that there was a blood test that he could have. I asked the Paediatrician. "Oh, haven't I given him that?", she asked, falling from the clouds. With the blood test, it was affirmed that he had Fragile X Chromosome, a genetic disorder that causes learning delays, mainly in boys and is the second most common cause of delays in boys. This means that he will be dependent for all his life. In the interim, he also had an epileptic fit, followed by a second one, which meant that he is now on medication full-time. Although he hasn't had a full-blown fit for about four years, the Fragile X Society literature tells me that the onset of adolescence is a time for epilepsy to kick in, so I have refused the paediatrician's idea of trying to take him off these pills. They might have side-effects on the kidneys, however, to be watched. He also has what I thought were cyclical petit-mal attacks, but after both a heart scan and a brainscan, no epileptic activity has been seen, his heart is fit (Fragile X children can have heart murmurs, which need to be watched out for)

and these attacks are now diagnosed as panic attacks. He gets very frightened, tends to crave comfort, cuddles and then they pass. Sometimes he is sick. The attacks are regularly monthly.

Generally speaking Rafi's problem is that he is shy of going out and does not really relate to his peers. Fortunately he has one very good friend at school, who we sometimes see outside school hours. Overall he relates very well to his brother's friends, and to my friends, and he really enjoys the company of adults, when they visit. Most commonly he will disappear to his room, or more recently I have bought him a laptop, on which he is relatively adept at seeking out You-Tube clips, mainly of Thomas the Tank Engine. He enjoys his food and is generally well-behaved when taken out to restaurants to eat and I have to say that most places are really very accommodating, although he tends to have a very loud voice and he has a habit of firing the staff, which derives from watching too much of The Apprentice.

His speech is quite difficult to understand at times, and this is called cluttering, characteristic of Fragile X. He is also double-jointed and has a gangling sort of gait, however he loves swimming. The water is good for those with double joints, as it tends to hold the joints together when the children move. He is also surprisingly good at ten-pin bowling, but with a tendency to agoraphobia, he really needs to be persuaded to go out. He is good on a bicycle, although he was 8 years old before he could cycle without stabilisers, about the same age for learning to do up a button. At 12 he learnt to tie shoe-laces. With a lot of patience he can be taught things, but he is almost ADHD, and has to be encouraged to sit still and not shoot things off too fast, something which impedes his capacity to write, and read for that matter.

He can now be left in the house alone for short periods, or an hour or so, but in the past five years an added complication has occurred. My father died and my mother has baulked at being left in the house on her own. Since the boys lived with my parents for several years, they have now grown used to being with their grandmother, and living with her still now. My older son feels it is his duty. I hate it. The problem with family relationships is that my mother has constantly treated Rafi as if he is totally normal and just either a silly boy or a naughty boy and meal-times are a continuous chorus of "sit properly", "be a clever boy", do this do that and all the paraphernalia of an Italian grandma. It has driven me bonkers, as she also took it upon herself to boss him about at table in restaurants. She is deaf and her only way of communicating is by bossing Rafi. I have noticed, however, that more recently, as she is becoming demented, she is taking less notice of Rafi and the atmosphere in the house is thus less tense, with a concomitant improvement in the behaviour of Rafi, who instead of having been bossed about and getting into a tantrum, now does courtesies for his grandmother, like holding her plate because this swivels around the table as she tries to cut the meat, or pouring her a glass of wine, which she imbibes regularly at dinner. In return she thanks him and a vicious circle of irritation has been broken. Overall, however, she told me that when I used to go out, he always behaved really well with her, saving his worst behaviour for when I return. He has a habit of calling her "silly woman".

He is most likely to be accommodated in a residential arrangement when he reaches 19 years. He has been down on the list for a place at the Woodchurch Rare Breeds Centre, the Canterbury Oast Trust for a while and they are aware of his needs.

Rafi needs to be treated with a lot of patience. However, he has an extremely sunny disposition, he doesn't hold grudges and he is surprisingly extremely empathetic, a situation which differentiates Fragile X children from Autistics. He is very loving, dedicated to his brother and always taking the side of my mother if ever I show irritation. The major problem? He is always in the house and he has no life of his own.