

No laughing matter: medical and social experiences of restricted growth

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People with restricted growth have liminal status in the disability community. Because people with these conditions appear to live normal lives, they do not always define themselves as disabled or participate in the disability community, nor are they always identified as disabled people by others. This paper reports from a project seeking to fill the research gap around the social and medical impact of skeletal dysplasia, finding that adults with restricted growth experience a range of difficulties. These include medical problems, social stigma, and employment disadvantage. For these reasons, it makes sense to consider this group amongst the wider disabled population.

Keywords: restricted growth; models of disability; impairment; identity; stigma; employment

Introduction

Disability is a very complex concept, and debates about the definition of disability have been extensive (Shakespeare 2006). For example, it is often difficult to agree how many disabled people there are in any given society. Nor is it always clear which individuals are disabled and which are not disabled. Despite the tendency to view disability as a coherent category marked by shared experience, there are wide disparities between different impairment groups. Identification and self-identification as disabled cannot be taken for granted (Watson 2002). Some impairment groups – such as blind people or deaf people – prefer to see themselves as distinct from the majority of those with physical impairments. Among people with physical impairment, those with restricted growth – known also as dwarfs, or Little People in north America – are also often reluctant to identify with the wider disability community.

While British disability studies has sought to replace a ‘medical model’ definition of disability with a ‘social model’ definition (Thomas 2007), in this paper we assume that disability is a multi-factorial phenomenon involving biological, psychological, cultural, and social dimensions (Shakespeare 2006; Gustavsson 2004). But from either a medical or a social perspective, it is not obvious that restricted growth is disadvantaging, particularly compared to other impairments. At first sight, people with restricted growth do not appear to experience functional limitations, beyond obvious issues of height and reach. For example, mobility and cognitive ability seem unaffected, and the condition thus seems to be more of a ‘difference’ rather than a classic ‘disability’. For example, the anthropologist Joan Ablon asserts that:

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although dwarfism is a dramatic, physically distinctive, and immediately identifiable condition, dwarfs are usually not physically disabled or handicapped in the general sense of these terms. (Ablon 1990, 880)

Nor generally would it seem that those living with the condition experience barriers in social integration, independent living, and family life. The dominant cultural image of the dwarf is of a happy, outgoing and entertaining person, usually male. This positive picture is promoted by organizations representing people with restricted growth, which promote integration and acceptance of their members in wider society and play down negative aspects of their experience.

Perhaps because it has rarely been seen as a major problem, there is a dearth of research, particularly robust social research, about restricted growth. This contrasts with the very wide coverage of restricted growth within popular culture and the media, for example films (*Time bandits*, *Living in oblivion*, *The station agent*), novels (*Mendel's dwarf*, *In the company of the courtesan*) and television documentaries. There appears to be a cultural fascination with dwarfs, but an academic neglect.

In general, available research evidence about restricted growth tends toward the clinical, and there is very little reliable material on social aspects of living with a skeletal dysplasia (Thompson, Shakespeare, and Wright 2007). Evidence is often focused on specific aspects, with little information available on general rates of morbidity, on rates of surgical and orthopaedic treatment, or on issues such as obesity. Children have been a more popular focus than adults, but for both attention has often focused on psychosocial issues such as the relative disadvantage of short stature per se. While a substantial section of the literature may appear dated, a small number of more recent studies have begun to address issues such as quality of life (Apajasalo et al. 1998; Mahomed, Spellmann, and Goldberg 1998), general psychosocial aspects (Hunter et al. 1998), a combination of health and social aspects (Gollust et al. 2003), or education and employment (Roizen, Ekwo, and Gosselink 1990). The list however is frustratingly brief, and the evidence presented is very often related to a single condition or to an undefined mix of conditions (there are approximately 200 different conditions which cause restricted growth). In addition, most studies are compromised by limited sample size, both in numerical terms and in their derivation from hospital patient lists or interest organization membership. Overall, as McKeand, Rotta and Hecht (1996) point out in the case of pseudoachondroplasia, very little is known about the general health experiences of adults with the condition, and this appears to be true both for the whole range of skeletal dysplasias, and in particular for their social experiences.

