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# Transitions into Adulthood: Disability, Ethnicity and Gender among British South Asians

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## Abstract

This paper argues that the life course of disabled young people from British South Asian families is different from their siblings. The analysis focuses on the intersections between disability, ethnicity and gender in life course transitions. Education and the transition into employment are examined as key stages. Disability is established as an important influence in the way others, including the young people's parents, responded to them. Consequently, they had to negotiate transitions with their families as well as external agencies. These negotiations relate to cultural hybridity, where the desire to find a space to express a variety of different and competing identity claims is experienced differently, again in comparison to their non-disabled siblings.

## Introduction

The transition from childhood to adulthood is shaped by social institutions. The following examines the life courses of young disabled South Asians with particular reference to their experiences in education and employment. The analysis shows how these experiences are socially constructed and regulated. Their place within society, the lives they lead, their relationship with others, and attitudes towards them, are part of a much broader social and cultural picture. In the South Asian (Pakistani, Indian and Bangladeshi) minority, life course transitions are further shaped by cultural and religious factors largely through the family and the community. Consequently the disabled person's experience is a product of a range of ideologies, social practices and social structures.

The interviews reveal the views of young people growing up with physical impairments. They talk about their lives, their socialization and the journey into adulthood in which issues of difference, gender inequalities and culture all figure. The interviewees probe and question their own predicaments, values and responses and recall how they come to terms with their own British South Asian identity and disability.

Gender emerged as an important factor, as the women interviewed are expected to behave in a very circumscribed way and their culture is different from that of the men. This influences their transitions from childhood into adulthood. Obstacles hindering the individual's progression are highlighted as all informants focus on how they are is disadvantaged in terms of fewer career and educational opportunities. Consequently, their life course experiences become indicative of not only a British Asian experience, but specifically a British Asian disabled experience.

The data used in this research arose from a study entitled 'Disability, Ethnicity and Young People', funded by the Joseph Rowntree Foundation. The project used qualitative methods and analysis, based on semi-structured interviews. Young people were interviewed as well as their parents and siblings. The inclusion of parents and siblings in the sample represented an important methodological principal, to ensure disability did not dominate the respondents' narratives. The interview probed family relationships, life transitions and social networks.

Twenty-nine disabled young people were interviewed (16 male and 13 female; aged 17-30). Nineteen young people were Muslim and ten were Sikh. In addition fourteen parents were interviewed; eight Muslim and six Sikh. Fifteen brothers and sisters were also interviewed, matched with the gender of their disabled sibling.

Ten interviews were in Punjabi, one in Urdu, and forty-seven were in English. The interviews were tape-recorded and transcribed and pseudonyms used to ensure anonymity for respondents (for more details, see Hussain, Atkin and Ahmad 2002).

## Disability, ethnicity and transitions

Despite its important role in asserting disabled people's rights, the disability movement has been criticized for not recognizing diversity (Stuart, 1996). These criticisms, although not dismissing the basic assumptions of the social model recognize that disability might be only one aspect of an individual's identity. Furthermore, impairment may only be understood against what is considered as 'normal' for someone of their own age, gender and social class (Ahmad, 2000). Normalcy is not universal and impairment needs to be seen in its social and cultural context. The implications of this are especially complex in relation to disabled young people from minority ethnic groups and their transition from childhood to maturity. Those are more dynamic processes, reflecting broader changes in the experience of South Asian young people in the

UK. For South Asians, their minority identity status, as well as cultural factors shape the life course.

Psychologically, the transition from childhood into adulthood is complex enough for any individual, but this process has added dimensions for those children born in minority groups. For any individual from the diasporic communities, adolescence marks a critical phase in the development of an ethnic minority identity (Hutnik, 1991). Identities are re-synthesized in an attempt to seek location both individually and socially (Erikson, 1964). The process is achieved by a re-evaluation of the past, where aspects such as cultural identification, religion and politics are examined. During this phase of development issues of differences are highlighted and ethnicity becomes a marker of difference vis-a-vis the indigenous population.

Growing up in a country that is culturally, socially and religiously different from their cultural homeland has a significant impact on the life course transitions of South Asians. The British-South Asian identity represents the two distinctively different cultures of those children of South Asian parents born or brought up in Britain - the one into which they are born, and that practiced at home. Their growing up involves a negotiation between the two cultures.

Young people engage with ethnic, religious and cultural values associated with their parents' homeland within the context of a Western society. Outright rejection of their parents' ethnic and religious identities is rare among the second generation, although partial and contingent acceptance, as well as reinterpretation of some values, does occur (Drury, 1991). It is not a question of forsaking one claim for another and choosing between a 'Western' or 'Asian' way of life (Modood et al., 1994). The idea of hybrid identities thus emerges (Papastergiadis, 1997).

