Getting our house in order

Physical impairment seems to have always been part of human existence. In the oldest of remains archaeologists find evidence that humans incurred severe, deforming injuries and still went on to live for many years. At some point this physicality took on a social meaning, and at least as far back as the first century AD, physical impairment has been stigmatised (e.g. as challenged by Jesus in John 9:1–12). As I am a disabled woman who is registered blind, I decided to investigate how contemporary society perceives disability; and because I was training to be a counselling psychologist at the time, I thought the field of psychology was an appropriate place to look. What beliefs, implications and assumptions regarding disability are revealed by and embedded in modern psychological research?

One of the first things I discovered was that there is an alternative to the traditional medical model that seems to dominate our society’s understanding regarding disability. Shakespeare (1993) differentiates between physical impairment and disability, asserting that the former refers to the embodied restrictions of a certain physical state, whilst the latter is the consequence of a society that categorises the former into a socially devalued and disempowered position. Such oppression stems from an environment that is hostile towards disability, in which physical and social barriers inhibit personal choice. This conceptualises disability as diversity within the human condition, rather than as a lack of ability (Oliver, 1996).

As disability was likely to be untreatable in the conventional sense, disabled people came to be seen as tragic and less valued than those who could recover from illness (French Gilson & Depoy, 2000).

As psychology developed, it played an inadvertent part in the predominance of the negative view of disability. Burman (1994) asserts that as developmental psychology participated in the establishment and measurement of norms, it created and perpetuated the concept of ‘abnormality’, which was applied to disabled people. This led psychology to focus on the guilt, shame and loss associated with the tragedy of being disabled (Lindemann, 1981), and on the presumed outcomes, such as maladaptive personalities and behaviours (Hersen & Van Hasselt, 1990).

In this article I will look at several different areas of psychological research, starting with how affect and cognitive style were linked to level of impairment.

Affect
Much of the research seems to emphasise the role that negative emotions play in the psychology of disabled people and how this may affect the way in which they experience their physical impairment. Depression seemed to be commonly associated with physical impairment, and Abberley (1987) suggests that such negative representations have given disabled people a detrimental status. Dennis et al. (2000) considered how emotional distress (rather than physiology) affects a person’s level of impairment. The study constructs stroke patients as being prone to emotional problems and links this to outcome after a stroke, measuring this using self-rated questionnaires complemented by information from medical professionals. Similarly, Hansen et al. (2001) suggest that the severity of an individual’s impairment is linked to their mental state. Also, Hommel et al. (2000) propose that psychological factors are as integral to disability as physical factors, suggesting that cognitive appraisal may affect the management of rheumatoid arthritis.

This seems to move towards an assumption that level of impairment is intrinsically linked to an individual’s emotional and cognitive characteristics. This focus on subjective qualities maintains a traditional focus on the individual as deficient, which minimises the need for change on an institutional or social level, as well as overlooking any contextual or societal factors affecting level of impairment. Also much of the research relied upon professionals’ assessments of the participants, which seems to place them as passive subjects. Often recommendations were made to change the individual’s way of behaving or thinking in order to facilitate improvement or rehabilitation. This may reflect psychology’s individualistic focus, as well as its assumption that disability will have a negative impact upon a person, which needs to be ‘cured’.

Quality of life
Quality of life (QoL) has been adopted by psychology as an outcome measure even though some assert that the concept remains poorly defined (Holmes et al., 1997). Research often seems to make a direct link between impairment or disability and QoL, implying that the former affects the latter. Much of the research (e.g. Koplas et al., 1999; Wahl et al., 1999) does not incorporate the participants’ own perspectives on their quality of life, relying instead on clinically or physically defined criteria. Meyers (2000) asserts that research on QoL displays a historical bias, focusing on the...
problems, which may affect the therapeutic relationship. This seems to echo the presupposition that disability fundamentally affects one’s personal attributes, which is evident in much psychological research. However, Chaudhuri goes on to assert that the therapist can work with their disability, using it to explore transferencial issues and facilitate a much-needed opportunity to consider the impact a therapist has on therapy. He feels that psychoanalysis needs to find a better understanding of disability, moving away from a purely negative concept of it as symbolic of death and castration anxiety.