In this paper, we will draw on evidence from a three year project in northern England funded by the Big Lottery Fund, which aimed to investigate the medical and social dimensions of adult life with restricted growth. This project was initiated and guided by the UK Restricted Growth Association (RGA), which wanted to know more about the experiences of the community, so as to direct better its services and campaigning. One of the research team was a clinical geneticist specializing in the diagnosis and management of skeletal dysplasias, who wished to have good data about natural history and prognosis of the condition so as to advise and support patients more effectively. Overall, the team suspected that the generally positive picture of life with restricted growth conditions concealed considerable variation in experience as well as possible unmet need. After a brief discussion of the methods adopted, the results will be presented in three areas: experience of impairment;

experience of prejudice; experience in the workplace. While the research covered a wider area of personal and public life, it was in these domains that disabling factors appeared particularly prominent.

Methodology

The research project used both quantitative and qualitative methods, with the aim of generating rich data about the life experience of people with restricted growth, covering both medical and social aspects. The objective was to avoid the ascertainment bias which undermined the validity of previous research, by recruiting widely and in particular reaching those who were neither members of support groups, nor in touch with specialist medical services.

Respondents were recruited in three geographical areas in the north of England, which it was believed would offer a sufficiently diverse population. Since there are no reliable statistics on the actual prevalence of skeletal dysplasias in adults in the UK, the team had to employ a variety of strategies to reach potential respondents. Copies of the questionnaire were sent out by the RGA to all adults on the membership list who lived within the project area. Relevant health care professionals were asked to forward project details to those with whom they had contact. Information was sent to other organizations whose members might fit the project criteria (e.g., Child Growth Foundation, Dwarf Athletics Association). Features in the local media advertised the project and appealed for participants. Finally, reply-paid 'Contact cards' were handed out by RGA members and project participants.

Anonymity was very important. In a community of limited numbers, where many participants were known to each other, and/or to members of the research team, it was vital to assure potential volunteers that their responses would remain confidential. Concerns about anonymity may account for the comparatively low response from RGA members: only 50% of eligible individuals chose to participate. The final numbers for the project group were 92 questionnaires returned, of whom 81 were retained as fulfilling the main project criteria of having, or likely to have, a skeletal dysplasia condition.

It was not possible to select a project group according to an 'official' diagnosis of a restricted growth condition. Nearly one fifth (19%) of the project group had never received a diagnosis from a health professional, and most of these were in the older age groups. Lack of diagnosis was often because the respondent had had no contact with relevant hospital services or because they or their family had not considered this important. This was especially so for some older respondents, who had grown up at a time when diagnostic procedures were less specific or there had been less parental interest in requesting investigation. Equally, it is possible that some had received an incorrect diagnosis. Project participants were therefore recruited if they were of disproportionate short stature with a final adult height of less than 4 feet 10 inches, or where they had been given a diagnosis of a skeletal dysplasia. Over half of the group (57%) had a diagnosis of achondroplasia, and the remainder had less common conditions.

The 81 respondents were a diverse group with a wide range of views and experiences. Of the total, just over half (45) were RGA members and the others were either ex-members or non-members recruited via snowballing, health professionals or media publicity. Nineteen respondents were male, and 62 (76%) were female: this may be at least partly explained by a greater willingness among women to participate in

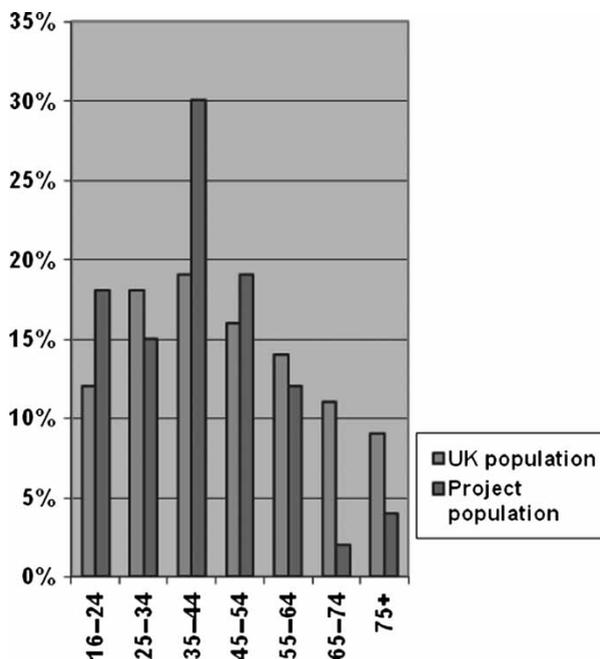


Figure 1. Age distribution of the project group.

research of this kind. The gender bias may be important in interpreting data on e.g., employment, as gender inequality as well as disability inequality may be relevant explanations. The age distribution is shown in Figure 1.

