



ARC guide for services –
Supporting disabled young people
from black and minority ethnic
communities through the
transition to adulthood

national transition support team

working together to improve transition
for disabled young people



Introduction

This guide will help local areas¹ to provide the best support in transition planning for disabled young people from black and minority ethnic (BME) communities as they make the transition into adult life. The aim is to provide information, highlight the differences (and often similarities) in planning for disabled young people from BME communities and share examples of good practice from across the country.

Research suggests that young people from BME communities have a less positive experience of transition than the rest of the population². Therefore local areas need to ensure they are providing support which helps all young people achieve their aspirations. The skills and resources required to meet the needs of young people from BME communities can be translated into work with all young people. For example, engaging and accessible information is useful for everyone.

The Race Relations (Amendment) Act 2000 places a statutory duty on all public sector bodies to promote racial equality in the implementation of public policy. Equally, there is a similar duty in the Equality Act 2010³. These duties give local areas an imperative for ensuring support is in place and of a high standard.

As the population demographic changes and more young people from BME communities move through transition into adult life, it becomes increasingly important to consider these changes in service and support planning these demographic changes may be more obvious in the cities and large towns across the country, but small and rural authorities also need to consider the needs of their populations.

The background and culture of people from different communities is not always immediately obvious, and the data from the last census becomes increasingly dated as each year goes by.

The need to consider background and culture is often more important where the numbers of young people from BME communities are lower as a percentage of the total population, as there may be fewer appropriate resources and support available from organisations and the wider community. Transition planning for disabled young people from BME communities will need to reflect this.

¹ The term 'local areas' is used to describe statutory services including local authorities and health agencies.

² The Association for Real Change, *Moving on up: a guide for professionals about transition for people with learning disabilities from ethnic minorities*.

³ Equality Act – In March 2010 the Equality Act was passed. It replaces equality legislation on a broad range of 'protected characteristics' including disability and thus replaces the DDA. The Equality Act came into force in stages from October 2010.

Comprehensive Multi-Agency working

All agencies working to support young people at transition need to work jointly to have the best chance of a successful outcome for the young person and to ensure resources are used most effectively. Evidence⁴ shows that developing a strategic level multi-agency agreement, for example, a transition protocol, can provide clarity to families and services about what support and options are available. Any protocols developed need to reflect the services available locally and the demographic make up of the local community.

The report *Transmap: From theory into practice - the underlying principles in supporting disabled young people in transition to adulthood*, describes a multi-agency transition protocol as:

“a strategic document to which senior managers and council officials have signed up and which details the roles and responsibilities of all agencies in the transition process. It is developed with a range of professionals so that each agency feels an ownership for the part that they play. The full involvement of young people and their families is key to ensuring that the protocol is effective.”⁵

Generally, the types of agencies that might be involved in supporting disabled young people can include Information, Advice and Guidance (IAG) providers like Connexions, schools, Child and Adolescent Mental Health Services (CAMHS) and children and adult social services. Other local government departments, like transport and housing, should be included in transition planning as they are important in planning support for young people as they increase their independence.

Given the current and projected increase in the numbers of disabled young people from BME and new communities, it is important that any transition protocol reflects their needs and that they and their families are involved in its development. It is not possible to plan for every eventuality or population movement, but developing joint teams and sharing information and training will serve to meet the needs of the majority of young people. Keeping young people and their families engaged in reviewing the protocol will ensure that the document and work it supports remains relevant.

Developing a strategic multi-agency transition protocol should include representation from or links with relevant local communities. This requires:

- An up to date picture of the demographic make-up of the community, including age profiles, in order to understand current and projected transition needs,
- Partnership boards with information about the needs and aspirations of minority communities and,
- Sound links with local available services.

By working beyond services leading on transition support and with services for communities, professionals with a lead on planning transition support can ensure they call on the widest range of expertise and get the most out of available resources to achieve the best outcomes for disabled young people.

⁴ Department for Children Schools and Families, *A transition guide for all services*, 2007.

⁵ Council for Disabled Children, *Transmap: From theory into practice – the underlying principles in supporting disabled young people in transition to adulthood*, 2009.

Developing a local transition pathway

“At the core of each transition pathway will be the legal duties of each statutory service. The most effective pathways have input from disabled young people and their families and from a range of other agencies likely to be providing support or services during the transition process.”⁶

The transition pathway is the means by which the transition protocol is explained and laid out in a clear and accessible format. It gives young people and their families information on who has the responsibility to support them at different stages as they plan for their future. Many local areas have developed Transition Information Packs which include a copy of their transition pathway.