For the second and subsequent generations of South Asians, there has been a level of adjustment without the loss of ethnic identity (Hutnik, 1991). Many of those born in Britain eat South Asian food at home, speak the ethnic language, wear ethnic clothes and watch South Asian films. Outside the home, they are also competent in English ways, speak English and succeed academically. A cultural synthesis has been created of two very different cultures, not out of compromise but by being critical and affirmative of both cultures. The result is an ability to find a secure identity in each (Hutnik, 1991). The transition, although problematic, succeeds to an extent.

Racism, however, remains an issue and is reflected in young people's engagement with the wider society. This is manifest, for instance, in the social inequalities between South Asian families and White families (Modood et al, 1997). South Asian families with a disabled child tend to be poorer then their white counterparts and have less access to services and benefits. Consequently, the variety and strength of barriers faced by minority ethnic families with a disabled child excludes them from society (Chamba et al, 1999). This is part of the broader context in which disability assumes meaning.

## Family intervention

Within South Asian culture, the transition from childhood to adulthood is overwhelmingly influenced by the family. The South Asian family is different to that of the indigenous population in the role it has within its members lives. The diaspora perpetuates the traditional joint/extended family system found in South Asia where members of the family live and work together sharing both domestic and production tasks (Anwar, 1979). This framework helps those more vulnerable to social exclusion such as the elderly and disabled people. Although migration has forced several changes in South Asian joint families, its structure is essentially the same; patrilineal descent group, patrilocal residential rule, patriarchal authority, respect related to age and sex and preferential marriage patterns all exist within the context of Britain. In South Asian families, parents and members of the wider family all contribute to the discussions about the younger members of the family.

Families' dual roles of caring for and protecting their child while preparing them for an adult life have added complications due to their child's impairment. All the young people who were interviewed were looked after by their parents and family with the exception of two, who were living on their own. Essentially the young person was at the core of the household; activities within the home revolved around the disabled person.

Those living at home had a close sense of identity with the immediate family. Family was established as important during childhood and remained crucial in the transition to adulthood, remaining central throughout the life course. Young people's lives were defined and entwined within familial expectations and requirements. The individuals interviewed talked about their roles and the impact their impairment had on the family. The family, in particular the parents, enabled the disabled person to sustain a quality of life. This support network existed very strongly within all the families interviewed, from day-to-day physical support routines to moral and emotional support without which the individual would have problems. The family were the most important people in their lives. In all the interviews, it was clear how dependent the disabled young person's life was on family support. For example, Sarita Malik talks about the support she receives from her family and it being important for her in the future: 'my family supports me one hundred per cent. They make life easier for me and I've got family, I don't really need anybody else.' These individuals talked about the future with the continuing support of their families and remaining within the same home.

There was a difference between those who had acquired an impairment during life and those who were born with it. The latter made plans for the future; their parents supported their children's efforts to better themselves. However, those who had acquired their disability felt that it had come as a devastating blow to the family. A view shared by their families. The transition to adulthood was handled positively in cases of impairment from birth but negatively among the others; these individuals could not and would not make plans for the future and nor could their families.

Family life is more than a 'dynamic space' in which individuals engage with disability and impairment. Members have to assume roles, obligations and fulfill expectations and reciprocities regarded as consistent with certain normative expectations. Socialization and cultural as well as religious reproduction inform this process and here gender becomes important with different transitional phases for men and women.

Parents perceived their disabled child to be far more vulnerable and in need of support and care than their non-disabled children, even though the disabled child was older than the siblings. The parents tended to treat the disabled young person differently from their siblings. Families were more concerned with giving extra care and support to the disabled child than with encouraging them towards independence. The young person was perceived as incapable of handling their own life. The non-disabled child was given more independence and was allowed more opportunities than their disabled sibling. Whilst the young people interviewed stressed the help and support they had received from their families, they were also quite aware that they had been treated differently.

The family remained during the transition into adulthood. Young people did not talk about the future without their families; in fact, they did not really talk about a future. Some people did discuss leaving the family household, but the parents and siblings had another perspective; they assumed the young person would remain within the household. Consequently the family was more central to the whole life course of young disabled people, their families helping to construct a future of dependence for them.

