

Seán Gray describes how working from the human givens approach is changing the lives of learning disabled adults in the care homes that he manages.

Enhancing the lives of learning disabled adults

JOHN came to live in one of our houses three years ago, when he was 30. He has a severe learning disability and was first brought into care at the age of seven, when his family broke up. His communication skills are extremely poor and he suffers frequent epileptic seizures.



When he arrived (negative 'labels' had preceded and accompanied him), his impact on staff and fellow residents was traumatic: he had little control over his emotions and his frustration led to violent assaults, including biting, kicking, and pulling people to the ground – sometimes by their hair. Most of his anger was directed at staff but residents were patently upset by the tense atmosphere that permeated the house before and after an episode of John's aggression.

In the past, the most likely outcome in such a case would have been for John's placement to be declared a failure and his removal to a more restrictive facility sought. However, this was not the route we took. Staff were understandably fearful but mostly remained committed to trying to find a way to improve John's life, along with everyone else's. Over a period of months, they worked hard to gain insights into John's own needs and to recognise the frustration that arose from his limited ability to recognise and to meet them. We all began to see how John sought choice, friendship and laughter and enjoyed sharing his home with happy people. He valued the attention and praise that he got from dressing smartly. He also had a passion for trains and cars.

We learned that John's mood was strongly related to the amount of good-quality sleep that he was able to enjoy at night. At first, John shared a room with another resident and this arrangement often resulted in interrupted sleep for him. We decided to finance an extension to the building, and John now enjoys a much improved sleep pattern in his own large room. John's support staff became sufficiently confident to take him to the shopping precinct to purchase his own TV. (John proceeded to choose which TV he wanted, much to the surprise of the support workers who were with him.) Accompanied by staff, John now also indulges his passion for trains and cars and regularly takes his mother out for a meal; he has built up his own DVD collection and clearly enjoys helping with daily housekeeping tasks.

We have seen tremendous changes in the quality of John's life – largely attributable to a

primary focus on John's needs rather than on his behaviour, and to the commitment of a dedicated, motivated and occasionally bruised staff team. John has not hurt anyone for the past 18 months and is now viewed as a happy and caring man. His rocky journey towards happier times is an impressive indication that our recent adoption of the human givens philosophy as central to our care provision is having a remarkable effect.

DRH is a registered charity and an independent provider of residential support to people with moderate-to-severe learning disabilities or serious long-term mental disorders (see box on page 32). Ten years ago, when I joined DRH, our services were strongly influenced by the medical model, and the people who used our services tended to be defined by their particular disabilities or by accompanying medical conditions. Most of us had worked for years in large psychiatric institutions and senior staff (myself included) were mainly qualified nurses. A tendency to focus on symptoms was fairly deeply ingrained: strong emotional expression or behaviours deemed to be 'difficult' were often considered problems that could be treated and there was an over-reliance on psychotropic medication to control inappropriate or undesirable behaviours.

Fairly basic behavioural approaches were also employed. One such was 'antecedent behaviour change' – known as ABC and equally simplistic, as it tended to focus on what had happened immediately before an undesired behaviour occurred, in an attempt to bring about behaviour change. In effect, it denied that what was going on in a person's life to make them disruptive was far more complex than an immediate event and included long-denied needs and responses learned as a result of many years of frustration. On occasions, punishments masqueraded as behavioural treatment. When, in 1998, NHS staff working in our homes transferred to our employment, we discovered, to our horror, that one resident had her handbag 'confiscated' if she was incontinent – a behavioural intervention based on an assumption that her incontinence was a conscious and malicious act! This and other such punishment 'programmes' were prohibited immediately.

Despite our organisation's new-found independence from the NHS, there was still a strong tendency in the late 90s to look to the NHS psychiatrist and clinical psychologist to

What DRH provides

DRH grew out of the gradual closure of the old institutions for mental illness and learning disability, when long-term patients were discharged to live in community homes. We are the main independent provider for people with learning disabilities in West Dorset. In 1998, we became organisationally independent of the NHS when 150 NHS staff working in our homes transferred to our employment. We are entirely resourced by NHS and local authority funding and now employ about 270 staff.