Still much to do!
The research I looked at was only a tiny sample of the work undertaken regarding disability, and my search stopped at 2001. I wonder if the picture has changed significantly in the last four years, or whether this is still an indication of some of the attitudes present within psychology? Are traditional medical perspectives of disability still predominant? Is disability still perceived as a largely negative phenomenon, associated with negative affect, lowered quality of life and diminished sexuality, as well as provoking anxiety in others? Or is disability research finally catching up with work done regarding other socially oppressed minorities in the areas of race, gender and sexuality?

Overwhelmingly, the assumption seems to be that disability is a physical problem, affected by an individual’s thoughts and behaviours. The research rarely considered any social or contextual issues that may contribute to the experience of being disabled. Furthermore the research seemed to treat disabled people as a homogenous group, sharing traits and experiences, with little or no consideration given to how such a category is defined or what diversity may exist within it.

The paradox is that psychological theory regarding disability will not evolve without fresh perspectives provided by research. But the research seems to be based on, and thus perpetuates, traditional, largely negative presumptions about disability and disabled people. Therefore, psychological practitioners need to be aware of what representations and assumptions they hold regarding disability, as well as how the institutions they train and work in deal with the topic of disability.

This is particularly important because psychology as a discipline plays a central role in the diagnosis, treatment and rehabilitation of disabled people. Thus such reflection is necessary in order to avoid perpetuating the past pathologising of disabled people, which has reinforced their status as ‘other’ and abnormal. In order to challenge such discrimination, psychologists need to research issues that are relevant to disabled people based on their perspectives and which embrace diversity, making space for a variety of perspectives on disability.

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DISCUSS AND DEBATE
Is the medical model of disability still prevalent within psychology and the NHS?
What do you think the implications of the Disability Discrimination Act are for psychologists?
Do you think disability issues should be treated as a separate field of study within psychology?
Have your say on these or other issues this article raises. Write to our Letters page or e-mail thepsychologist@bpsi.org.uk or at the Leicester address – 500 words or less, please. Or you can contribute to our online forum on this or any other topic – go to www.thepsychologist.org.uk.
Parents of disabled children face all the usual challenges of parenting: how to teach their child to sleep through the night; how to help them develop independence; how to ensure they are successful, academically and socially. But because we live in a society that views disability as a tragedy (e.g. Barton, 1996), parents of disabled children are likely to experience additional parenting challenges, such as coping with family and friends’ responses to disability. Furthermore, caregiving demands can provide a daily challenge, with child behaviour problems frequently reported (e.g. Roberts & Lawton, 2001). What help is available to them from psychological theory?

Importance of cognitive change
Recent research has focused on effective use of cognitive change in adapting to parenting a disabled child. For example, Lustig (2002) found that cognitive reframing of problematic events as manageable, rather than passive acceptance that parenting a child with a disability is problematic, was associated with family adjustment. Parents in another study (Scorgie et al., 1999) reported learning to think of their children as ‘children’ rather than ‘disabled children’, and viewing themselves as parents rather than therapists. Scorgie and Sobsey (2000) reported changed perception of what was important in life in three areas: personal growth, relations with others, and overall values. Parents in this study reported greater compassion, stronger marriages, expanded friendship networks, and making the most of each day.

But why is cognitive change required? Perhaps sharing societal beliefs about disability being a tragedy isn’t compatible with effective parenting of disabled children. Parents of disabled children may have a particular set of social-cognitive dimensions to address and may need to develop new attitudes and beliefs about disability in general and their child’s disability in particular. For example, when considering the area of problematic behaviour in disabled children, I have suggested (Woolfson, 2004) that viewing behaviour problems as part of the disability can hinder parents from teaching their children discipline as they would with typically developing children.

Which frameworks might help?
It is important then for us to understand parents’ beliefs about disability and about child-rearing. Only in this way can proposed interventions be tailored appropriately to parents’ needs. Psychological frameworks that have been applied to other areas can usefully be applied to this field.

