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Introduction

This report is based on a research project that was undertaken by a group of researchers all closely involved in the delivery of the BA (Hons) Learning Disability Studies programme at Manchester University.

The programme is unique in the UK, in relation to its underpinning epistemological and ontological stance. Historically, disability studies and disability research, specifically learning disability research, has adopted an approach that constructs people with learning difficulties as being in need of ‘treatment’ or ‘cure’; the assumption being that non-disabled academics/medics are the ‘experts’ that can provide this. However, from its inception, the programme has rejected this traditional model in favour of the social model of disability. The social model of disability rejects the medical view or model of disability and explicitly identifies the cause(s) of disability
as society’s failure to accommodate people with impairments. For example, a person who uses a wheelchair only becomes disabled when organisations fail to make their buildings accessible; therefore, the person’s physical impairment is not the disabling factor the lack of a ramp is.

In line with the programme’s social model approach, a key element in both the original and the ongoing development of the programme is the very real involvement of people with learning difficulties in the day-to-day delivery of the programme. A core element of this involvement is the programme’s Steering Group. This group oversees the running of the programme and is made up of academic staff, students and learning disabled researchers. The group is permanently chaired by a person with a learning difficulty and people with learning difficulties make up over 50% of the group’s membership. A key role of the Steering Group is to examine ways in which people with learning difficulties can have an increased role in both lecturing on the programme and undertaking learning disability research. It was from within the Steering Group that this research project evolved.

As part of its ongoing exploration of how people with learning difficulties could play a more active role within the programme, the Steering Group formulated a research proposal that would further this aim. The proposal was submitted to ESCalate and subsequently received funding.

It was agreed that the research would focus on increasing the involvement of people with learning difficulties in higher education; five key objectives were identified:

i) To enable learning disabled members of the Steering Group to develop, prepare and deliver a range of lectures across all three years of the BA (Hons) Learning Disability Studies programme.

ii) To enable members of the Steering Group to prepare and deliver a range of lectures at other HE institutions on programmes that prepare students to work in services that provide support to people with learning difficulties (For example, nursing and/or social work).

iii) To explore ways that Steering Group members can receive appropriate financial reimbursement for the work they undertake.

iv) To explore ways that members of the Steering Group can disseminate the findings of the project i.e. seminars, publications etc.
v) To build on the findings of the project by considering a larger scale research proposal that would secure a larger research grant.

The Research Process

From the earliest stages of the research project a participatory approach was adopted. This ensured that learning disabled researchers were actively involved in every stage of the project including deciding the original project aims, deciding upon appropriate data collection methods, undertaking data collection, analysing the data and discussing the findings.

It was decided by the research team (one full-time academic staff member, four learning disabled researchers and two part-time research assistants) that due to the range of issues that the project was seeking to explore a multi-method qualitative approach was required.

The four specific methods that were adopted were: group interviews, focus group work, action research and investigative research. The specific details of each approach are outlined below.

Group Interviews

Members of the research team interviewed groups of students to explore their thoughts relating to the lectures they had previously received from members of the Steering Group. Initially, each interview was led by a Steering Group member with the support of a research assistant. However, as the project progressed it was decided that the research assistants should undertake two group interviews with students without the presence of a Steering Group member. This decision was taken as the research team felt that some students may be less likely to raise any possible issues that could be viewed as criticisms of the lectures they received from Steering Group members if the interviewer was also a Steering Group member.

Focus Group

Following on from the group interviews, a focus group was held that involved students, members of the research team, members of the Steering Group and academic staff. The initial findings of the group interviews and the overall project aims were used as the initial discussion points for the group.
Action Research

This was considered by the research team as one of the key components of the project. Whilst a number of Steering Group members had previously lectured on the programme there was an acknowledgment that the support these members had received was minimal and did not enable members to plan the lectures in accessible and appropriate ways. This phase of the project involved the research assistants providing members of the Steering Group with detailed support to both plan and deliver a range of lectures. Following each lecture, discussions were held between the research assistant, the lecturer and members of the research team to analysis the session and both the impact on the students (each student was asked to complete an evaluation form after each lecturer) and how successful the lecturer felt the session had been delivered. Following each analysis/evaluation, the subsequent lecture would be planned taking into account the previous experiences.

