

Professions Allied to the Community (PACs) I

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INTRODUCTION

For my sins I have been afflicted with the challenge of living with the consequence of a broken neck, being a refugee from apartheid South Africa, cancer of the throat and surviving as a single parent following my wife's terminal cancer. I have suffered the vagaries of fashionable government policies whilst working as a clinical psychologist in the NHS, made wide use of health and social services concerning disabled people and witnessed the stultifying effect of the 'market' on disability studies in higher education where for over twenty years I taught practitioners working in the field. I have also been an active player in the growth of the contemporary disabled people's movement in the UK.

I can claim, therefore, some familiarity with a variety of issues and services for disabled people!

ASSESSING NEEDS

A few months ago I added to this list of qualifications by graduating from hospital following a stroke. Returning home set the scene for my latest sample of the, now politically correct, modernised social services approach to 'community care'.

The pressing issue, stimulating this paper, was quite simple: who should pay for a rail fitted adjacent to the toilet prior to returning home from the hospital? This arose as a dilemma because I was suddenly confronted with a choice: discharge from hospital without delay provided I arranged for a rail to be fitted immediately, or remain in hospital until social services could arrange the fitting. I could not return safely home without the rail.

Enquiries revealed that the earliest the hospital could arrange a home visit with me to assess the need for the rail, make a referral to the local social services, co-ordinate fitting the rail and enable my hospital discharge, involved a delay of at least a week. This meant staying in hospital longer than medically obliged. Alternatively, a friend and a relative could personally obtain the rail and a private builder (who happened to be doing work in my home at the time) could do the fitting immediately. I would need to pay for the rail and a small amount to the builder. Despite the depressing prospect of trying to reclaim costs from social services the advantage of immediate return to my family really gave me no healthy alternative. I say 'healthy alternative' because, quite apart from saving the health authority a week's hospital bill and the local authority costs of non-essential OT time, the inaccessible bed and toilet on the ward meant I was rapidly deteriorating into an unhealthy state of absolute dependency.

The rail was fitted and I returned home.

PROVIDING 'CARE'

The rail proved completely satisfactory and no 'care' professional has ever raised any concerns about the fitting. Naturally it took a little while to savour the effects of the stroke and begin the process of resuming an independent spirit. As soon as I was able I contacted Ms Kerry Rushdon, the pertinent OT at Haringey Social Services, to request payment for the rail. She was absolutely adamant that no payment could be made because I had the rail fitted without going through the right procedures. Bewildered by this apathetic response to an initiative, that undoubtedly saved the 'caring' professions time and money, I asked if I should now have the rail removed so that social services could fit a new one according to correct procedures? Any independent spirit I might have audaciously expressed was swiftly crushed. With the confidence of the morally 'right' I was told in no uncertain terms that if I did that I would go on a waiting list for the replacement!

Well now, let's see if I understand the rules correctly: I should have acted the total 'fool' and slavishly accepted the subservient patient role of dependency in order to obtain a service that everyone agrees I needed from the 'caring services', or be punished for taking an initiative

in regaining my own independence. In practice, then, the 'care' philosophy ('Modernising Social Services') appears to mean inhibiting intelligent patient self-management.

As a former employee of the NHS I was taught that being a 'professional' entails flexible decision making about the level of 'intervention' and appropriate allocation of resources. 'Professionals' used to have responsibility for their own actions; within guidelines but not entrapped by them. Sadly in this, my most recent experience of 'care', such professional judgements were not allowed or attempted. Does the provision of 'care' have to be a technical process that is merely managed by an anonymous functionary? Technicians, of course, can exercise some judgement but, more importantly, this role does not preclude compassion, courtesy, sympathy, or concern about one's state of health, etc. - i.e. an expression of 'care' in the most positive sense of the word. Regretfully, I have to say that in all my contact with social services on this matter I was never asked: "How are you feeling?"; "Was there anything else that I needed?"; "How else may we help?"; and so on. This was definitely not a therapeutic experience!