We manage eight registered care homes for people with learning disabilities, the homes varying in size and accommodating between six and 15 people. We also manage two independent hospitals for people who have a long-term mental illness – one with 14 beds, for those under 65, and one with 16 beds, for older people. (This distinction between care home and hospital is a product of legal technicalities but it enables us to continue to support people who may be detained under the Mental Health Act and who, therefore, cannot be accommodated in a care home. However, the hospitals look like, and are run broadly in the same way as, our care homes.)

Most of the people living in our two hospital facilities have been diagnosed with conditions such as schizophrenia or bipolar disorder. A number of the older residents had previously lived for many years in the local psychiatric hospital, but failed to respond to the largely drug-based treatment regimes which were in place then, and have additional impairments resulting from inadequate treatment and institutional care. Younger service users are often referred to us when they have failed to respond to treatment after a series of episodes in acute psychiatric and NHS rehabilitation services.

DRH also provides support to 20 people living in more independent accommodation and manages a short-term break centre, which supports 40 people with a learning disability and their families. ●

address 'behavioural' and 'emotional' concerns. (This tendency owed a great deal to the hierarchical power structures that had existed within the institutions for a century or more.) General practitioners took on primary care responsibility for residents previously classified as NHS patients but continued (and sometimes still continue) to bow to the assumed expertise of the psychiatrist, who was expected to approve any medication changes. For those of us who had spent many years learning how to observe behavioural variations from the norm, it was often all too easy for us to define behaviour that we would consider perfectly normal in ourselves (such as moping

around the house occasionally or being irritable) as aberrations to be treated. Stan, who had been diagnosed with schizophrenia, periodically spent longer periods during the day in his own room rather than in communal areas. While we all recognised the importance of residents socialising together, we tended to underestimate the value that Stan, and others, placed on solitude and privacy. Sometimes, perhaps, we underestimated how stressful communal areas could be, at times.

Anyone who has worked in care services for any length of time will be familiar with the awful phrase 'attention seeking', which was applied to certain service users. This is perhaps one of the saddest examples of the way that services could deny and dismiss someone who was attempting to meet their own needs – not least the basic need just to be acknowledged.

Normalisation

DRH had also inherited the fruits of 'normalisation'. During the 1980s, normalisation or – as more properly termed – social role valorisation (SRV) was introduced throughout the UK as a set of values or an ideology which staff in both mental health and learning disability services were expected to accept. The thinking behind normalisation is that, if you help someone to live the kind of life that is 'culturally valued', then that will improve their quality of life and will also reduce stigma. The approach has been instrumental in bringing about positive change but, too often, only lip service is paid to it, and, in the end, what is created may be just the *appearance* of normal life. SRV did not seek to promote an understanding of what makes living worthwhile for a *particular* individual but relied on generalisations drawn from populations. For instance, home routines may be structured to achieve a semblance of the ordinary, by requiring people to live according to the pattern of an 'ordinary' day – getting up at a set time, eating breakfast at a set time while sitting down at the table with other people, doing the cleaning, and so on, just as everyone else does. But insisting on these activities in this way, however good the intent, merely allows old, regimented, institutional practices to be perpetuated under the guise of a more 'modern' philosophy aimed at creating a 'family life'.

A significant aspect of normalisation is participation in the community – people are encouraged to make use of local facilities, such as the swimming pool or shops or library, unaided. This has indeed been a benefit to those who are more mildly learning disabled. But, for those who need help or whose looks serve to stigmatise them, the outcome has not been good. Research has clearly shown that the less able have not benefited from living a community life outside hospital, and that their quality of life has worsened. Normalisation principles may have served as reasonable, abstract guidelines for planning services for large groups of people

but they are quite inadequate when applied to an *individual's* life.

