Person Centred Planning with people from Leicester’s Asian Communities

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This document has been written by Rakhee Parmar, with assistance from Jo Brown, Carole Shelton and Malcolm Potter.

October 2004
What is Person Centred Planning and why is it important?

Since *Valuing People* was first published in 2001, a lot has been said about what Person Centred Planning is, and why it is important.

It is a way in which people with learning disabilities can get greater choice and control over their lives. It is also an important way for people with learning disabilities to get the services and supports they need to live life as they want it.

Person Centred Planning is a way of helping people to explore and communicate what they want from their lives. It is also about working out how this can be achieved, making use of both formal services, and other informal sources of help and support.

Person Centred Planning can help individuals to get the most out of sources of support that already exist. It can also help to change those existing services, or create new ones, so that they work in ways that are of the most benefit to the people they serve.

Person Centred Planning is important for people from our Asian Communities for the same reasons that it is important for all people with learning disabilities. However, there are some reasons why it is especially important.

It is recognised that people from Asian communities may not be well served by existing public services. This happens for a variety of reasons for all people with learning disabilities. However, people from Asian communities may face further barriers because of issues to do with language, religion and cultural practices. These barriers may result in people having a poor experience of services, or may prevent people from using services at all.

Person centred planning can help service become better by providing information that shapes the service. However, this can only happen if person centred planning addresses these issues in the first place, and if there are systems in place to get services to respond.

Because the experience of using public services may be unsatisfactory, family and community support may have greater significance for people from our Asian communities than for those from our white communities.
Person centred planning can help families and communities learn about what is important to people with learning disabilities, and find ways to help them achieve their ambitions. Person Centred Planning is just as important for helping people with learning disabilities explore and express their aspirations within the family and community context as it is for helping them to get the most out of public services. It is also a way of challenging restrictive attitudes towards disability (which exist to some extent in all communities).

People from Asian communities may recognise that services do not serve people with learning disabilities well, but may find it difficult to play a part in changing and improving services. This is because of the way that the planning processes take place.

Systems that are set up to gather information from person centred planning will provide a natural channel for involving people with learning disabilities and their families play a part in shaping services.

The Leicester Project

Leicester is a City of 280,000 people. It is the largest city in the East Midlands, and the 10th largest City in the country. It is a historic meeting place. For hundreds of years, people of different races and cultures have gathered in Leicester, giving it a rich and unique heritage.

The city’s ethnic minority communities now make up more than a third of Leicester’s population. The 2001 census shows that the largest ethnic group is of people who describe themselves as White British. They account for 61% of the population.

The next largest group is of people who describe themselves as Asian or Asian British, accounting for 30% of the population. Most of these people are of Indian ethnic origin, giving Leicester the largest Indian population of any local authority area in England or Wales. Within this population three main religious groups are represented. From the 2001 census, 15% of people in Leicester described themselves as Hindu, 11% as Muslim, and 4% as Sikh.

In Leicester we have a good Register of adults with learning disabilities. About 22% of people known to specialist health and social care services are from the Asian communities, and this number is steadily growing.

In terms of the services that are available to people with learning disabilities in Leicester, many of these were developed in the early 70s for what was then a predominantly white population. These services have obviously developed, and become more responsive to the needs of people from our Asian Communities, but we know there is still concern
that services do not meet the needs of people from these communities as well as they could do.

Person centred planning is important for people from Asian Communities for the same reasons that it is important for all people with learning disabilities. It can act as the driving force to improve the services that people use and improve the quality of people’s lives.

At a time of great opportunity and significant change as a result of *Valuing People*, and in the light of the concerns that have been expressed, the need to make sure that we get person centred planning right for people with learning disabilities from our Asian Communities is particularly pressing.

In 2003, the Valuing People Support Team gave the Leicester Learning Disability Partnership Board some funds to set up a small project to look at how we might do this. A part time Development Worker was appointed for one year. The worker was given the task of raising awareness of person centred planning amongst our Asian communities and getting them involved. At the same time we were also looking at what the problems might be, and how these could be overcome.

