# IATL Academic Fellowship

# Final Project Report

# Listening to and learning from the unheard:
# Interprofessional learning and people with learning disabilities who are non-verbal communicators

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## Project Objectives

Health and Social Care professional education espouses a commitment to the inclusion of 'patient' and 'service user' experiences as part of the curriculum. Over the past 30 to 40 years, it has become increasingly accepted that the views and expertise of people who use services provide a vital contribution to the learning experience (McKeown *et al.*, 2010). The increasing recognition of this aspect of health and social care education is welcome, but is often characterised by tokenism and representation by a narrow range of people and experiences (Kemshall and Littlechild, 2000). There are many potential reasons for these shortfalls, not least because the perception and reality of sharing that expertise in Higher Education Institutions requires both skill and courage on the part of the contributor. This runs counter to the stated intention of inclusion, and narrows the student learning experience, leaving the student professional; arguably, less prepared for the diversity they will face in practice (Anderson, *et al.* undated). This project engages with this problem and intends to find out whether people who could not engage in the traditional 'lecturing 'style might be involved in the education of Health and Social Care professionals. More specifically, we aimed to trial one approach to learning from the experiences of people with severe learning disabilities who are principally non-verbal in their communication.

A short note on terminology: The words used to describe the role played by people with direct experience of using health and social care services are problematic and discussed extensively in the literature (Beresford, 2005). Throughout this piece the term 'participant' will be used to refer to everyone involved in the session; where a distinction between roles is required, students will be identified as such. The 'participants with learning disabilities' will be referred to either in this manner or as 'service user' or 'expert' participants.

## Activities

**Making contact:**
Within the School of Health and Social Studies, we have a well developed collaboration between users of Health and Social Care services, the University of Warwick and the NHS, called UNTRAP (Universities/User Teaching and Research Action Partnership). UNTRAP ordinarily acts as a broker between the Teachers/researchers and people (with experience of using services) who are willing to be involved in teaching and research. This well regarded and established partnership exists to ensure "that service users and carers can have a direct influence on the skills and knowledge of professionals in training and on research and evaluation agendas" (UNTRAP, undated). UNTRAP provides one model of good practice assuring that service users are respected and supported in making their valuable contributions to knowledge. UNTRAP manages many requests for the involvement of its members, but would not be able to provide access to the more

marginalised target group required for this project. So the first problem we faced was one of 'making contact'.

At the time of applying to IATL, to fund this project, I was employed by Warwickshire County Council's Learning Disabilities Services, and may well have been able to make contact with a number of potential participants through my employer. Considerations of appropriate use of power, authority and influence, which came to characterise much of the planning and implementation of this session, influenced my decision not to approach people through Warwickshire County Council. Instead, I made contact with Coventry City Council, the neighbouring Local Authority. Both of these organisations are sub-regional partners to the University of Warwick and both have premises located close to the main campus. In my roles as Social Worker and as Tutor for students on placement in the sub-region I had existing contacts that could assist me in the initial planning stages. Office holders at Coventry City Council, notably those involved in 'in-house' provider services were able to very quickly identify a specific service which supports people with profound and multiple learning disabilities. This service supports a large number of people who are primarily non-verbal in their communication; the notional agreement of this service's involvement was a major milestone.

Having secured the involvement of this key partner, we felt confident that there was a good chance of the teaching session occurring, but this was just the beginning of a long planning process in which a number obstacles were identified and, in turn, tackled. Some of these challenges were  some specific to this particular approach, and others were more generalizable, and might occur in other projects of this nature.

**Gaining Consent:**
Given the complexity of the potential participants' cognitive and communication differences, issues of choice and consent were germane throughout, and presented the first specific dilemma. The standard written or verbal request for their involvement, such as would be employed by UNTRAP, would not be sufficient. Instead, we needed to adopt a method of communication which could advise us of the potential participant's willingness to be involved.  The ability of professionals to understand the preferences and experiences of people with profound communication impairments is often built up through long term relationships. It is usually through interpreting people's responses to specific stimuli that a 'picture' of the individual, their likes, dislikes, strengths and needs is constructed. This idea of using an individual's previous communication, which would include an interpretation of their facial expressions, vocalisations and body language, to determine their likely feelings about the activity proposed was considered to be the best approach.
Through some preliminary discussions with the operations manager, we were able to share our ideas about the likely content of the session, including the activities being considered, and we agreed that he would consider the suitability of potential candidates, based on their previous communication. The criteria for a person's inclusion were that it was reasonable to believe that the person could engage with the activities suggested in a relatively safe manner and that they would derive some intrinsic value or enjoyment from attending the session.  With the enthusiasm and support of the senior and middle management team, the staff at the service were able to identify the people we might approach.  With our potential participants identified, we moved on to the dual matters of confirming the content of the session and gaining formal consent. Both of these matters needed to be resolved before our expert participants could commit to being involved in such a session. We will explore the matters of session design and content  in a separate section of this report. Below follows a discussion around the matter of consent.

Given that the target group in this project are a recognised vulnerable group, We were required to apply to the Humanities and Social Sciences Research Ethics Committee (HSSREC). Such clearance would not ordinarily be required for an evaluated teaching intervention, but given the sensitivities involved in non-exploitative inclusion of people with such significant vulnerabilities, clearance was sought and granted. The matter of consent was of central importance to the ethical clearance process.