It is rather ironic that people working in our type of services have been exhorted to practise in an 'evidence-based' manner, yet, at the same time, are encouraged to absorb ideologies that have little or no evidence underpinning them. One of the most potentially damaging has been the principle of 'age appropriateness'. This includes the insistence that communication with profoundly disabled people must be 'adult appropriate', even if those people lack the ability to speak and have limited ability to understand, and was duly complied with in our homes. (I agree that language should always be respectful but surely it must be meaningful to the person concerned.) In an application of the same principle, soft toys were not infrequently removed from residents' rooms, even though many of the staff themselves had soft toys at home on their own beds.

The proponents of SRV had a genuine desire to reduce stigma and enhance the social reputations of the disabled but seemed little concerned with issues of individual wellbeing. SRV often came across to staff as preaching and sloganeering and introduced an era in which politicians and planners raised ever greater expectations while, in reality, staff and families were seeing resources and services decline. The government White Paper *Valuing People*¹ appears to direct resources towards the most able clients, particularly those most likely to enter some form of low-paid or voluntary employment. This rather perverse 'meritocracy' largely ignores the needs of those who have the most profound disability.

Searching for clarity

Put simply, 10 years ago, our services lacked sufficient clarity of purpose or a clear focus. We were well aware of the limitations (and sometimes counter-productive nature) of the medical model, of behaviourism and of normalisation. Fortunately, we had a couple of significant assets: first, within our organisation there was a genuine commitment to explore better ways to improve the lives of the people we support; second, we are relatively protected from the constant organisational restructuring, fads, fashions and targets that plague public services, although we are, in effect, an extension of those services. This has given us a great deal of organisational stability and the freedom to introduce meaningful change with long-term commitment to seeing those changes through.

We made some progress in reducing the variations in work practices and standards within each care team, and we introduced 'active support' – an approach that emphasises planned and purposeful activities and interactions, such as visiting cafés and garden centres. But we quickly realised that so-called purposeful activities weren't always meaningful for the individual concerned, unless based on a thorough understanding of what those activities brought to them

personally. We felt that there was still something important missing.

In short, we had not identified an 'organising idea', which could give us the direction, clarity and cohesion we needed. Meanwhile, as NHS services for people with learning disabilities reduced, we were increasingly receiving referrals for people whose behaviour could be problematic, if not downright harmful – for themselves and sometimes for the people around them. We did not wish to perpetuate the crude punishing behavioural approaches often used in the past. We knew we needed to improve our understanding of what these behaviours 'meant' for the individual acting them out. We knew we needed a model that would help to orient us towards the inner, emotional world of people who were limited in their ability to communicate their own needs to their carers. Then we came across the human givens approach and realised that it had to be the underpinning for our work.

Universal needs

There are two main barriers that seem to limit our ability to get as close as we might to understanding the needs and subjective experiences of severely disabled people. First, most of us are pretty poor at really understanding *our* own needs and spend little time reflecting on how we might get more out of our own lives. The ability to empathise with others is largely dependent on our ability to experience our own feelings and to identify them. Second, we tend to find it difficult to empathise fully with those whom we regard as very different from ourselves. Too often we seem to assume that people who have completely different lifestyles from us do not share the same basic needs. An unconscious assumption that learning disabled or chronically mentally ill people don't really have the same emotional needs as the rest of us seems partly to have arisen from a confusion of needs with cognitive/intellectual ability. The huge appeal of the human givens approach is that it is based on the universality of human needs, even though we are all different and the manner in which we seek to meet our needs may vary considerably. What makes me different, in terms of emotional needs, from a severely learning disabled or chronically mentally ill person is not that our needs are fundamentally different but the fact that I have the innate psychological resources (mostly) to meet those needs, whereas they do not.