This paper gives an account of the work that has been carried out, and some of the lessons we have learnt.

### How people get to know about person centred planning?

**Raising awareness amongst people with learning disabilities and their families**

In order for people with learning disabilities from our Asian communities to start making their own plans both they, and the important people in their lives, need to get to know about what person centred planning is. Special consideration needs to be given to how this can be done effectively. It has been recognised that people from Asian communities often miss out on information about services and developments that could help them.

In the spring of 2003, when the Development Worker started to talk to families about Person Centred Planning, she found that most had never heard of it. As a way of trying to raise awareness the Development Worker organised a special event in a community venue for an established group of Asian carers of people with learning disabilities to explain about person centred planning. A lot of effort needed to be put into this. Invitations were sent out to people who would not normally attend the carers group, and people with learning disabilities were
invited too. On the day, supporters were available to support people with learning disabilities who attended.

The presenter was our Development Worker who is of South Asian Heritage, has a good knowledge of person centred planning and speaks a range of community languages.

The event was well received, and there were a number of learning points;

- Having someone who knew about person centred planning and could speak community languages was vitally important. However, translating the same point into different languages slowed things down. The next step is to repeat the event at different community venues. The plan is to do the presentation at different times on the same day using the different community languages.

- Such events need to be held on a regular basis rather just being “one off” events.

- People attending the event said that it would be useful to have some basic written information. This includes a simple fact sheet, to be available both in English, and in the different community languages. Although many people from Leicester’s Asian community speak in Hindi, Gujerati and Punjabi, some people do not read and write in those languages. Translating documents into community languages is expensive. Through the East Midlands Valuing People Support Network for Person Centred Planning we are looking at developing resources and sharing costs with other regional Partnership Boards.

- There was a perception that Person Centred Planning is a process that is led by, and is mainly for the Social Services Department. To begin with this sometimes caused suspicion and resistance. It is important, at the earliest stage of raising awareness, to stress that person centred planning is a process that is led by the person with a learning disability, and supported by the people who are important in the person’s life.

**Making other community contacts**

Our Development Worker made contact with Community Groups and Community Leaders to make them familiar with person centred planning. The development worker also met with independent and voluntary sector organisations that provide residential services aimed at people with learning disabilities from our Asian Communities.

On following up Residential Providers some months later it was disappointing to find that little had actually changed, although there is now an increasing take up of places on the Leicester City Partnership
Board’s free Person Centred Planning Training Programme. The Learning Disability Service of the Social Care and Health Department is now looking at making changes to the way that it contracts with Residential Care providers generally. One of the aims of this is to make sure that providers take more account of person centred planning and person centred approaches.

How we help people to make their plans

Training for Person Centred Planning

In Leicester we have developed a rolling programme of training opportunities for person centred planning that range from introductory awareness raising to how to be a facilitator and how to “train the trainers”. The training has been unique in our own local experience because it has been delivered by a mix of people with learning disabilities, carers and professionals to similarly mixed groups of people.

As with our general publicity events, we have used interpreters to make the training accessible to people whom do not have English as a first language. As a way of trying to make sure that nothing gets lost in the translation, we have made sure that the interpreters themselves have been through the introductory training in their own right, and understand the principles of person centred planning.

The interpreters who have been through the training in this way also help people develop their individual plans where this is needed.

Through the Development Worker’s involvement with families, we realised that our training needed to reach out to more people. Some parents and carers said they would prefer that training and information sharing is in one language and at a venue where they would feel comfortable. In order to do this we have had to put forward some people with community language skills who were prepared to complete the helper, facilitator and “training the trainers” training to become helper trainers in their own right.

We shall have completed this by December 2004 and we have a training day for people with learning disabilities and carers from our Asian Communities scheduled for January 2005. There will be three workers from Social Care and one service user to help with the training. We hope to recruit some carers from this to become trainers.