People with learning disabilities are protected by the Mental Capacity Act 2005. This Act formalises the understanding that people must be presumed to have capacity to make decisions about their own lives, but that special circumstances apply where an individual is unable to make and communicate a reasoned decision in respect of a specific issue. In these special circumstances; family members, friends and professionals supporting the person have a responsibility to act in the person's best interest. This 'Best Interests' decision should include consideration of what the person would be likely to decide, had they the capacity to understand the question being asked; and as such should include what we have described above as 'previous communication'. All of the potential participants identified were assessed as lacking the capacity to make and communication a decision on the rather complex matter of being involved in this evaluated teaching session.

In order to afford appropriate weight to both the previous and reactive communication of the expert participants, but also to adhere to the legislation and its intended purpose, we laid out a dual process of consent. This process included seeking formal consent from those primarily responsible for the welfare of the people with learning disabilities (often parents or other family carers). This formal consent was intended to ensure that the people involved in this experience are thought by the people who know them best, to be likely to enjoy the experience outlined. The purpose and methods used in this evaluative piece were outlined as clearly as possible to ensure that representatives can make a reasoned decision.

In order that the wishes, thoughts and feelings of the participants with learning disabilities remained central to the facilitation of this project, their informal consent was sought throughout the delivery of the teaching session. It was agreed that should a participant express their wish to opt out of a specific activity, or indeed, to opt out of the whole experience, this would be respected. It was confirmed that the participant would be enabled to withdraw, supported as required. This was in evidence at the 'acquaint" visit carried out a week in advance of the session, during which, one of the participants spent quite some time outside of the teaching space in the neighbouring café and outside of the building with a support worker. During the actual teaching session, the video footage captures some people opting to take an 'observer' role during some activities and re-engaging with the students at a later time. During the session itself, all of the expert participants engaged with some of the activities, and crucially, with the students. Many 'opted out' of parts of the session, but none chose to absent themselves completely.

The matter of consent from student participants was also addressed in the HSSREC application; this was agreed in a more standard fashion through the use of approved information sheets and consent forms.

**Session design and content:**
Implicit in service user led learning, is the understanding that students consider direct communication with expert participants a credible and useful source of information (McKeown *et al.*, 2010). In keeping with this understanding, it was important to plan carefully the methods we would employ to encourage meaningful communication between

the two groups of participants. It was agreed that a standard classroom or lecture theatre would be restrictive and that standard large group lecturing would be very unlikely to encourage this, and may well be distressing or exploitative of the participants with learning disabilities. We needed to provide a more accessible format

We were very fortunate to have access to a number of potential venues, one of which is a purpose built open space learning studio called the Reinvention Centre (more information available at www2.warwick.ac.uk). This venue was chosen for its versatility and innate suitability. It has no fixed furnishings, no traditional seats and no tables which can create barriers; instead it has beanbags, benches and cushioned cubes which can be used to sit on. There is also the option to capture a great deal of natural light alongside versatile electric lighting options and a good quality sound system. These features allowed us to create an environment that was welcoming for all of our participants, especially important to those people who are anxious in new spaces and those who have visual impairments. Through planning discussions, and a preliminary visit in which the participants with learning disabilities were able to visit the venue and become acquainted with the space, we attempted to reduce anxieties for the teaching session.

Having access to a large, safe space allowed us to be creative in our approaches to facilitation. We used a mixture of whole group activities and smaller, more direct interactions to encourage engagement and communication. We engaged the support of a theatre practitioner and drama teacher who has experience of working with people with a range of learning disabilities. The theatre practitioner did not know the individuals involved in the session, but has experience of working with other people with similar needs. She designed a suggested session which was discussed with people who know the participants with learning disabilities well. The programme for the final negotiated session was supported by a small piece of 'pre-reading' for the students which outlined the goals of the session, as well as providing some background information which was intended to ensure similar 'baseline' expectation. The Programme for the session itself was as follows:

| Activity | People/groups involved | details |
|---|---|---|
|  |  |  |
| Participants arrive, room well lit, beanbags, benches and cushioned boxes organised roughly into a circle, 'easy listening' music on quietly but audible. |  |  |
| Welcome, introductions consent forms and pre session questionnaires | Students and facilitators only | Students given a printed copy of : Pre-reading, information sheet, consent form and pre-session questionnaire. |
| Preliminary discussions | Students in pairs and groups of 3 | Discussion about non-verbal communication including manifestations of this |
| Participants with learning disabilities arrive |  |  |

| Name games and ice breakers | Theatre Practitioner leads whole group activity | All participants involved with: Name game using a beach ball, and accompanying vocalised noises as the ball bounces, rolls and is thrown between participants, each giving their name as they gain possession. Eye contact used to identify the recipient. Parachute game used as an opportunity to engage in a shared task and reinforce the learning of people's names Parachute game used as a joint sensory activity, using balloons and vocalised noises. Opportunity for students to gauge the responses of the non-verbal participants |
|---|---|---|
| Create a person profile | working teams of participants. | Working teams create profiles of one or two members of their group. Showing likes and dislikes, ways of expressing ourselves, things that are important to and important for us, the things on the outside that affect us and the way we respond or feel on the inside. Physical and emotional. |
| Signed songs and gauging feedback | Theatre Practitioner leads whole group | Participants join in singing to experience and explore different communication methods and preferences. Students to observe and interpret others' responses. |
| Sensory activities | Self directed 1:1 or small group interactions | Participants have free choice to use props to engage with each other. These include percussion instrument, glove puppets, different fabrics and bubble wrap, 'dressing up' hats and telephones. |

| Person profile feedback | Large group activity led by lecturer | Person profiles discussed as a large group |
| --- | --- | --- |
| Shared lunch (including the opportunity for students to support those people with learning disabilities who require assistance with meals and drinks) | | |