Celebrating what is shared

This seemingly subtle shift in emphasis makes a huge difference and its import hit us like a ton of bricks. With the human givens model we had found a profoundly different way of looking at things: a recognition, and celebration, of what was shared, instead of, as in the medical model, a concern with difference. Ensuring that this approach would become central to everything we did would not be straightforward, however. Some



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of us had been around long enough to remember when learning *not* to empathise was almost promoted as a professional skill. We were just about managing to get through the day, with only two or three staff on a ward to support 30 severely learning disabled or chronically mentally ill people: we had to *protect* ourselves from connecting with our patients. But, in smaller settings, like our own, it is very different and we can afford to be more open to how people feel. Many staff, however, while strongly committed to the wellbeing of the people they cared for, were understandably suspicious of yet another exhortation to change the way they worked. Attempts to promote positive change can often be seen as veiled (and not so veiled) attempts to criticise the commitment of well-motivated staff.

It was clear that, if we were to implement a human-needs-based approach to support successfully, we would need to commit the whole organisation. (We would, for example, have to show that our financial decisions were judged according to the extent to which they genuinely helped people to meet their needs, such as the decision to build an extension to give John his own room.) In 2005, the Board unanimously

accepted the proposal to adopt the human givens approach as the philosophy underpinning the organisation's work. We then sent a statement to every staff member, explaining the human givens approach and what it meant in terms of what we wanted to do: focus first and foremost on identifying and helping individuals to meet their emotional needs.

Last year, we held a major workshop for staff, where we

discussed the human givens approach as well as the concept of subjective wellbeing. We asked a team from each home to prepare two examples showing how successfully (or unsuccessfully) they had worked towards meeting individuals' needs. One of the examples concerned Vera, a lady who had spent many years in a secure hospital and has only begun to enjoy a better quality of life in the last few years. Vera has a very short memory and a poor attention span – both good examples of impaired innate resources. Her support worker is tackling her lack of self-esteem and poor self-identity by helping her create for herself a lovely bedsitting room that she will value and want to preserve (Vera can be destructive). Given the organisation's formal commitment to this approach, it was relatively easy to agree to commit resources to this project. Staff are also preparing tailor-made DVDs, which will enable Vera to orient herself to the day of the week, time of the day and the events coming up in her immediate future. This involves a sequencing, repeated at five-second intervals, of familiar images such as the bathroom, clothes, her hand-



bag, her work bag (which she takes to the day centre), a bus, her escort and the day centre. There will be different DVDs for weekdays and weekends, to communicate the different daily patterns. This is an innovative attempt to strengthen the under-developed psychological resources that have so been hampering Vera.

“Sandwich!”

In another example, staff described how Fred's violent outbursts ceased after staff stopped talking to him in 'age-appropriate' language. As Fred had very little understanding of language, he was clearly frustrated when given instructions such as, “Fred, would you please go into the kitchen and open the fridge and get your sandwich, which is on the second shelf”. He felt completely out of his depth and therefore out of control. But when staff started simply pointing to the kitchen and saying, “Sandwich!”, he knew what to do and could experience a valuable sense of autonomy.

Development across DRH is inevitably still rather uneven. There remains a tendency to over-emphasise problems, although sometimes the need is 'hidden' within the problem. A recent goal plan aimed to support a resident in the care of his fish and fish tank. The 'problem' was his tendency to overfeed his fish and the need to prompt him to clean the tank. The staff concerned had something of a eureka moment when it suddenly clicked with them that the important point was the resident's pleasure and satisfaction in caring for a living creature, rather than his inability to carry out a routine task without supervision or prompting. The 'problem' was subsidiary.

On the other hand, seeing instant change in the people they are caring for has helped attract staff to the human givens model, and the feedback we have received so far is that most are very keen to put it into practice. For many, a different view on attention seeking has been educative. It is easier for us to accept that we all seek attention because we *need* it and that, if we don't get it when we feel we need it, we may come up with creative ways of attracting it! After 10, 20 or even 30 years of living in an institution, people have often learned dramatic ways of meeting their needs – not least attention. If we want to stop people exhibiting inappropriate behaviours, such as destruction of property, then we have to find other, better, more attractive ways to help them achieve attention or status (such as making sure that we freely offer our time).