Investigative Research

From the outset, one research assistant was assigned the task to liaise with the local Jobcentre Plus (Benefit Agency) and with the central Department of Work and Pensions (DWP). The aim of this strand of the project was to begin to clarify the position of Steering Group members in relation to their ability/inability to receive financial payment for the work they undertook relating to the university. It was planned that as a result of this phase of the project Steering Group members would be clearer on the financial payments they could receive whilst in receipt of benefits. The research assistant provided regular updates to the research team who, in turn, provided ongoing support in relation to the direction of this piece of work.

Ethical Issues

There were a number of complex and interesting ethical issues encountered from the outset of this project. The issue that the research team felt was the most significant to them related to the requirements of the University of Manchester’s Committee on the Ethics of Research on Human Beings.

In order to receive ethical approval from the committee a formal application was submitted. A requirement of the committee was that a participant information sheet and consent form were submitted prior to the project commencing. It was this requirement that the research team found problematic for two reasons:
1. As the project was undertaken using a participatory approach, all members of the research team were considered to be researchers not research participants. However, the Ethics Committee required that each member of the Steering Group (with the exception of academic staff and research assistants) received an information sheet and signed a consent form. This requirement immediately ‘threatened’ the participatory nature of the project. The Steering Group felt that by requiring members to sign a consent form it was differentiating non-disabled researchers and researchers with learning difficulties; in essence placing power with academic staff and resigning members to the role of passive participants. The Steering Group felt strongly that this issue needed to be raised with the Ethics Committee. However, due to the need to progress with the project it was decided that all members of the Steering Group would sign the consent form; however, this would include the research assistants and the Principle Investigator.

2. The Steering Group prepared the information sheet and consent form with the needs of all members in mind. It was decided that as some Steering Group members found the addition of pictures and graphics helpful both documents would be designed in this manner. However, when these documents were forwarded to the Ethics Committee, the committee requested that the graphics be removed as they made it appear that the people receiving them were ‘people with low levels of understanding and was perhaps condescending’. Again, the Steering Group did not agree with this decision and felt that the committee did not understand the needs of some people with learning difficulties.

Clearly, the requirements of the Ethics Committee concerned the Steering Group and reinforced the traditional dominant academic view that people with learning difficulties are the subjects of research whilst the non-disabled academic staff are the ‘experts’. All members of the research team felt that this needed to be challenged. It was therefore decided that on conclusion of the project a copy of this report would be provided to the Ethics Committee and an offer made for members of the Steering Group to attend a committee meeting in order to discuss the issue further. It is hoped that as a result of this project the Ethics Committee will develop a better understanding of both the needs of some adults with learning difficulties and the complexities of research that adopts a participatory approach.
Data Analysis

The focus group and interviews were tape-recorded and later transcribed. These, along with the written student evaluations, were analysed using a combination of grounded theory and discourse analysis. Emerging themes were identified and these formed the basis of future interviews and lectures. The analysis of data was an ongoing process and the research team met at regular intervals to analyse the emerging data and to make decisions on how the emergence of new themes should influence the direction of the project.

From the outset, it was decided that Steering Group members would be fully involved in all areas of the project; this included data analysis. However, as the project progressed, two challenges to this approach emerged:

1. As previously stated, the programme (under the direction of the Steering Group) has adopted the social model of disability as its underpinning philosophical stance. This approach, that views society as the cause of disability, has been the dominant discourse within the academic discipline of disability studies since the late 1980’s. However, there is an ongoing debate within the discipline as to the relevance and, specifically relating to this project, the accessibility of the social model of disability for people with learning difficulties (Boxall et al 2004). The issues relating to the inaccessibility of the social model of disability for people with learning difficulties was summed up by one of the research team in one of their previous publications:

   “We might want to study the social model ourselves but we can’t because it should be in pictures and large print.”

   (Docherty et al, 2005: 34)

The specific challenge of the inaccessibility of much of the social model literature that Docherty et al discuss presented itself during a number of the data analysis meetings. Whilst, to a certain degree, these challenges were minimised by the research assistants supporting members to access as much literature as possible, the inaccessibility of much of the literature emanating from the academy clearly restricts people with learning difficulties ability to undertake this type of work independently. The Steering Group did not fail to identify the irony of the inaccessibility of literature that is concerned with how institutional barriers disable people!
2. The practicalities of regularly meeting to carry out data analysis was a significant challenge. It was hoped that at every analysis meeting a combination of Steering Group members, research assistants and academic staff would take part in the data analysis. However, for a range of reasons these meetings proved difficult to convene. Often, meetings would be arranged and then at short notice Steering Group members would be unable to attend. From discussions with members of the Steering Group it is evident that as there is no financial reimbursement for undertaking this work, if other commitments occurred, then understandably, the work of the project would not be seen as a priority. The result of this is that whilst overall, members of the Steering Group were involved in the analysis of data, there were occasions whereby the Principle Investigator would undertake analysis alone and then share this with the Steering Group. If Steering Group members had different interpretations/thoughts then this was included within the specific analysis.