**The use of words:**
Despite the emphasis on non-verbal communication throughout the session, there were some instances in the delivery of the session where the use of the spoken word was very valuable. Reviewing these in chronological order, firstly, on the 'acquaint' visit, in meeting the participants with learning disabilities and their support workers, it is customary to say hello, to introduce oneself and consider follow the social conventions as expected; these practices are socially conditioned for most people, and are likely to have had an impact even on those people who do not respond verbally.

The verbal discussions with support workers at this stage were also crucial in planning the finer detail of the session. For example, one of the support workers commented that it was pleasant to hear background music played during their arrival, but was able to advise us of specific types of music which may cause anxiety. There were a further two specific uses of language which were key in the session – the instructions as delivered by the facilitators clarified what was expected of the participants, but finally, and perhaps most importantly. It was necessary for the students to be able to converse with the support workers. The session reinforced the importance of communicating, in the first instance, with the person themselves, but in many cases, the students required reassurance and support from the support workers who know the people with learning disabilities well. This communication took the form, for example, of checking their interpretation of the participant's non-verbal communication. It can, for example, prove quite difficult to be sure whether a loud, high pitched vocalisation is indicative of enjoyment or discomfort; support workers are able to clarify this easily. This is important for the wellbeing of the participant, in supporting them to withdraw if desired, but is also important in the student learning experience. These experiences can allow the student to gain confidence in their 'listening' and 'observing' skills.

**Access requirements:**
A specific note about the involvement of support workers; they attended this session, and participated in the activities in their usual role as supporters. The people who access this specific City Council service are considered to be at risk without the support they currently receive. It would, therefore, not have been easy to ensure the safety of participants with complex needs without the support and engagement of their regular support workers. It also seems likely that without the reassurance offered by familiar faces, that people may have faced heightened levels of anxiety, which would have been undesirable from both pedagogic and ethical points of view. Although the session was a little out of the ordinary from their usual supportive role, they supported as required, for example, introducing participants in the name games and, as noted above, facilitating communication when required. This was intended to mirror the role they would ordinarily take, for example, in supporting a service user to visit the GP's surgery.

Most of the participants had physical impairments/health conditions as well as learning needs. 5 used wheelchairs on a full or part time basis, and 4 also had specific dietary requirements including limited ability to chew or swallow. This raised some specific issues in respect of washroom facilities and catering. Having gathered information about the specific dietary needs of the participants, I was able to negotiate a suitable soft menu which also included some finger foods, one pureed meal and offered a vegetarian option for those who wanted/needed it. The catering team were very helpful in also providing assorted extra crockery and cutlery which assisted people who eat/drink in a way that is adapted to meet their needs. Those people who needed specialist equipment (such as a plate guard, drink thickeners and soft grip cutlery) brought these with them.

The matter or accessible washroom facilities proved more difficult to solve. Although there are 'standard' accessible WCs around the University campus, (which are suitable for people who are fully or partially ambulant) we were not able to access a washroom suitable for all of our participants. The University does have some facilities which offer a hoist and changing bed, but none of these are accessible to campus visitors. They are only provided within adapted student halls of residence – so none were available for our participants. This had the effect of limiting their time with us.

### Outcomes:

The outcomes of this evaluated small group teaching exercise were gathered in three main ways: Paper evaluation -Students completed a pre-session and post session questionnaire, as well as a session evaluation, Video recording – a camera was set up at each end of the room and ran throughout the event, capturing verbal and non-verbal responses and finally, informal comments – some verbal and e-mail comments solicited from the students and support workers during the period directly after the session up until a fortnight later. The feedback identified a number of key themes, which will be discussed below.

### Measured confidence:

The pre and post session questionnaires included questions about the students' self-perceived confidence and competence in a number of areas. The area in which the session appears to have had the most positive effect is the students' confidence in approaching and engaging with people who have severe learning disabilities and people with significant communication challenges. However, the session seems to have had very minimal impact on the students' confidence in being able to rely on their interpretation of the non-verbal communication they observe. Students made written and verbal comments about the benefit they derived in simply spending time with the expert participants. Some specific comments were made around the limited opportunity to meet people with more complex health and social care needs. It was also useful to hear the students' comments on the beneficial input of the support workers. This feedback seems to reinforce the importance of preparing students to communicate directly with people who do not use words as their primary method of communication; but also to recognise the important contribution of those people (family, friends, informal and paid carers) who have gathered an understanding of the individual's communication methods over the long term. An example of this measured confidence was in evidence through a verbal discussion with a student directly after the session

### Strong blueprint for the future:

One major success for this session was the extent to which the activities and environment promoted a positive reaction from the expert participants. This can be problematic in service user led education (McKeown *et al.* 2010). However, the feedback we received from participants seemed positive and two support workers asked specifically about the possibility of running a similar session again in the near future.