Research into the quality of post-institution community services has shown, however, that many people sit alone for a great deal of the time and don't ever ask for or provoke attention. That doesn't mean they don't need it or wouldn't like it. So we are looking more closely at how best to spend time with people who don't seek attention and how to find the balance between meeting the need for attention and the need for privacy.

How Edna was helped to meet a host of needs

EDNA's need for control, choice and a sense of autonomy were inadequately met and this was clearly leaving her unhappy; as a result, her behaviour could be both challenging to support and harmful to her own wellbeing. To increase Edna's control we introduced a support plan that included her choosing who, from the staff on duty each shift, supported her to get up, bath and take care of her personal care needs, and when she would do these things (within a timeframe explained in terms of relevant events, such as "the bus to the day centre will be here at 8.30am"). This gave Edna more control over what was happening in her life. We ensured that Edna prepared all her own meals, with support, and that she had chosen what she wanted to eat – we helped her to understand what she needed to know about healthy eating. Main meals were

served into serving bowls so that Edna could help herself to the amount that she wanted.

To increase her sense of achievement, we linked the activities that Edna found more difficult to the ones that she really enjoyed and was good at. We clearly identified what type of support or prompts Edna needed to help her succeed, so that she could experience a sense of competence. By helping Edna to engage in activities and regularly reviewing her support, we ensured that she continued to develop skills, thereby creating a stronger sense of purpose. All this increased Edna's sense of status, as it was clear that her views were respected and people no longer deprived her of her sense of autonomy by taking over from her. We also supported Edna in self-medication, to ensure increased sense of control. ●

The human givens approach encourages us to make meaningful observations about a person's situation to help us conclude whether a person stays apart because this meets a real need, or because shyness or anxiety is getting in the way of greater social interaction. While we might benefit from a greater awareness of our own needs and the strategies we employ to meet these, we should guard against too readily assuming that our way is the best way. Human needs may be universal but there is still considerable scope for difference.

Having the human givens framework to work from helps to ensure that team members take a consistent approach to their work with each individual, whereas in the past individual staff members were more likely to bring their own beliefs and values to bear. One carer, for instance, might have insisted that everyone should eat together 'as a family', regardless of individuals' discomfort, while another would let them eat in their rooms. But if it is recognised that Elsie likes to eat in her room and come down to the communal lounge when she feels like it, because this meets her needs for privacy and for community *as she experiences them*, her wishes can be understood and respected.

Not the status quo

Thinking about people's need for status has also created more understanding of what used to be seen as perhaps irritating or inappropriate behaviours. Residents are often surprisingly aware of hierarchical power structures. A resident may take a concern to the shift leader or a visiting manager when their own support worker is more than capable of addressing the issue. Sometimes, this kind of communication could be seen as manipulative. Perhaps we need to recognise it instead as a sign that the resident is trying to

raise their self-esteem as well as to achieve the kind of everyday attention that most of us seek but in ways that tend not to be so obvious.

One of the many problems with the normalisation strategy was its promotion of domestic duties because they are 'ordinary' and everyone has to do them at home. Certainly, there is a great deal to be gained from participating in the activities of an 'ordinary life'. But domestic duties have low status, and many of our residents are aware of that. So we are working on teaching people to carry out skills which they themselves value, such as ones which currently are the domain only of the care staff: for instance, changing the film in the video camera that is used to record outings or holidays is viewed as a high-status skill by those who would like to learn it. Recently, a staff member recounted the experience of a visit to a coffee shop, during which a resident operated the plunger in a cafetière and poured out the coffee. This was hardly a giant leap from the perspective of our own lives but the pleasure the individual experienced was palpable indeed. So how had a man reached his 50th year without ever having undertaken this apparently simple task? Well, many of us were trained to be professional carers and traditionally this meant it was our job to pour the coffee!