Findings and Project Outcomes

As previously stated, the programme, from its inception, has been committed to enabling people with learning difficulties to play a significant role in the development and delivery of the programme. One of the key objectives of this project was to increase this involvement and specifically the amount of teaching Steering Group members undertook. It was planned that a number of lectures would be provided by Steering Group members and that these lectures would be evaluated from the perspectives of the Steering Group members delivering the lectures and the students present during each session.

Student Perspectives

Through both previous discussions with students and the analysis of university unit evaluation forms, it had been recognised that the students on the programme found lectures from Steering Group members both interesting and insightful. However, the research team felt that it was important that throughout the project students views were sought and listened to in relation to the outcomes that these lectures provided for students. In order to measure the success of the project, students were requested to complete evaluation questionnaires and participate in group interviews at the beginning of the project and then once again towards the end of the project. The following themes were identified:
Lecture Relevance

Pre-project analysis

Whilst it was clear that the students overwhelmingly enjoyed the sessions, there was a subtle but consistent feeling that some students felt that they were not always able to connect the content of specific lectures to the learning outcomes for the unit or module. An example of this is provided by a final year student:

“The lectures are great, but sometimes they just aren’t that relevant to the unit.”

When this was explored in more depth with students, it was identified that students felt that although the lectures were useful, sometimes they felt that they were left unable to form connections between what they were hearing and the specific subject they were studying.

During the data analysis meetings, it was identified by Steering Group members that they also felt that on occasions they did not feel equipped to explicitly discuss their experiences and thoughts in ways that could be specifically connected to the overall programme curriculum. One Steering Group member who had been lecturing on the programme for many years stated that he was only aware of the content of his lectures and this made it very difficult to develop connections with the wider curriculum. It was also felt that due to limited support to prepare and deliver lectures, members sometimes found it difficult to remain focused on the purpose of the lecture if students pursued issues that resulted in other non-related areas being discussed.

Action

- Steering Group members were provided with support to gain an overview of the whole curriculum and to discuss where they thought their specific experiences and areas of expertise could be most appropriately connected.

- All Steering Group members who were delivering lectures were supported by a research assistant to formally plan each lecture. A key element of this support involved the production of accessible lecture plans that enabled members to ‘stay on track’ throughout the course of each lecture.

Post-project analysis

Following the changes made to the way Steering Group members were supported to both access the curriculum and prepare their lectures, students were once again
interviewed regarding their views on the lectures they received. The changes made to the support Steering Group members received resulted in extremely positive feedback from students:

“It makes such a difference hearing first hand about somebody’s personal experience in ways that you can understand”

“Fantastic, first hand knowledge is essential… rather than from someone who hasn’t experienced it or from a book.”

The research team felt that the relatively minor changes that had been made to the support members received clearly had a significant impact on the quality of teaching the students received. Furthermore, this finding supports the stance that it is not the presence of a specific learning impairment that disables people with learning difficulties but it is the ways in which institutions and society respond to people with learning difficulties that is the disabling factor. For example, prior to this project it is possible that students felt that because a specific lecturer had learning difficulties their lectures were difficult to connect to the programme curriculum. However, what has been found is that it was in fact the lack of appropriate support and access to relevant information that resulted in learning disabled lecturers being significantly disadvantaged in how they were able to prepare for a lecture.

When considering the wider context of people with learning difficulties teaching on courses and programmes that are relevant to their lives, this finding would indicate that, with the appropriate support and access to information, the inclusion of the ‘subjects’ of academic disciplines such as social work, nursing or psychology both increases student satisfaction and the overall quality of teaching students receive.

The Role of Academic Staff

Pre-project analysis

It was clear from both the student evaluations and the interviews that a number of students felt uncomfortable that Steering Group members were supported by academic staff throughout their lectures. Students comments centred on how they felt uncomfortable with academic staff being present throughout the lectures as they did not want to ask the ‘wrong’ questions. A number of students stated that they had not asked questions during lectures by Steering Group members for fear that the academic staff present would think that their question was inappropriate or naïve. These feelings are summed up by one third year student who stated:
“We worry that we will say the wrong thing.”