Students gave very positive feedback about the organisation of the session, the activities were positively received. This is in evidence both in the written feedback and through viewing the video footage. Despite my pre-session reservations about the active engagement of the students, it is clear that they valued the opportunity to use alternative (non-verbal) methods to engage with the expert participants. Students felt that the session was well prepared and that the pre-reading was beneficial.

**Numbers and ratios:**
The extent, to which any expert participant or group of service users can be considered 'representative' of service user groups as a whole, remains contentious (Robert *et al.* 2003). Similarly, the weight that this concern should carry is debatable (Crawford, 2001). Seven people with learning disabilities shared their time and experiences during this session. The diversity of the group allowed the students to gather an appreciation of the range of communication strategies employed whilst simultaneously responding to the matter of representativeness (McKeown *et al.*, 2010).

The session was designed with 15 students in mind; planned to maximise opportunities for interaction based on this 2:1 student to service user ratio. In fact, due to difficulties co-ordinating the time commitments of 3 professional courses across 2 institutions (a recognised risk in interprofessional education (Bluteau and Jackson, 2009)); it was not possible to include student nurses in the session. This, alongside some apologies received for student sickness, resulted in a total of 7 students attending (3 medics and 4 social workers plus one student nurse undertaking her placement with the City Council service provider).

In terms of participant numbers, our appraisal, taking into account the students' comments, is that it should be possible to raise the number of students to that which was initially anticipated, but if the group size became too large, the essence of the session may well be disrupted. It is clear that there is demand for this kind of learning as there was a waiting list of medics, and, interest from a number of student nurses – neither of which was known to the researcher until after the session had already run.

**Service user led learning:**
The matters of consent and coercion with the expert participants in this piece are very sensitive. As we were unable to include participants from planning the session in the fullest sense of the word – there was limited agency on their part until the day itself. As already stated, people opted into and out of specific activities. People were not coerced into involvement during any part of the session, and this was very evident towards the end of the session, when people were working in pairs and small groups, using the 'props' to engage with each other. There were times when the leadership of the facilitator was in evidence, with all student participants, and some expert participants paying full attention to her instructions, there were individual interactions where it was clear that the students or support workers were commanding attention. There were many instances in which students observed the general presentation of the expert participants in an attempt to understand their response to the session, but also a promising number of occasions on which it was clear that the expert participants were leading the communication. Examples included people with learning disabilities leading students by the hand, using 'eye-pointing' to demonstrate choices and making deliberate eye contact in order to engage the students.  These moments of experiential learning opportunities have greater impact on the development of the students' competence and confidence than any other method which attempts to teach these skills.

## Implications

**Embedding sustainability:**
This pilot session was planned and facilitated using a smaller budget than initially anticipated. There were a number of reasons for this, but the main factor was savings made to the cost of the theatre practitioner/facilitator. We had budgeted to cover the fee of

a nationally recognised theatre practitioner, but for logistical reasons, we decided to work with a local contact instead. This has proven to be beneficial in terms of ensuring the sustainability of this positive experience.

Fostering local relationships is important in service user led education (McKeown *et al.*, 2010). Through this project we have made contact with the theatre practitioner, who works for a local FE institution, teaching people with learning disabilities. We have also cemented our relationship with a support provider positive about this kind of engagement. As both parties are keen to partake in a similar session in the future, there is a real possibility to build on this good practice.

Although the funding context for service user involvement is changing, there remains a commitment to the importance of this work (Social Work Reform Board, 2011) such that the costs incurred in running this session can be met. Negotiations are now underway to embed this small group learning opportunity as a regular option for Student Medics and Student Social Workers. This would form, in both cases, an option within the existing modular course requirements. It is intended that we will also negotiate with the adult nursing course at Coventry University to see whether the logistical difficulties can be overcome (in terms of timing the session sympathetically). There is interest both from the course staff and a significant number of students, for an opportunity of this kind.

Discussions are now underway with Coventry City Council contacts to consider whether this specific service, or provider services in the Council more generally, may forma link with UNTRAP to ensure the maximum mutual benefit. It is also hoped that this project provides some examples of positive practice which can be adapted when working with other service users who find the traditional classroom approach inaccessible.


**Resources**
Appended to this report are:
Appendix 1    information sheets and consent forms
Appendix 2    Student pre-reading
Appendix 3    Pre-session and post-session student questionnaire proforma
Appendix 4    Student evaluation proforma

**Contact details**
For further information on this project or to discuss future collaboration with the individuals and organisations involved, please contact:
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02476574128
Stephanie.lunn@warwick.ac.uk

## **References**

Anderson, E, Lennox, A and Petersen, S,  'Learning from lives: a model for health and social care education in the wider community context', *Medical Education* . 37(1): 59–68

Beresford, P (2005) "Service user': Regressive or liberatory terminology', *Disability and Society* 20: 468-477

Bluteau, P and Jackson, A (2009) Interprofessional Education: Making it Happen Basingstoke: Palgrave Macmillan

Crawford, M (2001) 'Involving users in the development of psychiatric services – No longer an option' *Psychiatric Bulletin*  22(3): 155-157

Kemshall, H and Littlechild, R (2000) User Involvement and Participation in Social Care: Research Informing Practice London: Jessica Kingsley Publications.