Other considerations for this training include single sex groups, run at times that are suitable for carers and people from the Asian community. We are looking at using community venues such as Temples.
We have planned another information giving day similar to the first one that the development worker organised. Our aim will be to use a community facility to raise people’s awareness of PCP, which will include stalls about how to get information on housing, employment, community opportunities and how to get help with services.

We are also working in partnership with Leicestershire, Rutland and Northamptonshire with help from the Valuing People PCP Co-ordinator to arrange a similar event in each respective area. The first one is to be held in Leicester for the local community in March 2005.

As a result of this work, as time goes by, more and more people from our Asian Communities are gaining the skills and knowledge to help and facilitate person centred planning, and to act as trainers and supporters to others. Our Person Centred Planning Training Plan for Leicester acknowledges that, in order to involve people from all our different communities we must learn from our experiences and where necessary, change the way that we do things.

Cultural Competence

Person centred planning should address a range of cultural and religious issues. If some one with a learning disability is being helped to develop their plan by someone with a similar cultural background, it is more likely that these issues will be considered.

For others it may be helpful to have some background information. People who help others with person centred planning would benefit from knowing about the different cultures of the people they are working with.

In Leicester there are some good local resources to help with this, including an excellent “Cultural Resource Pack” produced by the Leicestershire Partnership NHS Trust. This includes

- A Guide to Cultural and Spiritual Needs
- Guidelines for the Culturally Sensitive Care of the Dead and Dying
- A Guide to Dietary Requirements for Cultural Groups.

A shorter guide to some important things to consider in relation to the three main religions of Leicester’s Asian Communities is included as Appendix 1.

Because of the importance of cultural issues in a city as diverse as Leicester, it is recognised that cultural awareness needs to be included as part of the training that is provided for person centred planning. The group that is responsible for planning training is looking at how this can happen.
Families and people with learning disabilities have told us about some of the cultural issues that they think need to be considered. This has been made into a basic checklist, to act as a guide.

- Names – are you pronouncing these properly?
- Language
- Diet and food
- Dress
- Washing and cleanliness – are these carried out according to the person’s wishes, for example the rinsing of dishes or personal hygiene?
- Gender issues – for example is there a preference for a male or female key worker, or for single sex activity sessions?
- Religion
- Festivals – for example what festivals does the person celebrate and what help is needed?

It is important to consider these issues because services are more likely than not to be based on White European cultural norms. If differences are not highlighted, then these norms will be applied, even when they are not appropriate. On the other hand, people who are helping individuals make plans who are from the same cultural background may take these important cultural issues for granted, and overlook incorporating them into plans.

In our experience, families are experts about their own culture. If you don’t understand, ASK. There is nothing wrong with asking. Do not be patronising or judgmental. Do not assume that if people are from the same community they will have the same views about religion and culture. Treat each person individually.

**Other things to think about**

The role of the family and community networks may be very important, and this needs to be taken into account when developing plans. It can take time, but it is important to develop relationships with families. Communicate as far as possible in the families’ first language. Use interpreters (who themselves understand person centred planning) where necessary. Try to make sure that if you need to have an interpreter you match the family as far as possible in terms of language, religious and community background.

Try to avoid using family members as interpreters because of potential biases and family dynamics that may not be helpful to the person with a learning disability. Talk to both parents and to important family members, not just the ones who speak English.
Family pressures and the dynamics within the family do need to be looked at and taken into consideration. Different generations may have different ideas. For example, elders would expect younger family members to look after person (follow tradition). Younger people may not necessarily agree.

Western ideas about independence and ways of life do not necessarily mean the same for people from Asian communities. It has been our experience that ideas about independence that emphasise individuality and free choice may clash with ideas about collective duties and responsibilities, and may be seen to be at odds with the value of close family relationships.

Some families are worried that person centred planning is about supporting someone with a learning disability to do whatever they want, without taking other factors into consideration. This can be an obstacle to getting started. It is important to stress that Person Centred Planning can help people think about choice and control within the wider context of family and community roles and expectations.

Western ideas about disability may also be different to those in Asian Communities, and this may need to be explored. Discrimination may be encountered from families and community. Parents may have low expectations of their learning disabled children, and may be overprotective, especially of women.