For example, the self-regulation model (Leventhal et al., 1992) provides a valuable framework for exploring patients’ views of their illness and how these regulate coping outcomes. The key idea here is that patients’ beliefs about their illness, for example what impact it will have on day-to-day living or whether it can be cured, play an important role in how they cope with that illness and in health outcomes. It is currently being used in the field of adult chronic illness, for example with Huntington’s disease (Helder et al., 2002) and irritable bowel syndrome (Rutter & Rutter, 2002), to investigate patients’ cognitions about the nature, length, cause, outcomes and curability of the conditions.

These dimensions may provide a useful framework for exploration of representations of disability, as for illness. Furthermore they may be applicable beyond regulation of self, as in the model, to regulation of other, where the focus is on parents’ beliefs about disability not in themselves but in their children. Parents’ beliefs about their child’s disabilities across the dimensions of nature of condition, causes, consequences and extent to which the condition might be cured or controlled, might similarly impact on parental coping, parenting behaviour and child well-being outcomes (such as child behaviour and social adjustment).

Another valuable framework for examining people’s beliefs about what has caused a particular outcome is Weiner’s
Have your say on these or other issues this article raises. Write to our Letters page on psychologist@bja.org.uk or at the Leicester address—500 words or less, please. Or you can contribute to our online forum on this or any other topic—go to www.thepsychologist.org.uk and follow the links.

**DISCUSS AND DEBATE**

What does responsibility and control mean for a child with severe learning difficulties and communication impairments?

To what extent can psychological models of illness be applied to disability?

A parenting paradox

So we have a thorny situation. On the one hand, attributing responsibility to the child for problematic behaviour is linked with parental negative emotional reaction that is itself associated with harsh parent behavioural responses (Graham et al., 2001), and aggressive child behaviour (Dix & Lochman, 1990); on the other hand, in order to begin to effect change in their children’s behaviour, parents need to view their children as having some responsibility and control over their behaviour.

Like parents of typically developing children, parents of children with developmental disabilities can also try to teach their children how to behave in more socially acceptable ways. Of course, many parents will not require professional interventions to address this; but for those who do, involvement can focus on three key areas. Certainly advice on strategies for management of their child’s behaviour will be a key area. But in order to help parents effect change in their child’s behaviour, psychologists may also need to help them identify cognitions about responsibility and control that may be barriers to planned strategies. Where parents view difficult behaviour as a necessary part of the child’s disability, psychologists can work to persuade them that behavioural improvement is something that parent and child can try to address, even though goals for change may be modest. Parents of children with cerebral palsy reported examples of such cognitive shifts following an early intervention programme (Woolfson, 1999), e.g. ‘I try now not to let her get away with things because of the cerebral palsy’, ‘I do check her now because she’s got to learn’. Parents in this study reported the positive effects of taking an active approach with their children: ‘I feel as if I’m actually doing something to help her. I feel much better about her and me.’

For some children with severe disabilities, behavioural change will be difficult to effect and even small changes will require considerable parental perseverance. Some of my most recent research suggests that parents of children with learning disabilities who used behaviour control in their parenting experienced more stress than parents who were more laissez-faire in their approach. Trying to achieve behavioural change, with its implications of parental and child responsibility and the negative affect that may be associated with this, suggests that a third key area for psychologists is provision of emotional support for parents who are engaged in such an emotionally demanding task.

**References**


Community psychology
Towards an empowering vision of disability

Is psychology a source of oppression for disabled people, or a resource for enabling individual and collective empowerment? Historically, psychology’s impairment focus has risked presenting a personal tragedy view of disabled people. This must not remain the case.

British disability studies – the radical academic and social movement that has given rise to the social model of disability – demands that psychologists rethink their understandings and practices in relation to ‘impairment’ and ‘disability’. If psychology is to be of relevance to disabled people then it needs to discard its view of impairment-as-tragedy; question why people with impairments are socially excluded; and, crucially, include disabled people in research processes that aim to challenge this exclusion. We suggest that such challenges can be met through bringing together the ideas of community psychology and disability studies.