In 2009 ARC carried out an email survey with local authorities. The survey asked a number of questions about provision. It included a question on transition pathway development as follows:

‘What activities have been put in place to ensure all young people and their families from minority communities fully comprehend the transition pathway?’ The responses showed that some authorities were still working on their protocols and pathways, although some had developed Transition Information Packs. For example:

- In Lincolnshire, the Positive Transition Framework was being reviewed. The existing version could be printed in various languages and interpreters were available if required. The new protocol would have a pathway available in a variety of formats, including easier-to-read, diagrammatic format with photo symbols and would be included on the authority’s transition DVD. Young people and their families were to

be engaged in the development of this pathway to ensure its accessibility.

- The London Borough of Richmond provided specific support for BME children with mental health issues and can provide accessible versions of their literature about transition support, protocol and pathway, which are also available in other languages.

Protocols and pathways need to reflect the needs of those from different communities and young people and their families should be involved in their development. Regular reviews of the systems in place and how these are meeting the needs of those from BME communities should take place. As local populations change then the needs of these new communities should be reflected in these protocols and pathways to ensure the needs of these communities are still being met.

The range of people who need to be involved in transition can be wider than expected. The individual’s local community and religious leaders may be important members of the transition plan and may already be closely involved with the family.

Transition planning for young people from BME communities may need to start a little earlier than for others, as they are not always starting from the same point. For some individuals and families to be fully engaged in the planning process they first need information about what transition is, the process and who will be involved. The information also needs to be in a format that individuals and their families can access and understand.

Good Practice Example

In **Oldham**, the Transition Team includes staff from special schools, settings and all agencies including the Ethnic Minority Achievement Team

⁶ Department for Children Schools and Families, *A transition guide for all services*, 2007.

involved in the processes and protocols of ensuring all young people have the appropriate support they need.

Participation of Young People and their Families

The participation of young people and their families is essential for successful transition.

Individual planning

Many families from BME communities have told ARC that they do not feel part of the transition process and many disabled young people enter adult services feeling that transition has 'passed them by'. The understanding of the transition process within BME communities needs to be considered and checked. If there is a poor understanding of the transition process, then participation with it is much less likely.

Working with the young person and their family from an early age will help to establish the relationships needed between the family (and their relevant community members) and the various professionals and agencies concerned with transition. It will enable the appropriate discussions to take place, the correct information and understanding of the transition process to be shared, and the needs and aspirations of the young person to be aired and followed through and, where appropriate, their cultural needs fully taken into account.

In their email survey in 2009 ARC asked local authorities:

'Young people from minority communities face many challenges at transition, and may have additional stresses and choices. It is important that their voices are allowed to inform transition development. What system do you have in place to capture the genuine views of young people from minority communities about transition, including those who have been through the process? Please indicate what

particular issues have been raised.'

Different areas indicated that they:

- Have a Compact agreement and one of its codes is specifically for Black and Minority Ethnic communities. They also have a Council for Young People that has direct links to management and is planning consultation with young people and their families regarding transition.
- Consult with the local minority ethnic communities and employ a Champion for Disabled Children and Young People, who works with young people in transition to obtain their views.
- Do some work with young people who have been through transition to identify what is working well and what needs to change.
- Have a Young People's Disabled Network to discuss and provide information to inform transition developments, and also hold an annual conference (but these are not BME specific).
- Have representatives from forums attending the Learning Disability Partnership, Transition Steering Group and Getting a Life meetings.
- Systematically collected students' and carers' views during the Getting a Life project and a good percentage of young people engaged in this have an Asian heritage.
- Run a reference group of young people with disabilities (not specifically from minority groups).

Good Practice Examples

The **London Borough of Richmond** has a young person's forum run by Mencap and

another at college. Members of these groups are representatives on a Learning Disability Partnership, the Transition Steering Group and the 'Getting a Life' leadership group.

Lincolnshire has had a Compact agreement since 2005 and a number of codes have been developed, including one specifically for BME community organisations. The council is supporting a key action within their Third Sector Framework to review and promote the Compact documents and are providing funds to employ a Compact worker based at Voluntary Action North East Lincolnshire (VANEL).