In my need for a bathroom rail I cannot help but conclude that Occupational Therapy is not about being 'occupational', it is not about providing 'therapy', and it is also not about being a 'profession'. So what is OT for disabled people living in the community? In practice a coherent philosophy for the 'profession' within the framework of 'community care' has proved elusive. This appears to have little to do with poor pay and conditions of work. Perhaps, then, in Therapy Weekly it is no surprise that within the Professions Allied to Medicine (PAMs) OTs consistently bemoan their insufficient numbers and lack of status.

Is de-professionalising the statutory education, health and welfare services, while maintaining worker illusions about who and what they are, the hidden agenda behind modernising public services? Transforming professionals into rule-following technicians who rigidly follow a covert cost-cutting agenda appears to be an extraordinarily effective way of making changes that otherwise would be instinctively resisted.

PROVIDING 'SUPPORT'

There can be no permanent vacuum in the provision of services that disabled people really want and need. If these services are flawed or do not exist they will inevitably be created. This process started some time ago when, for example, Ken and Maggie Davis, using their experience of alternatives to institutional 'care', went on with other disabled people in Derbyshire to found the first Centre for Integrated Living (CIL).

In my view CILs have not only been delivering embryonic services but seeded the momentum toward a new community based profession. However, if this is to be successful, and avoid the morass into which PAMs have fallen, then such a new profession will have to be a robust Profession Allied to the Community (PAC).

With this fundamental shift, both in focus and alliance, PACs could freely develop in harmony with disabled people's aspirations. There would then be no need for 'care' services to plug gaps believed to be caused by disabled people's personal deficits. Even as long ago as 1986 the 'care' professions were alerted to this inevitable shift in focus:

'We need personal assistance (not care) which will facilitate our desire to achieve full social integration.' Wood, 1986

While PAMs and 'community care' academic courses for practitioners in the health and social services continue to flounder in an intellectually bankrupt 'care' philosophy, developing a PAC could bring into production a virgin field for fertilising, cultivating and reaping user and service provider aspirations. Such an alliance has the potential to reintroduce innovation, initiative, excitement and personal reward in delivering the community based support that disabled people want.

CONCLUSION

Changes in personal circumstances can be a salutary experience. Having a stroke has not only added to the richness of my life but personally highlighted the quagmire into which health and social services for disabled people are floundering. The failure of established views about 'disability' have already triggered new approaches to service provision. We have seen, for example, a number of issues raised during the controversy about vouchers for wheelchairs, but perhaps little

debate about where the line should be drawn in the use of such vouchers. My recent experience in obtaining a bathroom rail makes me wonder whether we should now campaign for vouchers for all home equipment? Reducing humiliating contact with the 'care' professions is unlikely to make matters worse than at present?

Perhaps, then, the time has arrived for a public debate between representatives of organisations of disabled people and representatives from the 'caring' professions. I am sure that there would be no difficulty in putting forward names of speakers from the disability movement to debate:

Community care services for disabled people based on the assessment of need and managed by PAMs demean both workers and users. They should be replaced by services based on the identification of aspirations managed by PACs in an alliance of workers and users.

REFERENCE

Wood, Richard (1986) Disabled People Point the Way Forward. Social Work Today (21 January 1986) pp.23-24

Professions Allied to the Community (PACs) II

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INTRODUCTION

In my previous article I highlighted my experience of the way health and welfare practitioners appeared to equate professional decision-making with technical duties reliant upon rule-following consistency. The decline of 'professionalism' while maintaining an illusion of expertise in decision-making in the 'modernised' health and community care services is surely one of the wonders of our era. 'How have the Professions Allied to Medicine (PAMs) allowed this to happen?' was a question that repeatedly troubled me as I came to terms with a range of sympathetic and apathetic professionals on returning home from hospital after my stroke.