Whilst it is common across all disciplines that students often feel that their questions are ‘silly’ or that they are the only person who does not know a certain fact etc, the research team felt that it was important that students gain as much value from attending the lectures as was possible.

Action

The funding for this project enabled the recruitment of two research assistants. One of their key roles was to support Steering Group members in the preparation and delivery of lectures. Prior to receiving this funding, all the support required by members was provided by a member of the academic staff. The wide-ranging benefits of recruiting the research assistants are discussed later in this report. However, in relation to supporting members to deliver lectures their recruitment resulted in academic staff no longer supporting members during lectures.

Post-project analysis

The feedback received from the students following attending lectures where Steering Group members were supported by the research assistants indicates that students felt more able to participate in the lectures than when academic staff were present. This is illustrated by the comments of one third year student:

“It’s much better; I don’t feel like I am being tested now!”

These findings would indicate that if students are to receive the full benefit of the involvement of people with learning difficulties on this or other programmes, careful consideration is needed in relation to who provides support to the visiting lecturer. Whilst it is unlikely that programmes will have the resources to fund external support it may be possible to develop relationships with local advocacy projects or other similar community groups that may be able to provide this type of support. Finally, the Steering Group felt it was important to stress that whilst the needs of students are clearly important, it should be the individual delivering the lecture who decides how they are supported and by whom.

Sensitivities

Pre-project analysis
Many members of the Steering Group draw upon their personal experiences when lecturing students. Many of these experiences were unpleasant. For example, members discuss spending many years in large institutions or how they have been denied choice relating to major decisions in their lives. When discussing this with students it became clear that students found some aspects of these lectures uncomfortable. One second year student stated:

“I feel awkward sometimes as I’m not sure if I can ask certain questions… it was very uncomfortable when Sally [Steering Group member] began to cry”.

The Steering Group felt that students needed to hear about both the positive and the negative experiences of people with learning difficulties. The Steering Group recognised that, unfortunately, many of these experiences could be upsetting to listen to but they believe it is important that students, who are potentially going to be supporting people with learning difficulties in the future, needed to hear about them.

In relation to students asking questions, it was felt that this issue needed to be addressed for both students and Steering Group members who have, in the past, felt that on occasions students asked inappropriate or overly personal questions.

**Action**

It was felt that if five minutes was spent at the beginning of each lecture establishing a set of ‘ground rules’ for students this would assist both students and Steering Group members. The ground rules would cover areas such as what students could do if they became upset and how and when questions could be asked etc.

Additionally, it was decided that questions should be submitted in advance (for example, during the break half way though the lecture) as this would enable Steering Group members to decide how and if they would answer each question. This approach would also enable students to feel that they could ask a wider range of questions as members could simply not respond to the question if they felt it was inappropriate.

**Steering Group Perspectives**

Many members of the Steering Group have been involved with the programme from its inception. The research team felt that it would be useful to explore why members gave up their time to be actively involved in the delivery and development of the programme. It was felt that an understanding of this could both
enable the Steering Group to continue to develop but could also provide some insight for other academic programmes that are considering developing their own ‘user involvement’ group/committees.

Members of the Steering Group were individually interviewed by the research team and the issue was discussed within the focus group. Having analysed the data collected, it was clear that there was one major theme that motivated every member to be involved in the Steering Group. This is encapsulated by the following selection of extracts from the transcripts:

“We are teaching the people that will run future service”

“We can tell students what works and what doesn’t”

“I can relay first hand the experiences of lots of people with learning difficulties”

“Staff talk about changing and giving us choice but nothing happens”

“Community living is at danger of becoming the same as living in an institution”

It is evidently clear from listening to the Steering Group members that their main motivation for their involvement in the project is a desire to influence the next generation of staff and managers who will be responsible for staffing and developing services. Many members of the group explained that although on occasions their involvement on the programme restricted their activities in other areas of their lives, and in the contexts of delivering lectures, could be distressing at times, they were committed to ensuring that the quality of services for people with learning difficulties was improved. The Steering Group members felt strongly that by sharing their, in the main, negative experiences with students they could potentially affect real change in the future direction of services.

In addition to their desire to improve the quality of services people with learning difficulties received, some Steering Group members stated that they felt that they benefited as individuals through their involvement with the programme. One member stated,

“It’s the one area of my life where I can be myself. I can talk about my experiences and opinions and people listen to me and believe me”.