Nottinghamshire have a specialist worker in Connexions for Gypsy and Traveller Communities.

In **Oldham**, all Local Authority staff have basic training to ensure children from BME communities and their families receive information in a way that is culturally sensitive and appropriate support to maximise access to all services. Also, eight out of the cohort of twenty five young people engaged in the 'Getting a Life' project have Asian heritage.

Strategic planning

Parents and young people's groups that assist local areas with strategic transition planning and systems should reflect the make up of the local community. So local areas should ensure that such forums and groups are inclusive to people from BME communities.

The experiences of disabled young people and their families from BME communities who have gone through the transition process should be sought and learning taken from them.

Provision of High Quality Information

Information needs to be shared with young people and their families locally. This information should be clear, accessible and up to date. Information should be in a range of styles and from a number of places. Information shared in

this way will enable full participation in the process. This may mean offering much simpler information about transition and future options earlier to local BME communities and factoring this into the transition pathway would be helpful. There are a range of resources and information that already exist, and have proven to be effective, that can assist professionals with the transition process. An example of this is the information from ARC's Moving On Up website (www.movingonup.info) for young people with learning disabilities from BME communities.

Professionals will need to ensure they have an understanding of this information, are able to tailor it to meet local needs, and that local communities can gain access to it.

In 2009 the ARC email survey asked local authorities:

'Is your Transition Information Pack in a format for families who do not fully understand "the language" or "the system?" What formats have been tried?'

Responses mentioned several different formats and ways of communicating including:

- Pictorial,
- Easier to read / plain language / accessible leaflet,
- DVD,
- Translated material on request,
- Policy not to translate, but provide interpreter on request and guidance on how to do this is included in Transition Information Packs and leaflets,
- Information leaflets in different languages, Makaton and Widget, signs and symbols,
- Information available printed or online to view on computer or download.

In addition to written information, providing high quality translation services can be effective. The Suffolk Family Carer's report⁷ recommended that services 'develop innovative and cost effective translation and interpreting services and inform staff about how best to use them'. Many local areas already have access to professional interpreters. It is very important that professional interpreters are used, rather than using a family or community member. If an untrained interpreter (family member, friend, etc) is used, they may:

- Be too embarrassed or disturbed by the material to interpret it accurately,
- Deliberately edit what is said to prevent embarrassment to the family and/or the community,
- Not know the meanings of some words used, e.g. learning disabilities, autism, and may use words that convey a very different meaning,
- Embellish or delete information, or put a different emphasis from that intended,
- Not know the specific dialect of a national language and (unknowingly) use words that may not be understood,
- Not keep what is said confidential (or understand what this means) and may feel a duty to report back to their community leaders.

Any of the above could result in confusion or misunderstanding about what is said or discussed at meetings, and may completely misinform those present, which could be detrimental to decisions made by and for the young person during transition.

Given how easy it is for misunderstandings to occur, it is important to remember that even when information is translated, either verbally or

in written form, it is essential that checks be made throughout the process to ensure that everything is understood. There may be difficulties with terminology, non-familiarity with systems or even providing written material when families are not able to read it.

Where the information is displayed is equally as important as translating it. The Local Authority website may well have a range of information in different languages, but if internet usage is low in some of the local communities, it will not be accessed. Community groups, local religious centres and local stores may be better places for information to be made available and the use of audio materials can be beneficial, such as Ramadan Radio.

Good Practice Examples

North East Lincolnshire provide their transitional information in a variety of formats which includes pictorial, easier-to-read and DVD. Translated material can be provided if requested. Translation services are available to those who cannot communicate effectively in English.

In **Lincolnshire**, the Positive Transition Framework is currently being reviewed. The existing version can be printed in various languages and they are able to offer interpretation when required. The new protocol will have a pathway available in a variety of formats, including easier read, diagrammatic with pictorial symbols, and being included on their transition DVD. Young people and their families will be engaged in the development of this pathway to ensure its accessibility.

Birmingham have information packs and leaflets about transition (and are developing an easy read version of their information pack), which includes guidance on how people can access an interpreter if required.

⁷ Hammerton, Clare, *Black and Minority Ethnic and Learning Disabilities Research*, 2007, Suffolk Family Carers.

Responses to the survey showed that most authorities will provide translated material and interpreters if they are requested. For example, **Oldham** stated the most effective way of providing information to families is through dedicated interpreters fulfilled in part by the people whose roles are relevant to transition. Alternative formats and translated materials can be made available depending on the needs of the families.