One answer is that academic and training courses have been very effective in diverting practitioner skills onto the identification of an itinerary of criteria for intervention (expertise in form-filling) rather than the art of handling the complexities of flexible clinical decision-making. Cultivating worker satisfaction in 'correct' form-filling appears to be an essential qualification for the 'modernised' professional 'care' worker and academic institutions are unashamedly competing in this lucrative market. It seems curious, however, that there is so little discussion about form-filling skills being merely a rehearsal for technical proficiency in feeding computer compliant data into computers, which will then decide resource allocation. Far from enhancing the status of the 'caring' professions (PAMs), compliance with the deskilling practice inherent in 'Modernising Social Services' will eventually completely destroy any vestige of 'professionalism', in the very best sense of this word.

WHO 'CARES'?

My recent sample of the 'modernised' chiropody service seemed to capture the very essence of this de-professionalization process:

Perhaps not surprisingly, having a cervical spinal injury resulting in tetraplegia followed by a stroke, rendered toe and finger nail maintenance a little beyond even my ingenuity. My GP referred me to the chiropody service and a home visit was duly arranged. On the chiropodist's arrival I was obliged to feed information into one of the longest forms I have yet encountered. I of course complied by adopting the usual 'fool' role expected from a subservient disabled patient and answered all the questions without even joking that all the information was available in the referring GP's file. I even raised no objection when a sample of blood was taken from my finger without any explanation! (Mentally, of course, my mind was wild with speculation -something to do with detecting vitamin deficiency, etc., so that advice could be offered about the health of my nails; testing for the HIV virus?)

My toe nails were expertly cut and filed and the chiropodist then began packing away her kit. I was surprised by this because it was obvious that attention to my finger nails was long overdue and it was clear that these were going to be neglected without a word of explanation! The compliant patient was forced to change demeanour and ask a question. I enquired whether she would cut my finger nails (thinking maybe their condition hadn't been noticed)? Somewhat flabbergasted by the fleeting reply - that she was not insured for attending to fingers -I then naïvely expected to be informed who would provide this 'care': perhaps in the 'modernised' services one technician dealt with toes and another with fingers? But she volunteered no further information and continued packing her kit.

I tried to regain my composure after this worrying problem was impassively dumped on me by the 'caring' chiropodist. She proceeded to examine the blood sample test taken earlier. Adopting an all too obvious demeanour of sincerity, that she must have been taught to use in these situations, she announced that there was no indication of diabetes! This information was imparted as if she was giving an anxious patient good news. Now I was totally bewildered - the chiropodist could not provide necessary finger nail attention but she could give an unsolicited medical opinion (the mind boggles at the legality of this)! I was trying to make sense of this farcical situation as she closed up her equipment box and informed me that as I did not have diabetes she would not be coming

again. She proceeded to fold some leaflets which she then tried to pass on to me without further ado, except to indicate that the leaflets contained information which I might like to have.

Sadly I must confess that at this juncture I exploded. Why had she bothered coming at all -what was the point of handing me leaflets when the reason for obtaining a GP referral was because I could not manage on my own and I had no one to assist me; why insult my integrity by conducting a test, the result of which I (or my GP if disabled people cannot be trusted) could have informed her over the telephone; why service half my nails and then leave me with the urgent need intact? I calmed down and asked her where I might obtain the professional expertise that actually was needed, but in a terse response I gathered that even this information was not forthcoming.

I exploded again (and squirm at what could be recorded in the case notes), declaring that she was behaving like an automated technician with no freedom to decide what was appropriate for me on the basis of her own professional assessment. This seemed to hit a raw spot and for the first time she seemed genuinely animated. She was a 'professional' she asserted and had fully qualified.

So, sadly this is what matters have come to; it is a fancy piece of paper that makes one into a professional. It's not what you do but what certification you have that is the defining feature of the modernised health and social welfare worker.

As she left I felt my long finger nails and wondered where other than in the health and social welfare service could workers actually maintain so many illusions about the quality of the work they were providing -can anyone imagine half a car service because the technician is insured for the front and not the back of a car ?