Part of the process of Person Centred Planning can involve looking at these issues, and as a result of this, the person with a learning disability can be empowered. In other cases it may be apparent that what a person needs is extra support to make his or her aspirations known and to speak up. The involvement of advocates who themselves have the right language skills, and who understand cultural issues, can be very helpful.

The development of such culturally appropriate advocacy services supports the development of Person Centred Planning for people from Asian Communities.

Although for many people from Asian community, family and community networks play an important part in their lives, this may not always be the case. Studies have highlighted that the traditional organisation of the extended family, which is viewed as the support structure for members of South Asian communities, has in fact been greatly modified through migration to Britain. For various reasons, families have become divided and this has had an affect on the levels of support provided to people with disabilities and their parents. The process of social change may
also result in a range of value systems within communities. The important message again is, do not make assumptions.

**Basic information about culture and religion in Leicester’s Asian Communities**

There are a lot of things to think about when working with people from the Asian community. Many of these are relevant too for any social group, but some are specific to the Asian community.

The information set out below is a guideline only. if you have any further questions, it is recommended that you approach the family themselves. The information is provided to prompt further questions.

The information set out in the following table has been divided into sections for the 3 main religious groups represented in Leicester's Asian Communities.

This will help you to be able to cross reference cultural themes across the range of religious backgrounds. There are some similarities.
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<th>Muslim</th>
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<td>Punjabi</td>
<td>Urdu</td>
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<td></td>
<td>Punjabi</td>
<td>Gujerati</td>
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<td>Hindi</td>
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<td></td>
<td>Bengali</td>
<td>Hindi</td>
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| Clothing | Sarees         | Punjabi suits  | Salwar       |
|          | Punjabi suits  | (women)        | Kameez       |
|          |                | Kurta suits (men) | women will cover their hair. | (women) |
|          |                | Most wear turbans or patkas. | Some women will also cover their hair. | Most women will cover their hair with a scarf |
|          |                | Some women will also cover their hair. | | Some women will cover their faces with a scarf |

| Diet      | Mainly vegetarian and most Hindus avoid eating beef. | Mainly vegetarian. Sikhs avoid eating beef | No pork |
|           |                                                        |                                            | Most avoid alcohol |
|           |                                                        |                                            | All meat must be Halal |

| Festivals | Diwali (festival of lights)  
           | October/November  
           | Navratri (build up to Diwali) September/October  
           | Holi March/April  
           | RamNavmi (Rama's birthday) April  
           | Janmashtami (Krishna's birthday) August  
           | Most festivals occur between August and November. | Vaisakhi Diwali Birthdays of Guru’s Rakhri and Lokhri (January) | Eid-u-fitr Ramadan is the month long build up to Eid.  
           | Eid-ul-adha |

| Shrine    | Many homes will have a shrine in the house.  
           | Divas (candles) will be lit in the morning and evening. | Some homes have a shrine where the holy book is displayed (Shiri Guru Granth Sahib Ji)  
           | Heads should be covered and shoes and socks removed | |

| Fasting   | RamNavmi  
           | Janmashtami  
           | Ekadashi vrat (11th and 22nd day of each month)  
           | People may fast for a number of reasons throughout the year. | People may fast for a number of reasons throughout the year.  
           | During Ramadan, meals are only eaten between sunset and sunrise | |