Effective Transition Planning

To maximise their success, young people must be at the centre of their transition planning. All school pupils with a statement of special educational need should have a transition review in Year 9⁸. The resulting transition plan should reflect their needs and aspirations and specify how the relevant agencies will ensure that their needs will be met and aspirations achieved. The plan should cover future choices on issues including housing, education, employment and leisure. It should be reviewed regularly and in a way that is meaningful to the young person.

Regardless of culture, background or language, good use of person centred approaches should improve the transition process for young people⁹. This can be particularly helpful for young people from BME communities who may need more time and support to give their views and talk about their own aspirations for themselves. Person centred approaches are a range of tools that have been developed over several decades to offer a more personalised and outcomes-focused way of meeting disabled people's additional support needs.

Using person centred approaches to support young people in the formal transition planning

process can support them in:

- Deciding on what they would like to plan for,
- Choosing who will attend and support them at meetings,
- Making contributions if they want to at the meetings,
- Having a say in what is a priority in planning for their future,
- Accessing support to take part in the review in a way which suits them.

Effective person centred approaches are holistic and include the family as well as the individual. The views of young people are important, but their family or carers are significant in their lives, and usually continue to be so, even as young people mature and begin to make their own decisions. This is particularly significant for young people from BME communities where the culture of the family may differ from 'Western' ideas. This is where it is crucial to have the correct information for the review process. For example, it is important not to assume that because someone is from an Asian background they will hold certain beliefs, and not to be embarrassed or worried about causing offence if questions are asked to establish this information. Asking the family to take an active part in the process is beneficial for all young people, and for BME young people it is important to note that, as stated in *Valuing People*:

"The personal and collective values and experiences of people within minority groups are often different from those of the majority population. The concept of individuality, rights and relationships, for instance, differ substantially between different cultures; what

⁸ Department for Education and Skills, *Special Educational Needs Code of Practice*, 2001.

⁹ National Children's Bureau, *Person Centred Approaches in Transition Planning*, 2011.

may seem morally and ethically correct towards disabled people can vary from one culture to another.”¹⁰

Checklist for successful planning

Start planning well before the formal meeting

The best transition plans start early and continuously develop. They take time and effort to get right. Extra research may be necessary to find out about other options that may be available locally within different communities (or even those from farther afield). The transition process should ensure a smooth changeover into adult life, and for this the young person and their family need simple clear information and advice about what will happen before, during and after transition.

Take account of a person’s cultural background

Making the effort to understand a young person’s cultural background can help professionals understand why communication difficulties can sometimes occur in meetings. For example, cultural sensitivities can lead to females not making eye contact with males or not speaking up when males are in the meeting. The sense of embarrassment or concern at ‘getting it wrong,’ may lead to people not asking questions or seeking clarification, leading to misunderstanding.

Produce an accessible set of information

It is important to provide an accessible copy of the transition pathway and transition plan to the young person and their family. Professionals must ensure that the young person and their family fully understands the information in the transition plan, what the action points in the plan are, and that they agree with what has been put in the transition plan.

Meeting invites

The young person should be involved in deciding who is invited to their meeting. This may include a community worker who is known to them or is familiar with their cultural background. It is also important that the young person is involved in the work around any action points for the next meeting, in the same way as professionals are expected to be. This gives the young person a sense of purpose and promotes involvement and active participation.

Meeting arrangements

The timing of the meetings should consider the needs of the family as well as the young person. For parents who have a number of children at different schools, meetings need to take place when the parents can attend and not rush to/from the meeting due to their other responsibilities. (See Appendix 1 for Rahina’s story.) The meeting venue should be welcoming and accessible and suitable for the amount of people and format of the meeting (i.e comfortable and young-people friendly). There should be accessible toilets nearby and refreshments easily available.

Transition as an ongoing process

Ensuring that transition meetings are held regularly, rather than ‘one-off’ events, is crucial. This should enable the young person, family and staff to get used to meeting as part of a team and in an environment in which they can feel increasingly comfortable. If this is established, it is more likely that issues will be raised and discussed and solutions considered that are right for the individual. It may be necessary to consider informal visits and activities before any meetings take place.

¹⁰ Department of Health, *Valuing People*, 2001.