Parents did not refer to the life course transitions of their child and their future except in terms of care. Parents were the primary carers within the home, in particular the mother and would continue being so in the future. Parents saw this as their responsibility; according to Shaista Akhtar's parents: 'God has given us a child like this so we have got to prove to him that we will look after her, because she is a Muslim and our daughter'. The obligation of care would not end when the child reached adulthood but would continue until death. Parents who had cared for the child would carry on doing so for the adult. This was not discussed; the parents merely assumed this to be their role and even the young persons themselves acknowledged this to be the case. In kin groups, it was a continuing expectation that a son rather than a daughter would take responsibility for giving a home to the young disabled person after the death of the parents. Many of the parents talked about how their child would automatically be looked after by their siblings. However, the families worried that siblings would not be willing to assume such responsibilities. Shaista Akhtar's parents express this: 'Here children do not look after their parents, let alone their sisters..., we want her (Shaista) to die when we are alive so that we are able to take care of her, so that we can look after her ourselves'.

The relationship between the child and parents was close and dependent. Within the South Asian family structure, even though an individual reaches adulthood, their life continues to be influenced by the family (Anwar, 1979). Parents intervened in the lives of their children in terms of education, marital and career plans. These codes of behavior and the acceptance of fate as advocated by the parental generation, proved no longer satisfactory for the younger generation. The young people found themselves torn between the world's attitude towards them and their own definition of their roles in life.

The level of intervention parents had on the lives of their children was dependent on whether the child had an impairment or not. All decisions to do with the disabled young person were made by the parents. Yet in contrast the non-disabled sibling would have some room for negotiation with their parents about their future issues, having more freedom to pursue academic, employment and leisure activities. In addition, the young women, irrespective of disability, were controlled more although the disability added another restrictive dimension.

The young person people perceived this discrepancy. The reasons for this differing treatment were defined within the interviews with the parent. Physical impairment is often equated with mental impairment; the parents feel the child is inadequate and ill equipped to make decisions about their life. The impairment became a symbol of inadequacy and burden. Therefore movement into adulthood signified no real changes to their lives and individuals were either content to remain within the home environment or did not consider moving elsewhere, as they had assimilated the no-hope philosophy from their parents.

## Transitions through education

The life courses of young people were largely determined by their performance at school. Overall, respondents performed badly at school. Only two individuals had gone onto higher education, the rest had not even sat GCSE examinations if at a special school, or had failed them at a mainstream school.

There was a significant difference between those who attended special schools and those with physical and learning disabilities and those who attended mainstream schools. Those who attended special schools remained in a void, attending day care centers, unable to read or write properly, having achieved no formal qualifications at school. Although the facilities within these schools were praised most comments about special schools concerned the poor quality of education, according to Amjad Khan, 'they showed you how to wash your clothes, how to cross the road... I was so ashamed'. In contrast those attending mainstream schools achieved more, with two eventually going to degree level and others embarked on courses in information technology or accountancy.

In interviews with the young people about their schooling and their academic life post-16, it became clear how circumscribed their lives were by their experiences within the school environment. Many referred to their school days as a preparation for ordinary life, educating them in both the classroom and the playground. The school environment allowed individuals their first taste of how they will be treated in society at large. The lack of appropriate facilities, the prejudice from teaching staff as well as students and the lack of success were indicative of how they felt life was to be. Saira Raziq explains: 'You're not just in a limited atmosphere. You get to know what the real world is... it's a good way of learning how to deal with life later on... I think it gives you confidence really, to be able to go out into the world, and you know how other people are going to react and what their feelings are'.

Schooling was largely a negative experience for these young people, making the transition into adulthood more complex. Those who wished to pursue their education beyond school faced barriers at school, which blocked their careers. Here there was a contrast with the careers advice offered to the non-disabled and disabled siblings. The service was negligible for many respondents and those who were given careers advice felt they were being pushed towards softer options. According to Jameela Begum, her careers adviser was urging her to go onto a Youth Training Scheme: 'I spent like over half an hour arguing, she would say do a YTS and I said no, I'm not doing it and in the end I got really angry. I shouted at her and said I'm not doing YTS so don't you ever dare talk about it again'. Yet the able-bodied siblings were given constructive advice, which was heeded; none of the siblings interviewed complained of a lack of attention or career advice.

The siblings in contrast, had a good education, or were currently doing well and had intentions to improve themselves. The siblings talked about the support they had received from the family to pursue academic careers and their own self-motivation. There was concern towards their disabled siblings and the lack of goals in their lives. Furthermore, many chose not to discuss their schooling with their sibling because they knew it would be a painful subject. Whilst siblings were allowed freedom to pursue their education, the young people interviewed resented the lack of support given to them, they were angry at not been given the option of choosing their school. According to Sarita Malik, 'My sister can choose the school that she wanted to go to and what she wants to do, but I didn't have that choice.'