From impairment to disability
Psychology’s vision of disability is still, predominantly, a functionalist one: disability is the consequence of bodily or cognitive deficits (Goodley & Lawthom, in press; Swain et al., 2004). By allowing such a vision to dominate, psychology has indirectly or even directly contributed to the proliferation of an ‘individual model of disability’ (Oliver, 1990, 1996). This model can be found in the Disability Discrimination Act 1995, which defines disability in terms of a long-term consequence of impairment:

...a person has a disability... if he has a physical or mental impairment which has a substantial and long-term adverse affect on his ability to carry out normal day-to-day activities (Disability Discrimination Act 1995, s.1(1)).

Definitions such as these say something very simple – that impairment, whether it be physical or ‘of mind’, results in and creates disability. Following this, ‘impaired thought’ leads to a myriad of disabilities – disabled thought, disabled learning, disabled interactions with others, disabled personal relationships, disabled sex lives and disabled parenting (Goodley, 2000).

This seemingly unproblematic relationship between impairment and disability has been challenged by disabled people and their representative organisations. In 1976 the Union of the Physically Impaired Against Segregation (UPIAS) made a ground-breaking distinction between impairment and disability:

Impairment – lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.

Disability – the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities (quoted in Oliver, 1990, p.11).

These definitions direct the ‘social model of disability’ to uncover the ways in which society disables. Impairment and disability are not synonymous terms (Morris, 1996; Oliver, 1990). Instead disabled people are just that – people disabled by a contemporary social, economic, cultural and political climate on the basis of their purported impairments. This raises particular challenges for psychology and psychological research. In what ways can psychologists contribute to understanding and changing a disabling world?

A key feature of research that has emerged from British disability studies is the call for emancipatory disability research (see the 1992 special issue of Disability, Handicap and Society). This approach insists that disabled people must occupy meaningful, involved and
participatory roles in the research process, while directing research to challenge those social, cultural, political and relational barriers that continually threaten to exclude people with impairments from mainstream life. This is where psychology can play a real part – in particular the work of community psychologists.

Towards psychology for all
Community psychology (CP) is a set of approaches, values and beliefs. The view of psychology promoted by CP is inherently political. It situates psychology as a liberatory space (Kagan, 2002; Martin-Baro et al., 1996), in which researchers and theorists armed with theoretical and practical knowledge of the social and interpersonal world, aim to work alongside communities towards positive social change. The psychology of CP is one collectively owned by communities and pushed forward by the members of those collectives. This is not an individualised cognitive phenomenon. Instead, psychology is up for grabs – particularly by those communities whose psychologies have been traditionally pathologised by labour markets, poor housing, welfare dependency and material poverty. CP aims to work alongside community members to understand identities, behaviour and membership in the terms of the communities in which they are situated.

Working with people rather than on people often demands an action research approach. In contrast to other ways of measuring and monitoring human experience, CP takes social change and social action seriously:

Psychology as a liberatory space – aiming to work towards positive social change

A liberated academic psychology must position itself in solidarity with those who are marginalized and have hitherto been without a voice in the discipline, or indeed in society (Kagan, 2002, p.10)

Community psychologists work within an emancipatory paradigm, sharing information, collaborating with people who are experts about their lives, working with people often marginalised by the social system and working towards empowerment. This is a distinctly different agenda to the investigatory model of research that dominates the mainstream social sciences (Oliver, 1999).

In summary, CP can be viewed as a branch of psychology, a revolutionary paradigm of psychology, a counter-hegemony to much of psychology’s individualism. Its interdisciplinary context brings together politics, sociology, social policy, health and social welfare and economics. Crucial to most conceptions of CP is the notion of working alongside the primary source of knowing and thus the primary instrument of research: ‘the self-directing person within a community of inquiry’ (Reason & Heron, 1995).

We believe that psychology can become relevant to disabled people when we start addressing the problems and questions deemed important by disabled people – such as discrimination (Barnes, 1991), employment opportunities (Roulstone et al., 2003), inclusive education (Vlachou et al., 2003), inclusive education (Vlachou et al., 2003), inclusive education (Vlachou et al., 2003), inclusive education (Vlachou et al., 2003), inclusive education (Vlachou et al., 2003), public access (Tregaskis, 2003), self-advocacy and self-help (Goodley, 2000).