Be clear about options

Funding can have a huge impact on transition planning and the young person and their family should know what is available, even if they choose not to manage all their finances. Funding options can be confusing and comprehensive information and advice is essential.

A 'pupil passport' can be an effective tool. This can be made with a young person whilst at school or college, for them to take with them as they move on. It is for them to carry in their bag or keep in a specific place. It explains all about a young person; how they communicate, what they can do independently or what they may need some support with. It includes important information about their daily routine. Religious and cultural preferences explained in this passport can help new people in the young person's life understand and support them appropriately and can relieve family fears about these important aspects being forgotten as they move into a new environment. It should be illustrated in a way that the young person can understand fully what is written about them and enable them to refer people to the appropriate page.

Good practice example

In **Leicester**, in the special schools, Transition Plans are produced which record pictures of what happened at the review and who was there. The Connexions Personal Advisor oversees the Transition Plan and works with young people and their families to progress the plan. Schools and Connexions advisors arrange group briefings for parents/carers about the transition process and format of the review. Connexions Personal Advisors also do individual home visits prior to the start of the transition process to brief parents/carers and

help them focus on what's important for them to think about before transition reviews and what to discuss at meetings.

Support for young people and families

Advocacy

Advocacy should be available to those young people who want it, to ensure they are empowered to have their voice heard and that they are at the centre of the transition process. Some advocacy organisations run specific groups for their members from different minority communities, e.g. Bristol and South Gloucestershire People First who have a Black members group.

It can be difficult for young people in transition if they aspire to something that contravenes their parent's expectations or wishes – something that affects many young people and their families. Advocacy can be very helpful in this situation, but needs to be especially sensitive where there are strong cultural or faith issues. Advocacy support from someone from a similar background or culture (or at least with a good understanding of it) can really assist in such potentially difficult situations.

Key working

TransMap (Council for Disabled Children, 2009) highlights the need for key working or lead professional arrangements. It states that this role is often held by a 'transition worker' or the 'information, advice and guidance specialist personal adviser', but adds that it is important that both the young person and their family are involved in the decision about who will take on this role.

In their 2009 survey, ARC posed the following question:

'Research has shown how key workers empower families and young people from minority communities at transition. Please outline how key workers are supported to understand the culture of the people they are working with. Have you employed any specific key workers to work with minority families and what skills did they bring?'

Regarding key workers, different local areas said:

- This is the Connexions Personal Advisor.
- Some Personal Advisers come from minority communities.
- Approaches are being developed to offer choice to the young person about who will be their key worker.
- The dedicated transition social worker for the disabled children's team is lead professional for all young people in transition.
- Key personnel in the young person's life and key staff are employed to support young people from minority communities and their families at all stages.
- All 'looked after' or 'children in need' will have an allocated key worker.

Peer support

In the book *Something to do: The development of peer support groups for young black and minority ethnic disabled people*¹¹ a peer group is defined as one that provides emotional and social support to its members. The authors describe studies which have found that belonging to such groups helps young people in

their personal development, increases their skills, builds on their self-esteem and confidence, enables them to share experiences, including sharing their concerns about disabilities, and provides an opportunity to make friends.

The development of peer support groups for disabled young people from BME communities, as described in *Something to do*, has been positive. Some members say they join peer support groups to meet people, have something to do, have somewhere to talk to other young disabled people from BME communities, feel comfortable, learn new things and have fun. They speak about the confidence they have gained since joining the group.

It is important to note that in some cases young people have only been able to attend groups with parental consent and it has been found that giving parents adequate information about the group (what it offers, how it works, etc) has been vital in gaining this consent.

In supporting successful peer support projects local areas have identified these points as helpful:

- Good, safe and accessible transport is available,
- Travel training is offered to all disabled young people,
- Places to meet are available,
- There is some ongoing funding for activities,
- Someone has oversight and responsibility for organising and developing the group.

¹¹ Bignall, T., Butt, J. and Pagarani, D., *Peer support groups and young black and minority ethnic disabled and deaf people*, 2002.

Summary

The purpose of the transition process is to support disabled young people to achieve their goals as they move into adulthood. Planning should consider options beyond which services will provide support or funding and look at what the young person wants to achieve. The key issue for workers supporting disabled young people during transition, is to help them make the decisions that are right for them in their own cultural context.

This needs information that is:

- Available,
- Understandable,
- Accessible,
- Timely.