McKeown, M, Malihi-Shoya, L, Downe, S and The Comensus Writing Collective (2010) Service User and Carer involvement in Education for Health and Social Care Chichester: Wiley-Blackwell

McPhail, M. (1998) Service User and Carer Involvement: Beyond Good Intentions Edinburgh: Dunedin Academic Press

Mental Capacity Act 2005 London: HMSO

Robert, G, Hardacre, J, Locock. L, *et al.* (2003) 'Redesigning mental health services: Lessons on user involvement from the mental health collaborative', *Health Matters* 6: 60-71

Social Work Reform Board (2011) 'Service User and Carer Participation in Social Work Education' http://www.education.gov.uk/swrb/a0074256/social-work-education-the-qualifying-degree (Accessed 22nd March 2012)

UNTRAP (Undated) http://www2.warwick.ac.uk/fac/cross_fac/healthatwarwick/untrap Voluntary Action Westminster (undated) 'Involving People:  A Practical Guide' http://www.vawcvs.org/downloads/practical-guidepdf (Accessed 10th December 2011)

http://www2.warwick.ac.uk/fac/cross_fac/iatl/spaces/reinvention/about (Accessed 19th March 2012)

# Appendix 1

**University of Warwick Project Information Sheet**

**Listening to and Learning from the Unheard: Inter-professional learning and people with learning disabilities who are non-verbal communicators.**

**Can you help?**
- We are looking for people with learning disabilities who don't communicate with words.
- We would like our Student Nurses, Social Workers and Doctors to learn from them.

**What is the project all about?**
- We want to help our trainee professionals improve their communication skills by spending time with people who are non-verbal

- The whole group will work with a theatre practitioner in a drama studio at the University of Warwick – trying out different methods of communication.

- The session will last for about an hour and a half (with plenty of breaks for snacks and drinks as needed)

- This activity will include approximately 8 people with learning disabilities and approximately 15 students

- We hope that this experience might break down some of the fears that newly qualified professionals have about working with non-verbal people

**When will the project happen?**
We are planning the activity for a date in February – this has not been finalised yet – but we will keep you posted. This will fall at a time when the person you care for would normally be using the day service.

**Why are you contacting me?**
- We are contacting you because we think that the person you care for can help. We also think that they are likely to enjoy the activities we are planning.

- Because the person that you have responsibility to consent for would have limited ability to understand this information, you are being asked for consent on their behalf. We hope it will reassure you to know that the day service staff will remain on hand at all times, and if we see any signs of distress, we will help people to leave the activity without hesitation.

- Taking part is entirely voluntary and you can change you mind at any time. Whether or not you choose to take part, this will have no impact on how you are treated by Coventry City Council or the University of Warwick in the future.

- We value people's time, and hope that they find the experience rewarding. We will also provide some funding to the day service for them to spend on a fun activity for the people who took part.

**What will happen to the information?**

- We will record a DVD of the activity to help us to see what worked well, and what didn't. We will use this to help us write a report, and then pass it to the day service. A copy will be held on record, securely, along with the rest of the research records, at the University, but it will not be used for any other purpose

- The DVD, and the feedback we receive from the students will help us to write a final report. This will not include names or other confidential information. It will be a 'write up' of the whole activity. We hope to be able to learn from this, and improve the education of social workers, nurses and doctors in the future.

- We will send you a copy of the report so that you can see how the activity went.

**What happens next?**

- If you are willing to give formal consent for the person you care for to be involved (as described above) please contact Darren Robbins or Stephanie Lunn – we will arrange for you to complete a written consent form.
- If you have any queries, questions or concerns, please feel free to contact Stephanie Lunn on 02476574128 or at Stephanie.lunn@warwick.ac.uk

**Project co-ordinated by Stephanie Lunn (Social worker and Teaching Fellow) and funded by the Institute for Advanced Teaching at Learning (IATL) at the University of Warwick**

**CONSENT FORM**
**For people using Coventry City Council Day services.**

**Listening and learning from the unheard: Inter-professional learning and people with learning disabilities who are non-verbal communicators.**

**Researcher - Stephanie Lunn**

**I confirm that I have read and understood the information sheet dated 28th October 2011 for the above project which I may keep for my records and have had the opportunity to ask any questions I may have.**

**I confirm that I am entitled to give permission on behalf of:**
**(Participant)** _____

**I agree for (participant) _____to take part in the above study and am aware that this will involve:**

*Visiting the University of Warwick*
*Spending time with Student Nurses, Doctors and Social Workers*
*Being videotaped*

**I understand that (participant) _____'s information will be held and processed for the following purposes:**

*The evaluation of this educational experience*
*The writing of a report (in which all identifiable personal information will be removed)*
*The anonymous findings of the report, may be published and used for other research purposes.*
**I understand that this exercise is voluntary and that I am free to withdraw my consent at any time without giving any reason without being penalised or disadvantaged in any way. I also understand that if (participant)_____ decides not to engage, that their wishes will be respected.**

**I understand that a DVD will be made of the sessions and that this DVD will be passed on to Coventry City Council's Day Services; it may well be that the participant identifiable in the DVD footage.**

_____
**Name of Participant**

_____  _____          _____
**Name of person giving    Date                    Signature**
**consent**

_____  _____          _____
**Name of researcher          Date                        Signature**

## University of Warwick project information sheet
### Listening to and Learning from the Unheard: Inter-professional learning and people with learning disabilities who are non-verbal communicators.