The under-representation in the older age groups suggests caution is needed when interpreting some of the project data that could be age-related, such as for example the figures for marital status and living arrangements.

The questionnaire provided information on general personal details, education, employment, benefits, medical and health experiences and broader social issues, and incorporated a quality of life instrument (SF36). It was piloted with both RGA members and non-members from outside the project area. For those who wished, the questionnaire could be completed by telephone contact with the researcher. The questionnaire was deliberately designed to be straightforward to complete, while providing space for additional comments. The questionnaires were analyzed using SPSS (Statistical Package for the Social Sciences) computer software.

Interviews were carried out with 50 of the project group who had indicated a willingness to be interviewed: the interview group was constructed to reflect wherever possible the main characteristics of the wider population of people with skeletal dysplasia. The interviews used a piloted semi-structured interview schedule and examined the main areas covered in the questionnaire together with additional issues of importance to the interviewee. They were tape-recorded and transcribed. Interviewees were also offered a chance to keep a 'diary' for four weeks following the interview, in which they could record relevant events and/or symptoms, or add extra comments on issues raised in the interview. These diaries were also transcribed to provide additional qualitative data.

Throughout, the project the team worked closely with the RGA. The plans for the project were discussed with the Chair, Manager, and Committee during the bid stage. Team members continued to attend RGA Committee meetings and gave presentations and workshops at the annual Conventions explaining the processes involved, encouraging feedback and giving early information about issues and findings. Project updates appeared in each quarterly Newsletter of the Association and invited comment and feedback. Dissemination events to present and discuss the project findings with project respondents and members of the RGA were organized for five locations across the UK.

Experience of impairment

Research focusing directly on skeletal dysplasias and quality of life issues is sparse, but Apajasalo et al.'s (1998) work in Finland found significantly lower rates of health-related quality of life for adolescents and adults with skeletal dysplasias in their study, and the pattern was especially marked in the older age groups, which also ties in with the findings of Mahomed, Spellmann and Goldberg (1998) for adults with achondroplasia. A fifth of Folstein et al.'s (1981) skeletal dysplasia sample reported moderate or severe physical impairment. Savarirayan and Rimoin (2002) review the literature on a number of potential medical problems for people with skeletal dysplasias, including obesity, osteoporosis and premature arthritis, and stress the importance of coordinated medical management of people with the conditions.

Whilst the specific medical complications that might be expected to arise in an adult with skeletal dysplasia vary according to the particular diagnosis that they have, it is commonly accepted that many adults in this group will experience pain and stiffness in their joints and backs as they reach middle age. Adults with achondroplasia are particularly susceptible to problems with numbness or tingling in their limbs, especially their legs, as a result of spinal stenosis. The spinal canal is narrowed in most people with achondroplasia as compared to the average-size population, and this narrowing can result in pressure on the spinal cord and nerves arising from it, causing symptoms particularly after walking or standing for long periods:

My back, my spinal canal's narrowing, so they've told me, and I get muscle spasms in the lower part of my back... But so far I've got away without surgery, I just keep myself active. (252 female, age 36)

These symptoms are normally expected to arise for the first time in adulthood. Other diagnoses that are associated with abnormalities of the bones involved in large joints, for example spondylo-epiphyseal dysplasia congenital (SEDC) or diastrophic dysplasia, result in joint pain which can begin in childhood but is often not seen the second, third or later decades. Data from the project, however, suggest that, while some are relatively pain-free, a larger proportion experience pain, numbness, and reduced mobility at an earlier age than has so far been documented. Overall, 78% of the group found that their mobility was reduced and 84% reported pain and 68% numbness, on a regular basis. More surprising, however, was the age at which many began to experience pain and mobility difficulties.

From Tables 1 and 2 it can be seen that 61% of the respondent group were experiencing pain by the end of their twenties, indeed 9% had had pain for as long as they could remember. 53% were already finding that their mobility was reduced by

Table 1. Experience of pain.