In an example of the union of disability studies and CP, Kagan et al. (in press) report on an innovative approach to working with people labelled as having profound and multiple learning difficulties. During the planning process service staff, family members and other people labelled with learning difficulties took part in training and cultural change. Beyond this, some family members and some people labelled with learning difficulties engaged in raising awareness about it more generally, by establishing a mentoring scheme across the service and more widely.
to include people living in other parts of the region. The mentoring scheme, over a period of two years, became widespread. When the ‘person-centred planning’ was finally introduced, people labelled with learning difficulties and family members were, indeed, central to the process and could participate on an equal basis with professionals using any one of a range of creative ways of participating, including drama, life story work, advocates and ‘circles of friends’. Moreover, family members had developed skills not held by professionals in working with all stakeholders, training and mentoring other professionals and non-professionals alike.

This type of community psychological work engages with disabled individuals (using the social model), works at the level of the culture of the service organisation supporting them, and works with parents of people labelled with learning difficulties. The outcome is a more sustainable process of raising awareness of personhood which has wide ramifications of engaging with individuals. Research and professional practice, however, is political activity (from DoH papers to RAE submissions). Giving psychology away and working with non-professionals, sharing skills and competencies, possibly disrupts professional boundaries and training. If psychology is to be a 21st-century psychology then funding bodies, journal editors and psychology academies need to reframe what psychology can look like, who it involves and how it may work.

Community psychological understanding (here, with disability studies) frames psychology as potentially enabling for professionals and non-professionals alike. The time is long overdue for psychology to oppose its disabling tendencies and, instead, promote an enabling psychology of disability. What we envisage is a time when psychology is viewed by disabled people as a resource for
  ● changing the conditions of disabling society;
  ● redressing disabling cultures and communities;
  ● developing theories of ‘disability’ and ‘impairment’ that emphasise the disabling environments over impaired bodies;
  ● promoting approaches to research that meaningfully include disabled people in the analysis of the disabling world; and
  ● changing psychological practices that disempower and pathologise disabled people.

CP and disability studies allow key resources for such emancipatory developments to progress.

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References


Listening to the disempowered

ANY individuals and groups in society are denied opportunities to express their views about their own best interests. People with mental illness, people with dementia, learning disabled people… all these groups may lack the power and control necessary for their own well-being (Orford, 1992).

Some attempts have been made to access and disseminate silenced stories in order to empower individuals and challenge common preconceptions (e.g. Plummer, 1995). Morris (1995) reports disabled women’s experiences and advocates creating a space for their absent voice, in order to bring about changes in services that will meet the needs expressed.

The service-user voice is thus the key to gaining a new perspective on current services as well as to developing more appropriate ones (Bowes & Dur, 2000). Creating opportunities for hearing hitherto silenced voices becomes the driver of effective service delivery.

Adults with learning disabilities are one of the most oppressed and silenced groups of all, and the self-advocacy movement has attempted to give them a voice and challenge societal oppression (Goodley et al., 2002). The Department of Health (2001) has begun to address this in the White Paper Valuing People: A New Strategy for Learning Disability for the 21st Century, with a focus on rights, independence, choice and inclusion. One area highlighted for change is housing, making it a government objective ‘to enable people with learning disabilities and their families to have greater choice and control over where and how they live’ (p.70).

In this article we listen to the views of adults with learning disabilities about housing. As a significant area of decision making, it is an ideal vehicle through which to explore the question of whether service users’ voices are being heard. Essentially, it represents a case study within the broader context of the need to listen to the voices of all disempowered groups, to ensure that they have greater power and control in their lives.

Consulting adults with learning disabilities

For the past two years or so we have been commissioned by our local authorities to work with communicative adults with learning disabilities. The findings are used by the authorities to plan for and secure the sort of accommodation that service users tell us they want, in the localities they favour and with the facilities and services they tell us they need. For example, single occupancy in supported living, close to their day centre and with the sort of independence that most of us take for granted: freedom to come and go, have pets, to be visited by family and friends.

All of our work foregrounds the views of service users, although it does also include those of carers and support workers. However, in this article we focus exclusively on service users themselves. We know from the literature that the service user’s voice is far too often omitted when decisions are made about where and how they live (see Glynn, 1998). They have told us that too often their own carers and support workers either do not listen to, or are not hearing, what they have to say. It has also been suggested that a lack of knowledge about the needs and preferences of service users is the most significant barrier to an effective housing strategy: Foord et al. (1998) emphasised ‘the lack of a comprehensive structure for bringing user voices into the system’ (p.16).