| Religious days / prayers | There are no specific prayer times.  
                          | People may wish to pray in the morning and evening. | Some people will want to make time for prayers throughout the day and visit the temple (Gurdwara).  
                          | This visit could be daily, at weekends, or for religious festivals. | Men will meet to pray on Friday afternoons. This must happen at the mosque. (women, children and people who are ill should pray at home)  
<pre><code>                      | Prayers take place 5 times each day. | |
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<tr>
<th>Hindu</th>
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<th>Muslim</th>
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<td><strong>Births</strong></td>
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<td>For 21 or 35 days after the birth of a child, the house will not light the divas (candles) perform formal worship, and not visit the temple. Any shrines in the home will be covered. The naming ceremony happens at home on the 6th day. The new mother will stay at home for 21 or 35 days, except for medical appointments (the mother will visit the temple after these visits) After the 21 or 35 days, the new mother may go to the temple with the baby and family. No menstruating women should visit the house.</td>
<td>The newborn child and mother will stay at home for 5 weeks after the birth, except for medical appointments. At the end of the 'rest' the mother and baby will go to the Gurdwara to be blessed (Saroopa). Menstruating women should not visit the baby. If the mother worked, there will be a ceremony to mark her return to work. The child will be named at a special ceremony called Amrit. The name will include letters from the reading of the open page of the holy book.</td>
<td>The newborn child and mother will stay at home for 5 weeks after the birth, except for medical appointments. Menstruating women should not visit the baby. If the mother worked, there will be a ceremony to mark her return to work. The child will be named at a special ceremony called Amrit. The name will include letters from the reading of the open page of the holy book.</td>
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<td><strong>Marriages</strong></td>
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<td>A special prayer ceremony takes place either 3 days or 1 day before the actual wedding day and it is know as Manday Muhurta. The ceremony includes all rituals including Pithi, which is putting turmeric powder lotion on bride of groom. On the wedding day groom with his family/friends/relatives goes to the brides place. The wedding ceremony includes formal hand joining of bride and groom, four circles around the fire and seven steps - vows. After the marriage, girl (bride) goes with her husband and leaves her Parents house.</td>
<td>Many marriages are arranged or through introductions. The bride and groom may not be allowed to go out before the wedding. The ceremony starts 7 days before the wedding day. The marriage takes place in the presence of the Guru Granth sahib Ji, and invited guests. The wedding meal can be held at the Gurwara or special hall. Menstruating women should not go to the wedding ceremony.</td>
<td>White wedding dresses are worn. Lengha suits of salwar kameez are also worn. The ceremony is held in 2 rooms. Men sit in 1 room, and the women in another. The priest visits the groom first, with 3 witnesses. The bride and groom sit together for the registration ceremony.</td>
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<tr>
<td>Deaths</td>
<td>Hindu</td>
<td>Sikh</td>
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<td>Divas (candles) are not lighted and the home shrine is covered. A single diva with a photo of the deceased is lit, and flowers are placed around it. Women will wear white or pastel sarees. Married women will not wear bindi’s for 15 days. Men will not cut their hair or shave until the funeral. 7 or 9 days after the death, there will be a ceremony called ‘Sutak’. The whole house will be cleaned and the house will be sprayed with milk and water. Cremation will take place within 5 days of the death – the coffin will be brought to the house. The body will be cleaned by 5-7 people of the same gender, at the funeral parlour. When people visit the house to pay respect, they should remove shoes and stay until the end of the ceremony if possible. A large basin of petals will be available, and petals should be placed in the coffin. Menstruating women should not attend the funeral. A family ceremony will be held after the death. The priest will be asked to perform the ceremony – no women are allowed to attend.</td>
<td>There is a 15-day grievance ceremony. Women will normally wear white or pastel colours. Non vegetarians will normally not eat meat for 15 days. Burial normally takes place 5-7 days after death outside India. The coffin is brought to the home and then the Gurdwara (temple) before being taken to the cemetery for cremation and prayers. Flower petals are placed in the coffin. Family and guests will eat together. On the first Friday after the funeral, prayers will be said at the Gurdwara. The priest will read from the holy book for 3 days. (Akhand Paath) The family and community will be invited. A celebration will take place 6 months after the death.</td>
<td>Most families will make arrangements through the local mosque. Burial should take place as soon as possible after the death (same day is preferred) Black or white clothing is worn. The face of the deceased should not be seen by members of the opposite gender. Only men are permitted to go to the funeral. They should wash their hands and feet when they return. A meal will be eaten which has been prepared by the women, and the community. Respects are paid for 3 days, and invited to return 12 days after the death. 40 days after the death there is a celebration meal.</td>
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<td><strong>Other</strong></td>
<td><strong>Hindu</strong></td>
<td><strong>Sikh</strong></td>
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</table>
|           | Women who are menstruating should not go near to the home shrine, or to any religious ceremony. Shoes should be removed when you enter the house, and appropriate clothing should be worn* | Sikhs believe that you should comb your hair only once in a day, and not in the evening. Hair should not be cut. Sikh communities place a high value on voluntary work within the community. Many Sikhs will want to carry certain items with them at all times. (Five K's **) This will include the head covering, a bangle, a ceremonial knife, and a comb. Some Sikhs will not wish to be completely naked at any time. Sikhs believe in hard and honest labour, and in sharing their earnings with the less fortunate. At each Gurdwara's Langar, (temple kitchen) pure vegetarian food is served. It is expected that rich and poor eat together, sat on the floor. This shows equality between rich and poor, male and female, and between castes. This meal is prepared and paid for by people who go to the temple. Many Sikh names will include Singh (men) and Kaur (women). This may be used in place of the family name. Many Sikhs would prefer it was in running water. Showers would be preferable to baths. | Women should cover their bodies, and wear a scarf to cover their heads. Men and women should avoid social contact outside of the family. Modesty is a key element of Islamic lifestyles. Care should be taken when using photographs of people. Islam uses a lunar calendar with 13 months in each year. This means that festivals move around the traditional western calendar, and are not fixed to a particular date. Many Muslims will wish to wash before eating, and may wish to rinse their mouths. When shaking hands as a greeting – the right hand should be used. After using the toilet, many people would prefer to rinse themselves with running water rather than just using paper wipes. A pilgrimage to Mecca in Saudi Arabia is important. Most Muslims will try to complete the pilgrimage once in their lifetime. This pilgrimage is known as ‘Haj’.