	Age of onset	A problem since
Always been a problem	9%	
Childhood	20%	29%
Teenage years	10%	39%
Twenties	22%	61%
Thirties/forties	11%	72%
Fifties/sixties	4%	76%
Not relevant or not responded	24%	

the age of about 30, and 14% had always found that their mobility was compromised. For a number this early onset had been unexpected as well as unwelcome:

[I want] not to have back problems, not to have any pain, what I've gone through. I would have been able to accept pain or some sort of pain as I got to 60 or something like that, but not from 21. (242 male, retired early, age 57)

Pain and numbness were usually exacerbated by standing or physical over-exertion, and some respondents actually attributed current problems to the fact that they had followed unsuitable physical activities earlier in life, such as physical sports, or that they had been employed in jobs requiring heavy work:

I've had a lot of back problems since I was 21, because I've done a lot of daft stuff, you know, when you're a kid. (242 male, age 57)

I used to play hockey, netball, everything that any normal-sized person used to do, but looking at that it probably did damage my joints in some way... We were never really given any information [about unsuitable activities]. (437 female, age 41)

For some this had raised problems beyond those of a simple reduction in mobility. They spoke of the risk that they would be seen as not participating fully in the requirements of their work-role, and felt that not fulfilling the more physically demanding tasks would show them in a poor light:

I do really stretch myself, I'm not a skiver... and I can feel it in my back then and it's stupid really because I could do my back in at any time, but sometimes I do think to myself, hang on, you do have to give it your best... I do feel like I've got to be physically strong and keep... I don't want to look like a wimp. (216 male, age 24, working in a skilled but physically demanding occupation)

Table 2. Experience of mobility difficulties.

	Age of onset	A problem since
Always been a problem	14%	
Childhood	15%	29%
Teenage years	10%	39%
Twenties	14%	53%
Thirties/forties	16%	69%
Fifties/sixties	1%	70%
Not relevant or not responded	30%	

This is in contradistinction to the increasing recognition of the importance of maintaining health, and reducing the risks of injury, at work amongst the general population. It appears to be part of a tendency to deny the reality of disabling functional limitations arising from these conditions.

While a minority of respondents reported that they experienced little pain or numbness, the majority found that pain in particular was an important factor in their day-to-day life, and dealing with it had become a problem. For some pain was a constant companion and had always been a part of their life and dealing with it adequately often posed great problems. Painkillers had been prescribed, but often proved insufficient:

I'm now going to physiotherapy because I've got terrible pains in my knees and that. Now, I've been complaining to my GPs for the past 15 years, and all they've done is given me painkillers. (217 female, age 47)

The invisibility of constant pain was an additional problem for those who experienced it:

there's days when my hips are really really painful and people think that because they can see you walking about, they think there's nothing wrong with you. (423 female, age 25)

For some respondents with achondroplasia, spinal stenosis had entailed serious physical impairment and treatment involved major surgery: 24% had had spinal surgery, with a similar proportion needing operations on joints. Others recognized the possibility that the stenosis and other orthopaedic problems could occur in the future. For those who had previously known nothing about their risk, back problems came as a shock:

more recently, in the last couple of years, with my back . . . when my back was first bad they said it must be 'tissue tears', or that it was sciatica . . . It wasn't till I saw that doctor recently that I was told what it was, it was the first time I'd heard of it, spinal stenosis, first time I'd had any problems too. (325 male, age 29)

Other medical issues that arose for our sample included ear infections, bladder and bowel issues (often arising from neurological problems), obstetrical and gynaecological complications. There was a significant extent of unmet medical need: for example, the questionnaire incorporated the Epworth Sleepiness Scale, and responses suggested that over a quarter of the sample experienced mild to moderate sleep apnoea, with 4% likely to have serious symptoms. Only two individuals had been previously investigated for this problem. Another important finding was the extent of mental health issues: 37% of the sample reported having experienced mental health problems, predominantly depression; 23% had had professional help; 14% had been prescribed anti-depressants. Respondents attributed depression to feelings of loneliness and social exclusion and to experiences of pain and physical deterioration:

I have counselling, I see a counsellor, that works wonders for me. Before that though I would say I have had quite long periods of depression, I've been on anti-depressants. (374 female, age 40)

Increasing experience of pain and functional limitation with age changed the ways in which people conceived of themselves and their condition: what had previously felt like a difference now became reclassified as a disability. Asked whether she would describe herself as disabled, one woman said:

Yes, now I would. But 10 years ago, no. (213 female, age 50 with achondroplasia)