Interestingly the two respondents who had reached degree level were women. One had completed her degree; the other was pursuing one. Nearly all the female siblings had either pursued higher education or were currently doing so. All the second generation women interviewed irrespective of impairment were more enthusiastic about their education, and saw it as an economic necessity as well as a form of liberation. Parents encouraged their non-disabled daughters' education as part of their dowry package (Shaw, 1994). In contrast, the education of their disabled daughters was not encouraged, because their impairment would exclude them from the marriage market. The reason for allowing their disabled daughters to pursue an education was to fill in their time. Educational transitions were therefore shaped by disability, ethnicity and gender.

In comparison the young men, with or without impairment, were academic low achievers. Male siblings were either working or were unemployed. They were more pessimistic about life; had no real goals, and nothing to plan for. Non disabled men were disinterested in bettering themselves and those who were pursuing an education were doing so only because their parents saw it as a natural progression from school. All the disabled men had attended special schools and left without qualifications. After the transition from school they spent most of their days indoors and only went out to centers twice a week. They had no goal in life; many were defeatist, preoccupied with what they could not do and how death would be a way out of their current existence.

The disabled men were also encouraged by their parents to pursue activities outside of the home. Whilst many men attended colleges this was not for educational purposes, but for socializing, as some chose courses that did not necessarily produce useful qualifications. For instance life skills courses were popular and families encouraged this as a social life for their child. According to Laiqat Ali, 'it's just to get out of the house and do something'.

The transition from childhood into adulthood was difficult for those without qualifications. However, the data revealed that women were more enthusiastic about their education irrespective of impairment. Some returned to education in adulthood to improve their qualifications, and were more in control of their lives and positive about the future. They saw education as a means of escape from doing nothing. Although they had the desire to do well, decisions to pursue education and some activity in adult life were often not actively supported by family members, who regarded disability as a legitimate excuse for underachievement. This was the main obstacle facing individuals in particular the women, who had to fight for their right to go to college. This can be seen as an expression of intergenerational conflict about the nature of the transition into adulthood.

Their experiences of schooling both within the academic environment and at home, led to most of the young people irrespective of gender lacking confidence in their ability. Their ability to doing well at school was clouded by their lack of confidence in themselves. For instance Irshad Ilays talks about his inability to pursue an academic career. His lack of self-esteem is evident when he is asked if he would like to progress further: 'I'm not clever enough, like other people... I find studying very difficult.... I can't cope with the pressure'.

Kauser Parveen, currently doing a degree at university, also discusses the extent to which her dialysis and her physical condition had an influence on her education, in particular her self-esteem. 'I thought I was sort of intelligent sometimes, but I thought you know I won't be able to do it'.

This lack of faith in their own abilities to pursue an academic career, was also a direct consequence of their relations with parents. Kauser, although she is not following her dream of being a doctor, has opted for an alternative path less stressful than medicine. Her incentive to pursue a university education is not only for herself, but to prove her parents wrong for having always focused on her non-disabled sister as a role model: 'My mum's always saying, Sameena (her sister) gonna become a big doctor'. This was the driving force behind her desire to do well: 'That's why I wanted to go to Uni. To do a degree and say like look, I can do something, I might be ill but I have done a degree, you know.'

Physical impairments and the effects of disability changed lives. Educational experiences are shaped by society's concepts of disability, and thus create expectations of life after the transition from school. Most of the girls attended mainstream schools, and their transition from education and ultimately into employment is therefore much easier than those who went through special schools, having gained no qualifications before entering the labor market.

## Transitions into employment and unemployment

Educational attainment was important for individuals as it determined their employment status. Leaving school without qualifications limited their labor market opportunities. Six of the interviewees were currently in full-time employment, four of whom were women. They were in the lower levels of the job market, working as receptionists, teaching assistants and packers in mills. Their presence in professional areas was non-existent.

These individuals complained of structural inadequacies in the work place. For instance, Virender Singh: 'there's a ramp outside and I think that gives a very false impression...the most difficulty I experience is through not being able to access the building properly... not being able to get to where I wanna go because the facilities are not there to cater for me'. They also had experienced the prejudices of others. Shezad Akram said: 'This guy came up to me and said what are you doing working here, you should be claiming benefits'.