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The member went on to explain that as a result of living in a service where he was regularly denied choice and where other people would attempt to make decisions on his behalf, he felt that during his time at the university he was valued for who he was and for his opinions; several other members of the group expressed similar opinions. However, whilst it is highly significant that members of the group felt very positive about their involvement in the programme, the research team felt that it should be made clear that the data would suggest that it is not simply a case of involving people that ensures that people have positive experiences, but more related to how those people are viewed and responded to by academics and other professionals. There is a risk that without a real commitment to listening to the views of people with learning difficulties, any group that attempts to involve people could simply be tokenistic and could lead to outcomes that do not reflect the views of people with learning difficulties.

Teaching Skills

Pre-project analysis

Historically, a number of the Steering Group members have delivered lectures across all three years of the programme. However, Steering Group members have received little in the way of formal support to plan and deliver these lectures. Several members stated that they felt that they were not well prepared to carry out lectures. Two members of the group stated,

“People need training to talk to a group of strangers. It could stress people out or even make them ill so they don’t turn up.”

“I get really nervous, I would like some support to not be so nervous.”

Action

In order that Steering Group members who were delivering lectures felt confident to deliver each session, a research assistant supported each member to plan (and time) each lecture. Planning of individual lectures consisted of at least three planning sessions. Additionally, the research assistant provided support throughout each lecture. It was explained to the research assistant that they would be directed by the Steering Group member as to what support they would like during the lecture. A key element of the support provided was that all parties were aware that the research assistant was there to assist and NOT take over the lecture unless specifically asked to by the Steering Group member.

Post-project interviews
“I was still nervous but it was much better... I didn’t feel like running out.”

All Steering Group members who delivered lectures following the provision of planning support stated that they felt better equipped to teach the students.

Attitudinal Barriers

Although every member of the Steering Group stated that they felt included and valued by the programme staff, there had been instances where members had experienced negative attitudes from other university staff. One member explained that he was regularly stopped by security staff who appeared suspicious as to why he would be on a university campus,

“The security people stop me and ask me for ID and what I am doing here.”

Other members of the Steering Group explained that they too had had similar experiences.

Action

It was felt that the status within the university of Steering Group members was unclear. For example, on some occasions they were viewed as visiting lecturers and at other times as volunteers. In order to overcome this confusion and, importantly, have the contribution of Steering Group members recognised, it was negotiated with the university that Steering Group members would be made Honorary Staff members and would be issued with ID cards:

Post-project evaluation

Not only did this enable Steering Group members to demonstrate the purpose of them being on campus but it also indicated the value that the university placed on their involvement. Additionally, as Honorary Staff members they are now entitled
to access a whole range of facilities open to staff such as the library, online resources etc..

Payments and Reimbursement

Prior to the project commencing, occasionally some members would receive a small financial payment for delivering lectures. The amount individuals received was often minimal as all the members of the Steering Group are in receipt of welfare benefits and there are a range of complex rules relating to how much individuals can receive without the payment affecting their benefits. This area is highly complex as the rules relating to paid work vary from benefit to benefit and therefore no one standardised payment can be made.

This issue was highly significant to members and was raised many times throughout Steering group members. An example of this concern is raised by one member who stated:

“No offence, but you, Craig and Rohhss [academic staff] get paid a lot of money to be here and we don’t.”

It was felt that the lack of any real payment to Steering Group members was not only financially unfair but could signify that members of the Steering Group should not be considered as ‘real’ lecturers. The Steering Group and the research team felt this was a key area that the project should investigate.

Action

Given the significance of this issue the research team decided that one of the research assistants should be dedicated to undertaking research in this area. The research assistant spent many months liaising with a range of organisations and government departments to clarify the situation.

Post-project evaluation

The results of the projects investigation into how members could be financially rewarded are complex and highly individualised. For example, it is evident that one member of the group cannot earn any money as he would become ineligible to receive his current benefit and would be unable to receive that benefit in the future. In other instances, the work that has been undertaken has enabled individuals to receive significant payments for their contributions to the programme. For example, individuals on certain benefits can work for 16 hours without their benefits being affected (additionally, these hours can be averaged over several weeks).
The project revealed that given the current regulations, it is not possible to pay a standard rate to Steering Group members to deliver lectures to students. However, we are currently developing an accessible guide for Steering Group members in order that individuals can make informed choices relating to if and how much teaching they choose to undertake. Additionally the following outcomes were achieved:

**Support to receive individual advice from the Jobcentre Plus** – every member of the Steering group will be offered support to contact and attend the local Jobcentre Plus in order that they can receive individualised guidance relating to their ability to undertake paid involvement.