And support that is:

- Culturally relevant,
- Has authority in the transition process,
- Available to both the young person and their family.

Which is backed up by a:

- Clear Transition Pathway and protocols,
- Transition Information Pack,
- Transition Team with a key worker.

Appendix 1 Rahina's Story

Rahina is 15. She has autistic spectrum disorder and learning disability. She is slight of stature and appears younger than she is. She speaks a mixture of Urdu and English but appears to have her own understanding of the words she uses. She quite often laughs especially when seeing pictures of animals. She lives with her mother, Mrs A, and has three siblings, one older and two younger. The youngest, aged 8, has cerebral palsy. Her elder sister has recently got married. Rahina has attended a specialist unit for pupils with learning disabilities that is, in theory, part of a larger comprehensive but does have its own discreet building. It is time for her transition plan for leaving school.

School has managed to communicate with Mrs A via Rahina's transport driver who is a family friend and bilingual. Mrs A's husband has returned to Pakistan. Staff are uncertain of the home situation. Mrs A is invited to the transition meeting. The head of year requests an interpreter via a service offered by the local education authority. The meeting is set for 2.00pm. Mrs A worries about her youngest child who attends a different school and is returned home at 3.30pm. She worries that Rahina is in trouble. The driver translates the letter as, "a meeting to talk about what will happen to Rahina". No-one has ever explained to Mrs A the nature of Rahina's condition. She worries that it might be getting worse. She hopes that one day Rahina will be married like her sister and she hopes that one day she will get better.

At the meeting there are Mrs A, Rahina, the head of year (Mrs Rawlings), the education service transitions worker (Christine), Judith (a learning disability support assistant) and an interpreter. The meeting is held in the quiet

room next to the school library. It was hoped that a social worker, who has replaced the social worker who supported Mrs A when her youngest child was born, would attend, but he has sent apologies. Rahina is very surprised to be in the quiet room with so many people and surprised to see her mother. She climbs onto her mother's knee and plays with her mother's head covering. Mrs Rawlings tells Rahina to get down. Mrs A is worried because that is how she comforts Rahina at home. Rahina sits on a chair as asked and laughs. They each introduce themselves. Mrs A does not know what a transitions worker is but she is too polite to ask. Everyone is asked about the things that work well for Rahina and Christine records them on a flip chart. In an effort to make the meeting person centred, Judith shows Rahina cards of different activities and asks which she likes. Rahina likes the colour yellow. Judith has tried to make the pictures culturally aware. Rahina chooses the picture of curry. Mrs Rawlings says Rahina does well in home craft sessions. Mrs A is surprised, as she never lets Rahina into the kitchen because it is dangerous. It is agreed that Rahina should spend at least one day a week at the special life skills course at the local college. They discuss day services. Mrs A asks if there will be boys at the college and says she does not want Rahina to be with young men. The interpreter explains that Mrs A thinks Rahina might get into trouble. Mrs Rawlings says there is a high staff ratio at the college and Rahina will be safe. Mrs A asks via the interpreter if Rahina will ever get better. The interpreter asks, in English, if Rahina will "make progress". Everyone agrees this should be the case. Mrs A is very pleased. She asks if Rahina will learn the skills to make a home. Christine says she hopes that Rahina will learn independent living skills. Mrs A is told that Rahina will learn to live alone. Mrs A doubts this and worries. Rahina is bored and is picking the fringe of a cat collage on the wall. Christine asks

her if she likes the pictures. Rahina laughs and says, in Urdu, that it is a cat. Christine asks when Rahina was last assessed. She is concerned that budget restraints limit services to people with an IQ of 60 and below. The interpreter tells Mrs A that Rahina might be too clever for further help. Mrs A does not know whether to be pleased or very worried.

By the end of the meeting they agree:

- To meet again in 6 months,
- For Rahina to work on the computer with Judith on a transition passport showing her favourite things and her hopes,
- For her to visit the college with other transition level pupils,
- For Christine to organise an assessment for Rahina with a clinical psychologist and to make contact with Rahina's GP (with Mrs A's permission).

Mrs A is given some leaflets on transition in Urdu. She is too ashamed to say she cannot read but she hopes her nephew will read them to her.

Appendix 2 Terminology

It is important to define the terms that are being used about disabled young people from BME communities, as they may differ in other contexts.