* Appropriate clothing would include sleeved tops, and long skirts or trousers

** The five K's are – Kaacha (long underwear), Karha (iron bangle), Kirpan (small sword for protection on self and the weak), Kanga (comb) and Kesh (uncut hair)
Some tools that you can use

There are many different styles of Person centred Planning, and a number of different tools that can be used. Some of the main ones used in Leicester are;

**Essential Lifestyle Planning**

This planning tool has been developed by Michael Smull and Susan Burke-Harrison.

It is a very detailed planning style and looks at the individuals life as it is NOW. It looks at what can be improved and / or maintained. It looks at what is important to the individual and what support the person will need. There are sections on communication.

**Path**

This planning tool has been developed by Marsha Forest, Jack Pearpoint and John O'Brien.

It is best carried out by a group of people. It looks at 'dreams and ambitions' for the individual and maps out steps to achieve those goals.

**MAP**

This tool was developed by Judith Snow, Jack Pearpoint and Marsha Forest.

It again uses a group of people who know and understand the individual. The group look at the persons history, dreams and nightmares, and adds the individuals ideas. It describes the person, their gifts and skills. It thinks about how the individual can more towards their dreams and develops an action plan.

For more information on these toolkits, look at the website [www.paradigm-uk-org](http://www.paradigm-uk-org)
Where to get more help

For further information about Person Centred Planning in Leicester, contact:

Carole Shelton
Person Centred Planning Co-ordinator
Adults and Housing Department
1 Greyfriars
Leicester
LE1 5PH
0116 256 5157

For information about the Person Centred Planning Training Programme contact;

Jane Hemsley
Person Centred Planning Training Co-ordinator
Staff Development Unit
Martin House
London Road
Leicester
LE2 3JZ
0116 221 1700
Acknowledgements and Thanks

The information in this booklet has been taken from a number of sources, including:

**A guide to cultural and spiritual need**  
Leicestershire Partnership NHS Trust (June 2002)

**Guidelines for the Culturally Sensitive Care of the Dead and Dying**  
Leicestershire Partnership NHS Trust (June 2002)

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- **Yasmin Surti** – Ansaar

If you would like any more information, or would like this in bigger print, or a different language – please telephone  
Carole Shelton (Valuing People Support Worker) on 0116 225 4756