CONCLUSION

In all my contact with the community-based professions following my stroke extensive forms were completed but in the end the factor that determined whether or not I was to receive a service was dependent upon predetermined criteria embedded in an assessment form. No personal clinical judgements were ever required.

Not that long ago literature aimed at the 'caring' professions was awash with concern about assessing the 'needs' of disabled people as a requirement for providing better services. Now this seems to have vanished. Then we were inundated with discussion about 'empowering' clients. This concern too seems to have disappeared. Now interventions appear to be unashamedly determined by bureaucratic rules. My access to physiotherapy was ruled 'out of court' because I do not have contractures and the Rehabilitation Team (occupational therapist, physiotherapist and social worker) could not provide any assistance because I did not require more than one service (the knock-on effect of obtaining my own rail in the bathroom).

'Able to make you able', I see, is the latest adoption for the 1999 OT Day (Therapy Weekly, 7 October 1999, Vol. 26(15), p.1). As far as disabled people are concerned I cannot think of a more apt expression of the way 'assessment of needs' and 'empowerment' have been abandoned in favour of verbiage. The point about 'disability', of course, is that the individual has a permanent impairment and consequently the central issue is environmental restriction: making the physical and social world accessible to us. Making people 'able' is a medical goal that, outside advances in medical science, not even that profession would so grandly prescribe for us. While we might understand why professionals with abilities see the world in their own image there must surely be some awareness that after such fundamental 20th Century advances in disability studies it is meaningless if not actually offensive to confront disabled people with the phrase 'able to make you able'? This is one thing OT's cannot do.

But then unreal aims, confused objectives, increasingly restrictive practice and widespread illusion about what a 'professional' is, appear to be the hall mark of the modernised health and community care services. I cannot help feeling, when I contemplate the rigid restrictions imposed on 'caring' practice, that in this respect PAMs are very 'disabled'. External barriers imposed on the ability to control one's own decision-making touches the very essence of 'disability'. While it may make sense to provide 'care' for children and people who are ill this approach to service provision is totally misplaced for disabled people and I am sure other population groups. In my view there is absolutely no chance of

solving the 'PAMs' recruitment and retention problems' (Therapy Weekly, 7 October 1999, Vol. 26(15), p.5) and there is absolutely no chance whatsoever of 'Modernising Social Services' succeeding as long as these are guided by a 'community care' maxim and the hidden agenda is to disable decision-making in health and social welfare.

Perhaps I can be so bold as to suggest that it might only be disabled people who are 'able to make the PAMs able'. We have learnt that the counter to the disabling restrictions kept alive by a narrow dependent attachment to medicine (as in the PAMs) lies in changing orientation and developing support systems that are responsive to self-defined aspirations in the community. Centres for Integrated Living (CILs) are one structure created by disabled people to service such aspirations and, in my view, workers in these centres are an embryonic Profession Allied to the Community (PAC). This professionalisation process exactly replicates the progress made by women when they created their own midwifery service rather than seeing themselves as woMEN (!) with support needs wholly defined by males. User generated support services create opportunities for harmonising user and provider needs and at the very least avoid falling into the trap of seeing disabled people as disABLED (!) with support needs wholly defined by people with abilities.

Allying service development with community based aspirations requires substantially different worker attitudes and guidelines for providing professional assistance. Setting up CIL services involves a transformation in the way disabled people think about themselves and the public identity they wish to cultivate. In my view this has been the beginning of a journey in which a whole new cultural matrix of human relationships is waiting to be discovered. If PAMs do not wish to become increasingly alienated from the communities they are supposed to serve I can only suggest they join disabled people in their instinctive opposition to 'care' and make their own unique contribution to the new PAC service structures that, one way or another, will emerge over a period of time. Growing health and welfare service user self-confidence inevitably means there is less and less willingness to participate in training and academic courses that feed the 'care' debacle.