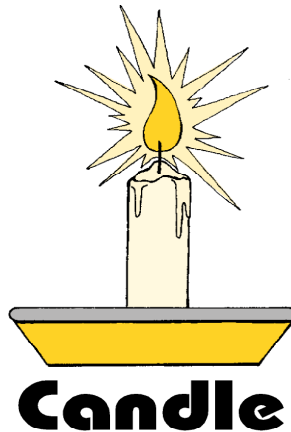


Ethnicity, Learning Disability and Transition - Case Study and ARC resources

David Grundy - ARC



About ARC

(www.arcuk.org.uk)

- Member led organisation (mainly voluntary orgs)
- Offers members a voice and representation at a national level
- News and policy updates
- Various training LDQ - NVQ etc
- CRB/POVA
- Undertakes a wide range of projects of interest to members





About ARC

- For example -
- Handling Medication In Social Care Settings
- Research project into Hospital Admission for People with a Learning Disability in Wales
- Clear Thoughts (www.clearthoughts.info)



About ARC

- Specifically for today -
- LDEN Learning Disability and Ethnicity Network (www.lden.org.uk)
- CAMHS and New Directions in Learning Disability and Ethnicity - the Candle Project
- Moving On Up (www.movingonup.info) Accessible transition information for young people from BME communities who have a learning disability



Moving On Up

- We have a website www.movingonup.info which has had over one million hits
- An emailed newsletter for professionals Moving On Update
- A guidance booklet based on the website has been produced for families
- A guidance booklet on key cultural issues for professionals has been produced
- Fun Days for Young People across England



Cultural Issues

- 2001 census information - the mixed race group had the youngest age structure - half (50 per cent) were under the age of 16.

The Bangladeshi, Other Black and Pakistani groups also had young age structures: 38 per cent of both the Bangladeshi and Other Black groups were aged under 16, and 35 per cent of Pakistanis also fell into this age group.

This was almost double the proportion of the White British group where one in five (20 per cent) were under the age of 16.

BME Transitions - Obstacles



- Identifying and engaging people, particularly those not using services (42%)
- Small, diverse, complex and constantly changing minority populations (31%)
- A lack of good local information (19%)
- Competing priorities (19%)
- Shrinking financial resources (17%)
- The cultural competence/relevance of local service providers (17%)
- Recruiting and retaining a diverse workforce with relevant skills (14%)

BMC Transitions - Overcoming the challenges



- Pro-active strategies to engage local communities (29%)
- Developing systems for getting better information (26%)
- Working with other local agencies and community groups (17%)
- Encouraging direct payments and self-directed support (14%)
- Engaging in research or audit work (11%)

Learning Disability, Transition & Mental Health

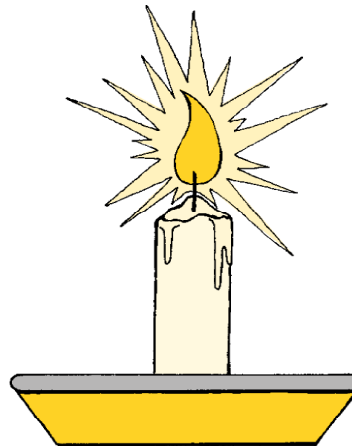
- Most young people with learning disabilities were not aware of the term 'Mental Health'
 - Families were suspicious of the term Mental Health and need for a separate, additional label
 - Most young people with learning disabilities had never heard of CAMHS
 - Young people with learning disabilities or the people they go to for advice are not well informed about mental health and mental health services
 - Some people from BME communities found situation more difficult due to 'stigma' from community members
-
- **FPLD (Foundation for People with Learning Disabilities)**

2006



ARC Resources

- Candle
 - Clear Thoughts
(www.clearthoughts.info)
 - Moving On Up
(www.movingonup.info)
 - Services For All
 - LDEN
(www.liden.org.uk)



Candle





Today's workshop

- Review a case study taken from our work with BME communities
 - Check the case study in line with (some of!) the Transition Planning and Development Tool
 - Share the information given by lead authorities in response to a questionnaire sent out by ARC asking for examples
 - All this (including feedback in from these sessions) will be developed into a BME Transition Guide for local authorities
- Interim Guidance April 09 - Full Guidance Autumn 09



Outline

- It is difficult to plan services and improve outcomes if it is not known who for and how many
- The census has given us some interesting statistics
- 7.9% of the population in 2001 classified themselves as belonging to a BME community.
- However a higher proportion of young people are from minority communities
- The prevalence of Learning Disability in people aged between 5 and 34 is 3 times higher in the South Asian communities



DRC Research

After leaving school, the transition to adulthood can be challenging for any young person, but disabled young people often face additional problems of low expectations, a lack of continuous service provision, unmet needs in further and higher education, and a disproportionate likelihood of not being in education, employment or training.