**Can you help?**
- We are looking for students training to be nurses, social workers or doctors, who are keen to learn from people with learning disabilities who are non-verbal communicators.

**What is the project all about?**
- We want to help trainee professionals improve their communication skills by spending time with people who are non-verbal

- We will recruit non-verbal people with learning disabilities who use Coventry City Council's day Service Facilities to support us with this teaching experience.

- The whole group will work with a theatre practitioner in a drama studio at the University of Warwick – trying out different methods of communication.

- The session will last for about an hour and a half (with plenty of breaks for snacks and drinks as needed)

- This activity will include approximately 8 people with learning disabilities and approximately 15 students

- We hope that this experience might break down some of the fears that newly qualified professionals have about working with non-verbal people

**When will the project happen?**
- We are planning the activity for a date in February – this has not been finalised yet – but we will keep you posted. This will be arranged in negotiation with your course teachers

**Why are you contacting me?**
- We are contacting you because we think you might be interested in this activity

- Taking part is entirely voluntary and you can change you mind at any time. Whether or not you choose to take part, this will have no impact on how you are treated by the University of Warwick now or in the future.

- We value people's time, and hope that they find the experience rewarding. We will also pay you £15 for your time and participation

**What will happen to the information?**
- We will ask you to complete a pre-session and post-session questionnaire. The feedback we receive from all of the students will help us to evaluate the activity. We hope to be able to learn from this, and improve the educational experience of social workers, nurses and doctors in the future.

- We will also record a DVD of the activity to help us to see what worked well, and what didn't. We will use this to inform our final report. This will not include names or other confidential information. It will be a 'write up' of the whole activity. The DVD

will be passed it to the day service for future use with the participants who use their service. A copy will be held on record, securely, along with the rest of the research records, at the University, but it will not be used for any other purpose.

- We will send you a copy of the report so that you can see how the activity went.

**What happens next?**
- If you are willing to give formal consent for your involvement (as described above) please contact Stephanie Lunn, who will arrange for you to complete a written consent form.
- If you have any queries, questions or concerns, please feel free to contact Stephanie Lunn on 02476574128 or at Stephanie.lunn@warwick.ac.uk

**Project co-ordinated by Stephanie Lunn (Social worker and Teaching Fellow) and funded by the Institute for Advanced Teaching at Learning (IATL) at the University of Warwick**

THE UNIVERSITY OF
**WARWICK**

CONSENT FORM
**For Students**

**Listening and learning from the unheard: Inter-professional learning and people with learning disabilities who are non-verbal communicators.**
**Researcher - Stephanie Lunn**
**I _____ consent to take part in the above study and am aware that this will involve:**
*Engaging in theatre based interactions/communication with people who are non verbal*
*Working with people who have significant learning disabilities*
*Being videotaped*

**I understand that   my information will be held and processed for the following purposes:**
*The evaluation of this educational experience*
*The writing of a report (in which all identifiable personal information will be removed)*
*The anonymous findings of the report, may be published and used for other research purposes.*
**I understand that a DVD will be made of the sessions and that this DVD will be passed on to Coventry City Council's Day Services; it may well be that I will be identifiable in the DVD footage.**
**I understand that this exercise is voluntary and that I am free to withdraw my consent at any time without giving any reason without being penalised or disadvantaged in any way.**


_____    _____    _____
**Name of participant**          **Date**                      **Signature**

_____    _____    _____
**Name of researcher**           **Date**                      **Signature**

# Appendix 2

**<u>Learning from non-verbal people with learning disabilities</u>**
**<u>Pre-reading</u>**
Students of medicine, nursing and social work will all be learning together at the learning disability focused session on 14th February. In order to ensure that students from all disciplines are able to gain the best possible learning from this inter-professional experience; <mark>please read and reflect on this short document prior to attending the session.</mark>