**Support to ensure maximum involvement without jeopardising benefits** – following the receipt of guidance from the Jobcentre Plus each member will be supported to ensure that they can maximise their involvement and financial payment.

**Ensuring people are not financially worse off** – there are complex and strict rules relating to the payment of expenses. For example, if a Steering Group member receives any payment for undertaking any work then their travel expenses are considered earnings. However, if they are not receiving payment, these expenses are not considered earnings. Therefore, Steering Group members will be supported to ensure that they are never financially disadvantaged as a result of their involvement.

**Liaising with the Social Care Institute of Excellence, Commission for Social Care Inspection and the Department of Work and Pensions** – the project has highlighted the difficulties faced by people receiving payment for their involvement on the programme. The research team are aware that this issue is of concern to many organisations that consult and/or involve people with learning difficulties. In order to share these concerns with government a conference was arranged to highlight how the guidance relating to benefits is, in many cases, creating barriers to involvement. The research team have been invited to attend the conference and will present the project findings to the Department of Work and Pensions.

**‘Real’ jobs with ‘real’ salaries** – The view of the majority of the Steering Group is that ultimately, the aim of the programme should be to employ a person with a learning difficulty on a contractual basis to undertake much of the work currently undertaken on an ad hoc and quasi-voluntary basis. This would enable the individual to cease receiving benefits and enter employment. All involved in the
project agree that this is a priority aim and it is hoped that following on from this project, funding for a significantly larger project can be secured that will facilitate this.

**Dissemination of findings.**

The project findings will be circulated widely within the University of Manchester to ensure that many of the internal issues identified within this report are highlighted to the relevant departments/senior staff members. Members of the project team have delivered seminars based upon the findings of the project to university staff and students.

Similarly, the findings will be shared with other universities that have been involved in the project. Members of the Steering Group delivered lectures to social work students at Manchester Metropolitan University (MMU) as part of the project. Detailed feedback relating to the project findings and their possible implications for increasing user involvement/voice as part of social work training will be shared with colleagues at MMU.

A copy of this report will be provided to the Department of Work and Pensions, The Commission for Social Care Inspection, and the Social Care Institute of Excellence in the hope that best practice can be shared widely.

The research team and members of the Steering group have formed a writing group with the aim of increasing the numbers of publications produced by or in partnership with people with learning difficulties. It is envisaged that one of the first publications of this group will be based on the findings of this project.

A summary of the project findings will be included on Manchester University’s website.

**Conclusion**

This project has highlighted the benefits that involving people with learning difficulties in the delivery and development of the BA (Hons) Learning Disability Studies programme are substantial, and in many ways, irreplaceable. People with learning difficulties offer a unique and first-hand view of how society and institutions have both historically responded to them and continue to arrange contemporary society in ways that serve to exclude them.

The findings have demonstrated that having the label of learning disabled need not exclude people from being involved in the provision and on-going development of an academic programme. Furthermore, it has been shown that for many individuals
with learning difficulties, the disabling factors in their life are very much external to any impairment they may experience. For example, this project has shown that with appropriate support members the Steering Group were able to deliver highly relevant lectures to large groups of students.

As a result of seeking and listening to the views of students, it has been possible to conclude that the involvement of the Steering Group members improves both the quality of the student experience and the ability students have to consider their academic work in the context of people’s lived experiences.

The issue of paying Steering Group members for their contribution to the programme remains problematic. However, through the work that has been undertaken with a range of relevant government departments/agencies, Steering Group members are now able to receive the maximum financial reward for their participation without their benefits being adversely affected. Steering Group members continue to be actively involved with the work currently being undertaken by a range of organisations that are lobbying government to amend the benefit regulations in order that users of services can receive the appropriate financial reward for their involvement.

**Future Developments**

The Steering Group, research team and the programme development committee all strongly recognise the valuable and irreplaceable contribution that people with learning difficulties make to the programme. This project has enabled the exploration and expansion of that contribution and has highlighted the need for this to continue. Therefore, the Steering Group has decided that following on from the project, further more substantial, funding will be sought to enable the project to be expanded. It is hoped that a successful funding application will enable the recruitment of a person with learning difficulties to join the programme team on a contracted basis. It is envisaged that this person will undertake both teaching and research.
References