In our research (McGlaughlin & Gorfin, with Saul, 2004) a total of 231 service users living in various settings were selected from local authority data sources, of whom 147 participated in the semi-structured interviews. The remaining 84 were not involved because of personal circumstances or lack of formal communication skills. This is not to say that this group’s views are inaccessible, but obtaining their views does require imaginative communication strategies (see Williams, 1990). The development of strong relationships and learning how people communicate through non-verbal cues are crucially important (Morgan, 2000). These advanced communicative strategies required were beyond the scope of this project, but there is an urgent need for other research to address the views of those who do not communicate verbally.

Of the 147 service users interviewed, 125 considered their housing suitable for their needs, 60 said that they would like more independence and 15 more support. However, we do not know the extent of their experience with alternatives or their level of expectation with services. Where additional support was requested this was to facilitate independence, for example developing skills or assistance with finances. When asked whether they would choose to live where they live now or somewhere else, 49 stated that they would like to move either now or in the future, with 44 stating a preferred type of alternative provision. Of these, just over a third want self-contained accommodation and almost half want to share a house, ideally with between one and three other people. What is wanted is ordinary housing with greater independence, suggesting that more individualised approaches to housing provision are required. The other five who would like to move but were unsure of options need readily accessible information and support to help with this decision.

The sense of powerlessness was striking, with some service users finding it...
difficult even to comment on their housing, considering it as outside their control. Instead, they often viewed decisions as the remit of professionals and family carers. This is highlighted in this quote from Ann (all names fictitious), who is living independently yet still views her housing as within the control of her family:

It’s not up to me – it’s up to my niece.

However, many service users were well able to discuss their preferences, to think through potential options and to make their own decisions. For many, their key aspirations were increased independence and having a home of their own. Emily told us:

This isn’t the place for me. My heart’s not here. If I got the chance I’d love to have a flat, a flat of my own, to have my independence back. That’s what I’d like in the future. I’d love to live on my own. To have my life back.

These are things that most people take for granted, but which remain difficult for these service users to achieve. They could articulate their preferences, but felt powerless to realise them, stating that they have no choice. For example:

I feel so angry, I’ve got no choice. I want to move, I feel like I’m ready to move. If I said anything to the staff here, they’d say ‘no chance, they’d say ‘no way’.

I want to choose for myself, but they don’t listen. It’s like a dream – it’ll never come true. It never does, does it?

The lack of choice described by service users highlights their belief that professionals restrict and control them. This is also something that families may do; interviewees often stated that their decisions were controlled by parents:

We went to see a few places, but Mum decided on this one. I would’ve liked a bit more choice.

Other interviewees commented that their request to move had been overridden by their parents. For example:

I asked my mum if I could move, and she said, ‘No, you’re not, you’re stopping where you are.’ She won’t talk about it.

By contrast to the powerlessness experienced by many, there were some examples of clearer control. Gayle’s voice has been heard, resulting in an active plan for her future housing:

I want my own flat; I’m working very hard towards that. I’m working with the team to get the right place, somewhere I like and that. I’m taking small steps towards it, taking it one day at a time. It’s what I want. I want supported living.

By stating what she wants, Gayle indicates greater control. She has discussed options and is more positive and informed about them. This emphasises the importance of accessible information in enabling such service users to make informed decisions.

A move into more independent housing had been achieved by some, and was something they were proud of. As Matthew says:

I like it. I’ve always wanted to live on my own. I know these other places – they tell you what to do, when to go out and all that. I want to do what I want to do, to be independent. I wish my mum could see me now, living on my own and doing well for myself.

Being in control of his life is clearly very important to Matthew, and this is echoed by Thomas:

It’s the best thing that ever happened to...
me in my life. I like to be on my own, my own boss. I suffered a lot of depression where I lived before, I was ready to move on. I couldn’t live in a place like that. It’s made a big change to my life. I’m really happy for the first time.