Transition

In this guide transition is used to refer to the formal transition process which begins at Year 9 for all young people with a statement of special educational need. For more information on the formal process please see A Transition Guide for all Services

Disability

Although it is usually understood what is meant by the term 'disability', it can be viewed very differently, as shown by these definitions from the Open University website¹² and this could have a significant impact during transition.

Medical model

In the medical model, disabled people are seen as the problem. They need to change and adapt to circumstances (if they can), and there is no suggestion that society needs to change. This model reflects the World Health Organization definition of disability. Under the medical model, disabled people are defined by their illness or medical condition. They are disempowered: medical diagnoses are used to regulate and control access to social benefits, housing, education, leisure and employment.

The medical model promotes the view of a disabled person as dependent and needing to be cured or cared for, and it justifies the way in which disabled people have been systematically excluded from society. The disabled person is the problem, not society. Control resides firmly

with professionals; choices for the individual are limited to the options provided and approved by the 'helping' expert. The medical model is vigorously rejected by organisations of disabled people, but it still pervades many attitudes towards disabled people.

Social model

The social model of disability has been developed by disabled people. In their view, disability is caused by the barriers that exist within society and the way society is organised, which discriminate against people with impairments and excludes them from involvement and participation. The social model has been developed by disabled people in response to the medical model and the impact it has had on their lives.

Under the social model, disability is caused by the society in which we live and is not the 'fault' of an individual disabled person, or an inevitable consequence of their limitations. Disability is the product of the physical, organisational and attitudinal barriers present within society, which lead to discrimination. The removal of discrimination requires a change of approach and thinking in the way in which society is organised. The social model takes account of disabled people as part of our economic, environmental and cultural society. The barriers that prevent any individual playing a part in society are the problem, not the individual. Barriers still exist in education, information and communication systems, working environments, health and social support services, transport, housing, public buildings and amenities. The devaluing of disabled people through negative images in the media – films, television and newspapers – also acts as a barrier. The social model has been developed with the aim of removing barriers so that disabled people have

¹² Open University, *Models of disability*, 2011.

the same opportunity as everyone else to determine their own life styles.

Learning disabilities

The term learning disabilities is quite difficult to define concisely and can mean different things to different people. The British Institute of Learning Disabilities factsheet¹³ states that the World Health Organisation defines learning disabilities as a 'state of arrested or incomplete development of mind.' It then says that somebody with a learning disability is said to have 'significant impairment of intellectual functioning' and 'significant impairment of adaptive/social functioning and that a final dimension to the definition is that these impairments are present from childhood, not acquired as a result of accident or following the onset of adult illness. These definitions are not the way people with a learning disability like to be labelled, but helps start to explain what is meant by the term.

In education different terms are used to describe those children with varying 'special needs'. Similarly, local authorities use specific terms, often resulting from assessment processes, regarding eligibility for different services and access to funding such as Direct Payments. Health services may also define a child according to their specific needs and the potential funding sources.

Ethnicity

All human beings have an ethnicity. It refers to 'a number of shared characteristics, including a shared background, origin, culture, tradition and language'. "However, to distinguish groups whose values, beliefs and practices are not shared to a significant degree with the majority group, the word minority is placed before or after the word ethnic" (Sallah and Howson, 2007).

Culture

It is very difficult to define 'culture' as "it exists below the level of consciousness, and is so deeply embedded it escapes everyday thought" (Connolly et al., 2005). Spindler (1963) describes culture as "a patterned system of tradition derive norms influencing behaviour" which includes thoughts, communication, actions, customs, belief, values and institutions.

Cultural norms are not static. They are constantly evolving and there can be numerous sub-cultures within a mainstream culture. Perhaps a simple way of explaining it would be 'the different beliefs and behaviours of groups we may belong to' or even 'the way we do things here'.

Race

Race is a way of classifying people on the basis of geography and physical characteristics, which was first developed in the 17th century (Connolly et al., 2005).

¹³ British Institute of Learning Disabilities, *Fact Sheet – learning disabilities*.

Appendix 3 Resources

- Association for Real Change, *Moving on up: a guide for professionals about transition for people with learning disabilities from ethnic minorities*.
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To find out more about the Association for Real Change visit <http://arcuk.org.uk/>.

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National Transition Support Team (NTST)

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NTST is based at the Council for Disabled Children (CDC), the umbrella body for the disabled children's sector in England. CDC is hosted by NCB. www.ncb.org.uk/cdc

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