## Learning disability in context
Approximately 0.35% of the UK population have learning disabilities that are moderate, severe or profound. This proportion increases to between 1 and 2% of the UK population when we include people with mild learning disabilities (BILD, 2007).
The people who will participate in this session have severe or profound learning disabilities. Many have other, associated health difficulties such as mobility problems, and all have very limited verbal communication. The people contributing to this learning experience will have access to general medical services such as General Practitioners, but will also access a number of specialist services and benefits including: Speech and Language Therapy, Physiotherapy, Learning Disability Nursing Services, Residential care commissioned by the local Authority (LA) and/or the Primary Care Trust (PCT), Residential respite support also commissioned by the LA/PCT, self-directed support funded through direct payments from the LA, day services provided by LA, other support designed to give unpaid carers a break from their caring role and targeted benefits awarded due to functional limitations. As such, these service users and their families will have contact with a wide variety of health and social care professionals.
The Governmental Publication 'Valuing People Now' (2009) recognises that the life chances of people with Learning Disabilities and those of their families and carers are less promising than those of their non-disabled peers.  Valuing People Now highlights the need to improve access to health and social care services for people with learning disabilities. The implications of poor access to appropriate health and social care can be profound, as highlighted by Mencap (2007) in 'Death by Indifference' and the following Ombudsman report (2009). In order to improve social and health care service for people with learning disabilities, both documents identify the need for improved communication between people with learning disabilities and the professionals supporting them. They also call for more 'joined-up' working between those professionals.
When working with non-verbal people, the total communication skills of professionals are paramount. Often people who know the non-verbal person best, such as family carers and residential providers can give invaluable support. However, health and social care professionals must be alert to the possibility of conflicts of interest between service users and their carers, and in rare instances, the abusive relationships which can exist where power is unequally divided. The importance of understanding non-verbal communication is also key in our interactions with individuals who do use speech as a preferred method of communication. For these reasons, developing awareness of our own non-verbal communication and that of others is valuable for all practitioners.

## Learning from patients and service users
Social work, nursing and medical professional education all espouse a commitment to involving patients and service users in the training and development of professionals at pre and post-qualifying stages. And whilst many educators strive to improve the quality and diversity of patient input, it can, at times, appear patchy and piecemeal (Kemshall and Littlechild, 2000). The style of patient led learning usually follows a traditional, didactic, approach; so it is almost exclusively the most confident and verbally articulate service

users are who contribute to the learning of health and social care professionals. This can leave professionals unprepared for working with less articulate people in need of services.

**Learning outcomes**
Stef Lunn has been awarded a small amount of funding by the Institute of Advanced Teaching and Learning (IATL) at the University of Warwick; to investigate how the experiences of non-verbal people might be directly incorporated into the education of health and social care professionals. With an open minded approach on the part of facilitators and participants, we hope to achieve to following learning objectives:

- Increase student awareness about the prevalence and common experiences of people with profound learning disabilities

- Improve confidence in working with, and for, non-verbal people.

- Train and encourage students to use non-verbal communication when interacting with people with communication differences, as well as the wider population.

This is an evaluated learning exercise, from which IATL hopes to gather an understanding of what methods might work when including non-verbal people in the education of health and social care professionals. As such, your detailed evaluation of the session will provide valuable information on the student experience. Your support in providing considered responses is greatly appreciated.

**Session plan**
10:00 am      Pre-session questionnaire
10:30         introductions
10:50         Facilitated interaction and communication
11:20         break and informal discussion
11:30         Facilitated interaction and communication
11:50         feedback, discussions and conclusions (including debrief opportunity)
12:00         Post session questionnaire
12:10         shared lunch and informal discussions
12:30 pm      Formal session closes.
        (All participants are welcome to stay for as log as they wish up to 1:30 pm)

**References**
Department of Health, 2009 'Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities' London: HMSO
British Institute of Learning Disabilities, 2007 'Factsheet – Learning Disabilities' http://www.bild.org.uk/docs/05faqs/Factsheet%20Learning%20Disabilities.pdf (accessed 30th December 2011)
Kemshall, H and Littlechild, R, 2010 'User involvement and participation in social care: Research informing practice' London: Jessica Kingsley
Local Government Ombudsman and Parliamentary and Health Service Ombudsman, 2009 'Six lives: the provision of public services to people with learning disabilities' Norwich: TSO
Mencap, 2007 'Death by Indifference' http://www.mencap.org.uk/sites/default/files/documents/2008-03/DBIreport.pdf (accessed 30th December 2011)

# Appendix 3

## **<u>Pre-session Questionnaire</u>**

Student Name (Optional): _____

Student Number: _____

Profession of study: Medicine/Social Work/Nursing * please delete as appropriate

Year of study being undertaken: 1 / 2 / 3 / 4 *please delete as appropriate

Please rate your confidence and competence on a scale of 1 to 5.

Choose N/A if the item is not applicable

|  | Strongly agree | agree | Neither agree nor disagree | disagree | Strongly disagree | N/A |
|---|---|---|---|---|---|---|
| The learning objectives for this session are clear to me | 5 | 4 | 3 | 2 | 1 | N/A |
| I am confident approaching people who are non-verbal | 5 | 4 | 3 | 2 | 1 | N/A |

| | 5 | 4 | 3 | 2 | 1 | N/A |
|---|---|---|---|---|---|---|
| I am confident engaging with people with severe learning disabilities | 5 | 4 | 3 | 2 | 1 | N/A |
| I have experience of communicating with people with learning disabilities | 5 | 4 | 3 | 2 | 1 | N/A |
| I have experience of supporting people who communicate non-verbally | 5 | 4 | 3 | 2 | 1 | N/A |
| I can recognise non-verbal signs of distress | 5 | 4 | 3 | 2 | 1 | N/A |

| | | | | | | |
|---|---|---|---|---|---|---|
| I can recognise non-verbal signs of happiness/contentment | 5 | 4 | 3 | 2 | 1 | N/A |
| I feel confident attempting to interpret non-verbal communication | 5 | 4 | 3 | 2 | 1 | N/A |
| I am competent in working with carers/support workers to interpret the preferences of people with learning disabilities | 5 | 4 | 3 | 2 | 1 | N/A |

# Post-session Questionnaire

Student Name (Optional): _____

Student Number: _____

Profession of study: Medicine/Social Work/Nursing * please delete as appropriate

Year of study being undertaken: 1 / 2 / 3 / 4 *please delete as appropriate

Please rate your confidence and competence on a scale of 1 to 5.