As in education there was a difference between those who were born with an impairment and those who had acquired one later in life. Those who were working were disabled from birth, they were positive about their employment and comfortable with their disability. Their confidence was evident from their comments; they blamed society for not allowing them to participate fully due to inadequate facilities. For instance, according to Virender Singh, 'I don't think of myself as disabled, it's society that is disabled by not enabling me to do things'.

However those who had acquired a disability were more fatalistic in their outlook. Employment failed to register as an important part of their lives. There was a concentration on the barriers and obstacles that prevented them effecting a transition into employment, instead of optimism about removing these barriers. They also focused on life before the incidents which led to their impairment and talked about themselves negatively, as they were still coming to terms with their disability and saw it as the cause of their unemployment. Attending college or remaining at home in front of the TV were regular activities. Employment failed to feature as a realizable goal for them. It became acceptable in the family's view not to work, and no pressure was exerted by the family who regarded the disability as sufficient explanation.

More women than men were working, yet men were encouraged to work while women were not. Furthermore, a surprising amount of voluntary work was being done. In fact the number of those who had done voluntary work at some stage in their lives significantly outweighed those who were actually in paid employment. The voluntary work took place in various organizations, ranging form sticking labels on envelopes in an office, to working as helpers for community organizations, magistrates or helping out in support groups. Significantly, they did not encounter any obstacles for this type of work.

Some were objectively unable to work, but others seemed to use their disability as an excuse. They could cite discrimination and prejudice as barriers to the transition into employment, whilst complaining about the consequent shortfall in household income. Some felt their chances of obtaining employment were curtailed by their disability.

Mansoor Saeed felt pessimistic about future and employment: 'My cousins, they can't get a job, so it would be harder for me'. Problems are also anticipated with employers. According to Shezad, 'You don't want a disabled person working for you as much as an able-bodied'. The only role that some saw for themselves in the future was in self-employment.

Despite the pessimism around employment, there was optimism too. Amjad Khan was more positive about his plans: 'Sometimes I do feel that, but then again, I do believe that if I've got the right qualification I might get a good job and I will be alright'. Even the women had this ambition. Shabana Ali refers to herself as a counselor for Asian girls: 'People who are not Asian, they just see the good face, they don't, you know, see behind the closed doors. There's a totally different person behind the closed door'. She believes she can use her own experience, like several of those interviewed, to help other disabled people in the future.

According to Karminder Kaur, 'You forget your own problems when you're listening to someone else'. For the men it was an issue of respect and dignity in the face of the family. Many wanted to work because of financial constraints. Satvinder Singh said: 'I'm living off me brother ...it gets pretty hard...I'd like to go back to work, but it depends on what the situation brings'. None of them considered it impossible that they might ever work.

There was no support from agencies to enable them to follow their employment plans. Knowledge of groups that find work for disabled people, was almost non-existent. Many respondents relied on family support and encouragement. However, with the family setting the agenda, this shaped the young people's own perspectives. In many instances, they wanted desperately to work outside the home but the family created barriers in the belief that disability made them unemployable. Parminder Kaur said: 'I want to find a job soon... that's what I want to do, to work in an office, to be a secretary'. However, her mother's opinion was that: 'She will not be able to work for anybody. She hasn't got it sort of in her to... she wants to be a businesswoman, but she won't be able to get around much'. As her mother is the main person who supports her, without her mother's approval, she will not be able to get employment.

In several of the households, the very thought of their child or sibling working was almost taken as an offensive statement. The family members generally understood that a disability excluded them from the sphere of employment. Again we have seen how the transition into the labor market, a key aspect of achieving full adult status in the eyes of society, is shaped in ethnically specific and gendered ways for young disabled people.

## Conclusion

The life course of the disabled young person was without doubt different to that of their non-disabled sibling. Disability was an important influence in the way those interviewed made sense of their lives and progressed form childhood to adulthood. However this experience did not occur within a vacuum. The life course of the young person was overwhelmingly influenced by others in particular their parents, consequently, they faced negotiations on all levels. These negotiations expressed the hybridity that influenced their self-identity and relationships with others.

It is not a question of forsaking one claim for another and choosing between a 'Western' or 'Asian' way of life (Modood et al, 1994). Young people wanted to find a space to express a variety of different and competing identity claims. The disabled youngsters saw their parents allowing their non-disabled siblings a space to explore their identities but failed to allow them the same freedom. Although the family is more caring and this can be seen positively, in practice this helps to construct a certain kind of dependence for the young disabled people. Disability was an important influence in the young person's sense of identity.

Inevitably although the respondents had multiple identifications, some held more strongly than others, they used these flexibly according to situations. This often meant some became more salient in certain circumstances as highlighted in the discussion on education and employment.

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