This is a period which will continue to require particular attention especially during the planning and implementation of reforms to children's and youth services.

(Disability 2020 DRC March 2007)



Research

Culture is a key part of young people's identity:

'The majority of young people identified themselves primarily according to their cultural identity and not according to the fact that they had a disability or learning difficulty. Many strongly resisted any suggestion that they had a disability or learning difficulty. This contrasts with the way staff in services view them.'

(Aasha: working with young people with a learning difficulty from a South Asian background, 2003)



CSCI Research

Only 42% of the senior managers in children's services and education were able to provide details of young people's ethnicity in out of area placements.

The needs of young people and their families from ethnic communities were less well addressed in protocols, commissioning documents and during the interviews. Councils covering diverse populations told us that their 'practice was ingrained' in meeting the needs of all communities.

Overall, however, there was little evidence that councils had given diversity issues sufficient attention.

(Growing Up Matters: Better transition planning for young people with complex needs, Commission for Social Care Inspection, January 2007)



Differences

‘Adolescence in British South Asian communities may be seen differently because there is less emphasis on separation or autonomy and less expectation of independence than in the majority of British families.

Thus the ‘competent adolescent’ would be skilled at meeting obligations to family, respecting family elders, diffusing tension and employing conflict avoidance strategies. Patience and self-containment may be more highly valued, and teenagers may be expected to be ‘guided by their elders’ more than in many British families. Religious obligations become increasingly salient as children reach puberty.’

(Supporting Minority Ethnic Families, Becher and Husain



BME Families

- BME families are often unaware of the route of transition.
- They frequently do not know about transition planning, connexions services, or specialist services.
- The transition process seems to have passed them by.



Research

‘While transition plans for children with disabilities aged 14 and over are a current policy, no parent in our study reported being aware of a transition plan for their teenager. However, transition plans are urgently required, as parents reported great uncertainty and anxiety about services for their child after education stopped.

Greater consistency between child and adult services is also required, as some parents reported that adult services that had been offered to them did not meet the language, cultural or religious needs of their child.’

(From Supporting South Asian Families with a Child with Severe Disabilities, Hatton et al, JKP, 2004)



Research Findings

Research findings show that professionals need to make themselves aware of the different range of attitudes that may be held by parents and carers who are thinking within from their personal value system and the culture of the community to which they belong.

A lack of enthusiasm from a South Asian parent towards greater independence for their child through housing or employment, for example, does not automatically indicate a failure of the parent to want best outcomes for their child. Their understanding of 'best outcomes' may differ from that of professionals.



Family Concerns

- Families/carers from minority communities are frequently very concerned about the safety of their young person with a learning difficulty and can view drives towards independence as actually neglect.
- Some families may never have had learning disability explained to them and may be hoping for a cure. They cannot adequately therefore plan a future for a disabled child.



Facilitation

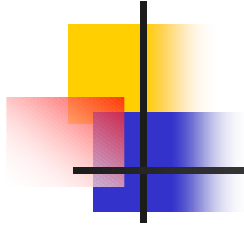
- Trained facilitators help everyone at the meeting and can help the young person and family get ready for the meeting.
- A good facilitator makes sure everything goes as well as possible. (This is not the same job as chairing a meeting.)
- The facilitator asks questions, helps people work out what they want to say, and makes sure everyone takes part in the meeting.
- People like the fact that many of the facilitators were independent. This means that they were not part of the school or working with the young person.



FPLD Research - Bradford

“...families who had received support from the liaison worker felt better-equipped to help their son or daughter, whereas those who did not receive help reported continuing difficulties in gaining necessary access to services, help and support”

Making Us Count, FPLD, 2005



- A key issue for workers supporting young people at transition is to help them make the decisions that are right for them in their own cultural context.
- To this end the information and support offered to them as individuals should be fully explained to their families.
- Much evidence points to the need for families supporting young people to have a link worker at transition who understands the culture and the various different pulls that the young person may be experiencing.



Young people from BME communities face more difficulties than most

- Poorly prepared
- Different demands/expectations of them
- Lack of good support for their families
- May not be supported/encouraged into independency e.g. work or independent living.
- Want to have the same things as other young people – security a place in society and a chance to find their dreams.



Good Practice in Summary

- Review numbers and start planning now
- Liaise and build relationships with families over a long period of time
- Use link workers and facilitators as much as possible
- Make sure all staff (including interpreters) are trained in both cultural and learning disability issues
- Person Centred Planning at transition is meaningful
- Make all records and plans clear and understandable to all involved
- Research and use the resources currently available and keep up-to-date with developments
- Set out the procedures clearly



Thank you

- Any questions?
- david.grundy@arcuk.org.uk