Thomas clearly illustrates the positive impact of empowerment, on his quality of life. His emphasis on becoming his own boss exemplifies the central issue in this research; the essential importance of service users having power and control over their lives.

A role for psychologists
These findings point to a need for a cultural shift whereby the voices of adults with learning disabilities are heard and acted upon. While the views of professionals and carers are important, they should not override those of service users who are the fundamental experts about their own needs and preferences.

Psychologists, because of their interviewing and interpretative analysis skills, are in a strong position to listen to service users with a learning disability, and other disempowered groups.

Future research and practice must maintain a focus on the user voice to ensure that services are informed by the views of those who actually use them. In this way adults with learning disabilities and all disempowered groups should become more powerful agents in relation to their housing and in all aspects of their lives.

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THERE is no such thing as a typical working day for a neuropsychologist working in a rural area (or for that matter, working in an inner-city area). An amalgam will have to do. Here the day usually starts with a drive, not to a base, but into the communities where the people live who use our service. Map reading, patience with slow-moving tractors and route planning are important non-clinical skills.

A map of the UK can easily mislead one to think that North Wales represents a small geographical area. Closer inspection of a detailed map reveals mountains and twisty country roads crossing sparsely populated areas. Both English and Welsh are spoken widely. Our service covers six local authorities (three NHS trusts). It is a multidisciplinary; community-based neuro-rehabilitation service. We have strong links with the School of Psychology at the University of Wales in Bangor. People referred to us are seen at our unit, GP surgeries, nursing homes, community hospitals, district general hospitals and, often, at their homes.

‘Canol-y-dref/Town centre’: the road sign directs us to the GP surgery for our first appointment of the day. The person we are seeing had meningitis and was discharged from hospital a couple of weeks ago. Now he is easily fatigued, anxious and finds it difficult to remember things. Our social worker asks about the support he is finding it difficult to remember things. Our service provides the potential lack of anonymity can be a problem; employment and educational opportunities may be fewer, but local employers may sometimes be more accommodating; poor public transport can limit access to recreation and other activities, but by default stimulate local community projects.

On the way back we review someone known to our service for three years now. He sustained a severe traumatic brain injury as a young boy, more than a decade ago. He has recently encountered difficulties at work, which our occupational therapist is attempting to address. Following up service users where they ultimately live provides a unique opportunity to learn about what actually happens to individuals and their families after sustaining a severe brain injury. We see how people come to terms with their drastically altered lives and sometimes create new meaning or opportunities; the way individuals compensate for impairments and prevent disability; and how close-knit communities help them do this. The opportunity to learn about these issues helps our practice to evolve and involves those who will support individuals long after clinicians have left.

The diversity of each working day demands careful planning. Experienced administrative staff based at the unit allow us to concentrate on clinical tasks and work more directly in the community. Once a week all members of staff are at the unit for the whole day. On this day we screen referrals, have academic presentations and generally catch up with administrative tasks.

We leave the unit during the early afternoon. Two of my colleagues join me. We are going to a nursing home where we will attend a multidisciplinary review meeting. The placement is about to break down. The person we see has very little access to social activities outside the nursing home, because of poor mobility and a lack of funding. She had a stroke five years ago. We decide against the plan of employing a project worker to help with physiotherapy and social activities. She would much rather have the obstacles removed that prevent her family from doing this. We agree with her suggestion that transference of physiotherapy skills by training family members and staff in the home, as well as arranging transport, is the way to go.

Back at the unit it is time to write up the day’s clinical notes. But the day ends with a discussion about what to discuss in peer supervision next week. Although we work in a rural area, we are by no means isolated professionally. Perhaps all psychologists working in rehabilitation, irrespective of setting, can benefit from an awareness of how people with disability are supported by rural communities. The working environment provides opportunities to learn as much from my colleagues as I do from our service users. Without both the job would be meaningless.

To protect anonymity, the people described, while representative of our caseload, are not actual cases.

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Further reading


WEB LINKS
Institute of Rural Health: www.rural-health.ac.uk
Conwy & Denbighshire NHS Trust: www.conwy-denbighshire-nhs.org.uk/
The Brain Injury Association: www.headway.org.uk.