Experience of prejudice

A second area where the research findings revealed significant disabling factors is in social interaction and cultural prejudice. Being small in a tall world can be tough. Even in the absence of active hostility or curiosity, people of short stature found that crowds were intimidating – they feared being unwittingly knocked down or crushed. For all these reasons, many respondents used words like ‘unsafe’, ‘vulnerable’ or ‘nervous’ to describe their experiences of the average sized world. But these feelings are exacerbated by the reactions of others. Restricted growth is a very visible difference, with associations to folklore and humour. Our research showed that the rarity and novelty value of restricted growth meant that it was impossible to escape the curiosity, and occasionally the hostility, of non-disabled people. Quantitative data demonstrates that, of the research group:

- 96% have experienced staring or pointing.
- 77% have been on the receiving-end of verbal abuse.
- 75% feel they often attract unwanted attention.
- 63% of respondents have often felt unsafe when out.
- 33% have been physically touched by people in public.
- 12% have experienced physical violence.

It is these reactions which reminded our respondents of their difference:

I can spend most of the day and not think about it, but something will happen, I'll find people staring at me and I think, what are they looking at? And then I think, it's because it's me. (243 female, age 49)

Negative reactions ranged, as our statistics show, from the ubiquitous staring to occasional more violent abuse:

When I was younger I used to take the dog for a walk and these lads threw stones, well bricks really, and I had to go and sort it out, it was quite dangerous, it hit the dog, they never hit me, but they were aiming for me. They threw stones at you because you looked different. (219 female, age 37)

People tried to ignore these reactions, and many succeeded most of the time. While staring was inescapable, it was the rude comments which were particularly objectionable. Similarly, respondents differentiated between children – who knew no better – and adults or youths who were more culpable for their bad behaviour. Several of the older respondents described bullying and harassment at school or in their local neighbourhoods, but the evidence of younger interviewees suggests that maybe some find that the problem has not gone away:

I think the world is changing and it isn't changing for the better. They say in some ways disabilities are being accepted, but there's still a lot more yobbish behaviour than there was when we were kids. (252 female, age 36)

For many short people, there was also the problem of being overlooked or patronised:

I've gone through life trying to make a joke, but I can't stand being patronised, I can't stand being patted on the head, you pat children and dogs on the head. Not me ... I fight hard to be dignified and I fall flat on my face every time! (434 female, age 72)

Many respondents found that work colleagues or contacts tended to treat them as less intelligent or responsible: because they were the size of children, they tended to be infantilized. Being taken seriously or treated normally was an important issue.

Remaining positive and good humoured was sometimes a struggle for our respondents, and the strain of social reactions is one factor underlying the mental health problems reported above. As for other disabled people, managing other people is a necessary social skill for restricted growth individuals. 'Managing' interaction with new contacts in a way that did not make them feel awkward was important to a number of respondents, and they described making a definite attempt to smile at others and to initiate conversation, as a means of dissipating discomfort:

I think it's something you've got to adapt when you've sort of got any. . . Any difference, I feel as though you've got to reassure the other person that you're average, you're normal, there's, nothing different from you, and I try to do that as soon as I meet somebody. (217 female, age 47)

Having supportive and understanding family, and gathering a circle of close friends, usually of the same sex, were important factors in ensuring positive identity and social integration. These special friends physically deterred bullies in school. They shielded the restricted growth person from hassle or abuse in nightclubs. They might be the one who did the clothing alterations. They often stepped in when strangers were staring:

it's reassuring to have friends around me who will look out for me and fight my corner if necessary. (369 male, age 27)

Above all, they accepted the individual for themselves, not as an oddity.

Some restricted growth people were intimidated by staring and abuse, and ended up isolated:

When I left college I was more isolated, because I felt like everyone was staring, pointing, and I wouldn't go out for a few years. Even now there are some days when I can't face going out (252 female, age 36)

Several respondents described themselves as 'antisocial' or as 'loners'. It is hard to know whether this is just individual personality, or a way of justifying lack of social contact as a voluntary choice, not as deprivation. Statistics suggested that our respondents were more likely to be single (47%) than the general population (30%), and a third lived alone, twice the national average. Often, those respondents who had married, had married later in life than their non-disabled peers.