Choose N/A if the item is not applicable

|  | Strongly agree | agree | Neither agree nor disagree | disagree | Strongly disagree | N/A |
|---|---|---|---|---|---|---|
| The learning objectives for this session are clear to me | 5 | 4 | 3 | 2 | 1 | N/A |
| I am confident approaching people who are non-verbal | 5 | 4 | 3 | 2 | 1 | N/A |

| | 5 | 4 | 3 | 2 | 1 | N/A |
|---|---|---|---|---|---|---|
| I am confident engaging with people with severe learning disabilities | 5 | 4 | 3 | 2 | 1 | N/A |
| I have experience of communicating with people with learning disabilities | 5 | 4 | 3 | 2 | 1 | N/A |
| I have experience of supporting people who communicate non-verbally | 5 | 4 | 3 | 2 | 1 | N/A |
| I can recognise non-verbal signs of distress | 5 | 4 | 3 | 2 | 1 | N/A |

| | | | | | | |
|---|---|---|---|---|---|---|
| I can recognise non-verbal signs of happiness/contentment | 5 | 4 | 3 | 2 | 1 | N/A |
| I feel confident attempting to interpret non-verbal communication | 5 | 4 | 3 | 2 | 1 | N/A |
| I am competent in working with carers/support workers to interpret the preferences of people with learning disabilities | 5 | 4 | 3 | 2 | 1 | N/A |

# Appendix 4

**TEACHING SESSION - EVALUATION QUESTIONNAIRE**

Student Name (Optional): _____

Student Number: _____

Profession of study: Medicine/Social Work/Nursing * <sup>please delete as appropriate</sup>

Year of study being undertaken: 1 / 2 / 3 / 4 *<sup>please delete as appropriate</sup>

*Your feedback is appreciated and will be used to develop future learning opportunities. Thank you.*

**Section A**

In this section, **please circle your response** to the items.

Rate each aspect of the workshop on a 1 to 5 scale. Choose N/A if the item is not applicable

| DESIGN AND CONTENT | Strongly agree | agree | Neither agree nor disagree | disagree | Strongly disagree | N/A |
|---|---|---|---|---|---|---|
| This session was a good way to learn about non-verbal communication skills | 5 | 4 | 3 | 2 | 1 | N/A |

| | | | | | | |
|---|---|---|---|---|---|---|
| The content was relevant to my professional development | 5 | 4 | 3 | 2 | 1 | N/A |
| The content was relevant to my personal development | 5 | 4 | 3 | 2 | 1 | N/A |
| The activities gave me sufficient opportunity to practice my communication skills | 5 | 4 | 3 | 2 | 1 | N/A |
| I received sufficient feedback during the teaching session | 5 | 4 | 3 | 2 | 1 | N/A |

| The session lived up to my expectations | 5 | 4 | 3 | 2 | 1 | N/A |
|---|---|---|---|---|---|---|

**ORGANISATION AND FACILITATION**

| | Strongly agree | agree | Neither agree nor disagree | disagree | Strongly disagree | N/A |
|---|---|---|---|---|---|---|
| Instructions received prior to the session were clear | 5 | 4 | 3 | 2 | 1 | N/A |

| | 5 | 4 | 3 | 2 | 1 | N/A |
|---|---|---|---|---|---|---|
| directions given during the teaching session were clear | 5 | 4 | 3 | 2 | 1 | N/A |
| The facilitator (Romy) was well prepared. | 5 | 4 | 3 | 2 | 1 | N/A |
| The facilitator was helpful | 5 | 4 | 3 | 2 | 1 | N/A |
| The input from support workers was appropriate | 5 | 4 | 3 | 2 | 1 | N/A |

**Section B**
In this section, **please tick all the boxes that apply.**

| **SUGGESTED IMPROVEMENTS** | |
| --- | --- |
| In my opinion, the session could be improved through the following measures: | Please tick here |
| Allow more time | |
| Provide more 'pre-reading' prior to the session | |

| Include different activities | |
| --- | --- |
| Allow <u>more</u> time for informal chat/communication | |
| Allow <u>less</u> time for informal chat/communication | |
| Change the venue | |

Increase student numbers

Reduce student numbers

## Section C

The final section of this questionnaire asks for some more **open questions** for general feedback

What was the most valuable part/aspect of this session?

What was the least valuable part/aspect of this session?

Any other comments/suggestions:

Thank you for your time and efforts today. You will receive a follow up e-mail in a few weeks time, asking for your general reflections on the learning experience. We hope that you will be able to provide a short response to assist in our evaluation of this session.
Many thanks – have a safe journey home