Negative social reaction influenced lifestyle choices. For example, respondents tried to avoid locations where they were liable to be harassed or laughed at, for example city centres or places where children gathered. While public transport often presented problems of accessibility, a more significant issue seemed to be potential exposure to staring or other negative responses. For this reason, access to cars was prioritized by these restricted growth people: not only did a private vehicle solve mobility problems, it also made the individual less visible and insulated them from negative comments or reactions:

Well [a car is] a safety thing, it protects you, because I can walk down the street now and I know that somebody will say something, whereas in your car, you're in your little

bubble and all you do is get to the next place. Because when I'm driving past a load of kids, if I was walking through those kids I would get some grief. (219 female, age 37)

A related phenomenon was that some individuals who had begun to use wheelchairs as a result of spinal problems restricting mobility reported the beneficial side effects of becoming socially invisible: wheelchairs users are more familiar and tend to be ignored, whereas dwarfs are very unusual, and get stared at.

Experience in the workplace

A third area where having restricted growth was potentially disabling was in employment. The disadvantage here is complex. Partly, it seems to be a result of discrimination; partly it arises from possible unwillingness of restricted growth people to promote their own careers; partly it is caused by physical limitations, particularly problems with mobility and pain.

Our respondents on average had educational qualifications equivalent to or exceeding the general population. This may partly be explained by the age structure of the sample, in which younger age groups – more likely to possess higher educational qualifications – were over-represented. Over a quarter had degrees, while only a fifth of the general population do; only 22% had no qualifications, whereas the rate in the general population is 29%. Unlike other disabled people, on the whole our respondents did not appear to experience major barriers to finding employment: 57% were in paid work (2001 UK Census found 61% general population in paid work). While 16% were in the category of permanently sick and disabled, more than three times the general population, they were less than half as likely to be unemployed, so it is likely that non-working restricted growth people are reclassified as sick rather than unemployed.

When we looked closer at the types of job which people were doing, we found that respondents were concentrated in lower status lower paid roles: they were twice as likely to be found in lower supervisory and technical or routine occupations than non-disabled people. They were half as likely to be in higher managerial/professional roles, and a third as likely to be in lower managerial/professional roles. Given that they generally had good education, it was common for respondents to feel over-qualified for their jobs:

I love what I do but I am probably over-qualified for what I do as no-one else with the same job has a degree. (226 female, age 24, working as a teaching assistant)

As a result of lower employment status and role, restricted growth people were likely to be living on lower income, particularly if they were working part time. A significant finding was that the majority of respondents who were retired had given up work early through ill health. A consequence of lifelong low status employment followed by early retirement may be low income in old age. As one respondent said:

Well [retirement] might be forced upon with me with ill health myself, it depends how long my spine holds out, doesn't it? . . . when we get to middle age, when we should be enjoying a comfortable life, a lot of us end up back on benefits because of poor health, with our spines and whatever and we don't end up having the life that we should do, that we've worked for. (243 female, age 49)

Restricted growth people strongly valued employment, not least because it was a major marker of independence:

I've done it, I've shown . . . that I can actually do something, because I have been told that I am unemployable. (252 female, age 36)

Commonly, respondents found that careers advisors and potential employers had low expectations of their abilities:

Originally I wanted to be a teacher, a high school teacher . . . and the college I went to for an interview said unless I did nursery teaching they wouldn't give me a place because they couldn't guarantee that I'd get a job because of my size. (234 female, age 47, dissuaded from teaching, now a teaching assistant)

I went to the Careers Adviser when I was 15, 16 and I said I wanted to be a nurse and they said 'well you can't be nurse, you're too small to be a nurse, you'll have to be something else'. (219 female, age 37, started work in a sewing machine workshop, now a training officer)

Our sample included one nurse and several teachers, so it is evident that restricted growth need not be an obstacle to a successful career in those fields. However, a high proportion of the project group were in office employment, nursery nursing or were working as teaching aides. Those in office jobs often spoke of being advised to choose this destination because of its suitability to their size, in that they would be able to spend much of the time sitting down. It is very common for disabled people to be steered into routine or undemanding administrative roles:

one of the teachers had said to us 'if you want to do typing, you know you would get in an office probably and it's a sitting-down job'. (213 female, age 50)

I'd always wanted to be a nurse . . . The school said 'I think you really need to look at being something like a medical secretary'. (424 female, age 55)

Having obtained a job, respondents were very conscious of the need to prove themselves capable:

I've always felt that you've got to work that bit harder from anybody else in the job. (234 female, age 47)

Restricted growth people appear to be less likely to be sent on training courses or promoted, particularly to roles involving managing other people:

I'd been in the office for years and I'd seen heads of departments come and go and I'd had to teach them. Nobody thought that I could do the [head of department] job . . . and I could understand it – you are at a disadvantage when you're my size if you're having to rule other people. (440 female, age 79)

Some felt that they were treated in exactly the same way as colleagues, whereas others found out that things were different for them – indeed one respondent discovered that two average-height younger colleagues, whom she supervised and had trained, were being paid double her own wage, and that management were quite clear about the reasons behind this:

I had to go right through the company and ended up tackling the managing director and saying why was I only getting half pay to what the other two girls that I worked with were getting. And he said 'well I haven't got a bother, you wouldn't get a job anywhere else' (243 female, age 49, left that job immediately and found another job the following week)

However, it is also the case that respondents themselves were not always motivated to progress. Having succeeded in a role and got through the social barrier to being accepted in the workplace, people seemed reluctant to take the risk of going for

another job, where they might fail or not be accepted by new colleagues. While respondents did experience discriminatory barriers, they also sometimes were satisfied to stay in more junior roles.

Conclusions

People with restricted growth have liminal status in the disability world. Most people with restricted growth can do most everyday tasks and function effectively, despite limitations, and many do not think of themselves as disabled:

It depends on the definition of disability doesn't it? If your definition of disability is looking different, well yes I've got it, if the definition of disability is leading a normal life, then yeah, I lead a normal life. (219 female, age 37)

Several people told us that their parents had brought them up not to think of themselves as disabled. In common with most of society, our respondents thought of disability as indicating people who used wheelchairs, or were blind or deaf or had other stereotypical conditions. Many, like this woman, resisted the suggestion that they might be disabled:

I'm just like everybody else, but just shorter, that's how I see myself. (437 female, age 41)

Many of our respondents did not receive disability benefits, nor a blue disabled parking badge, and had not been registered as disabled for employment purposes, and consequently did not feel entitled to call themselves disabled due to lack of any 'official' status. Several others who were in receipt of such disability entitlements still did not think of themselves as disabled. While half our respondents were involved with the RGA, it was rare for people to be involved in disability rights groups or other mainstream disability organizations.

Overall, people felt they had a good quality of life and were happy the way they were. While a third (33.4%) stated that they were dissatisfied with their own health, 40% classified their quality of life as 'good' and 20% as 'very good'. Comments explained that respondents often saw positive aspects of their lives which outweighed the problems they might be experiencing with, for example, pain and reduced mobility:

My life is a great one and, although achondroplasia is a hindrance, [life] is as full and active as my normal height siblings' and parents. (326 female, age 26)

But despite these subjective feelings, objectively our sample also clearly experienced disability and disadvantage in various areas. The title of this paper plays on both the significant impact that skeletal dysplasia has on health and social experience, and on the tendency of non-disabled people to see restricted growth people as figures of fun. Mobility restrictions and pain were a fact of life for most respondents. Ageing exacerbated these symptoms and made it more likely for people to identify as disabled. Staring and mockery were also a common feature of daily existence. Isolation and loneliness were not unusual, and up to half of people were dissatisfied with their social lives. More than a third of people had experienced mental health problems as a result of these experiences. It was common for people to fear the future, for example the worsening of their physical symptoms and the necessity of early retirement.

This data enables us to develop a balanced understanding of restricted growth, one featuring nuance and complexity. Whereas British debates on disability often distinguish ‘medical tragedy’ from ‘social oppression’ accounts (e.g., Oliver 1990), we conclude that most restricted growth people, most of the time, are coping and leading fairly normal lives. It is necessary to recognize the disabling features of negative medical and social experiences. But although these are important, and justify categorising restricted growth as a disability, these problems do not define our respondents. We do not believe that they would see themselves as either tragic or oppressed. Achieving independence and normality was very important to almost everyone. Even in the face of difficulties, there was considerable resilience: for example, the following respondent, who despite being a single parent and having back problems which prevented her working, nevertheless reported:

I can honestly say, even though I’ve had bad personal experiences, I’ve had mostly a happy experience, you know, it’s been happy. I have a lot of friends and family, a lot of good friends I can count on, if I’ve got problems I can go to them. (426 female, age 45, non RGA)

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