Putting risk into perspective

Also, pouring coffee carries a certain amount of risk, and risk was always viewed as best avoided as far as possible. However, the human givens approach encourages us to explore the opportunities that can be exploited to enable severely disadvantaged people to feel better about themselves and their lives. So, the more we focus on the benefits *to the individual* of any activity they might want to undertake, the more we can put its risks into perspective and do what we need to

maximise safety without also sabotaging the activity itself. Challenging the risk-avoidance mentality that stops people undertaking new challenges when they are ready for them is, therefore, much easier to do from the human givens perspective.

Encouraging connection

We are nowadays doing much more to encourage emotional connection. Intimacy, for someone who is severely learning disabled, may mean feeling able to confide in a member of staff about something of concern to them, and choosing *which* member of staff to confide in. It also means being allowed the space to be angry or upset, without having their emotion pathologised. In the old institutions, if people were angry, they were “disturbed”; if they were sad, they were “depressed”. Even today, noting episodes of irritability somehow signifies a clinical event, instead of the ordinary expression of feelings, which everyone else is allowed without question. Now, because there is less emphasis on categorising moods throughout the day, people who use our services are feeling freer to be themselves – and also to show some insight into their own emotions. (“Remember what I did yesterday? Wasn’t it awful!”)

The concept of just spending time with residents for their own sake rather than in the course of a specific and often care-related activity is having a significant effect. It is the very first step in creating emotional intimacy – just letting someone know that they are deserving of another person’s presence and time. It also, of course, raises status – an employed member of staff choosing to sit reading with ‘little me’, instead of talking with their clever colleagues. We can be sure that ‘spending time’ conveys – and elicits – something deeply important.

We had moving evidence of this in the case of Lynette, who is elderly, severely learning disabled, and has lived in institutions almost all her life. She spends most of her days sitting and staring blankly and was long ago assumed to be incapable of communicating in any way at all, verbally or non-verbally, although staff at the home she lives in have diligently looked after her physical needs. Then, one day, one of the care staff decided to sit next to her and read a magazine. As she flipped through it, she would read occasional bits out loud that caught her interest, glancing at Lynette to include her. She did the same the next day, and the day after as well, just for 10 minutes or so. Lynette, who has no speech and who sits almost motionless, started to turn towards the staff member as she read and to make noises that clearly indicated pleasure. Small responses, perhaps, but they represented a level of attention that could never have been expected.

The human givens approach also generates insights into the way that staff’s own unmet needs can prevent them engaging appropriately with the people they are supporting. While emphasising that everyone’s needs have to be met

appropriately, we have to ensure that staff don’t look to the people they are caring for, to meet them. For instance, although we are very clear that physical touch is often an important need, it has to be at a level the resident concerned finds acceptable, whether that is a hand on the shoulder for one, or hand holding for another. Some staff get emotional satisfaction from being tactile but the person they are caring for doesn’t, so that is clearly not appropriate. And, yes, it is always nice to be appreciated but the people we work with don’t necessarily show appreciation, or else cannot show it. Attention and care must be given unconditionally. *We* get paid and should get our attention needs met elsewhere. Fortunately, the human givens approach gives staff the confidence to offer themselves emotionally to the people they are caring for, without needing evidence of the value of their ‘investment’.

No tick-boxes

We have to stay vigilant against any regression towards tick-box mentality, such as ‘working through’ the emotional needs and how they can be met, as if they were all separate from each other. Even though the emotional needs audit lists important needs separately, as a guide to information gathering, one activity or action may meet several needs at once. Also, we have to be careful that, when we consider innate resources, such as long-term memory, ability to plan, use of the imagination, building rapport and so on, staff don’t find themselves reverting to a focus on resource ‘deficits’, and problems, instead of abilities. We stress that it is important always to concentrate on how to make best use of resources, rather than look at limitations.

Sense of purpose

It is early days yet and we are still getting used to all these new ideas. But there is a sense of excitement and purpose around our homes. We have been subject to a lot of ‘sloganeering’ over the past few years. Government pursuit of, for instance, ‘quality of life’, ‘normalisation’, ‘choice’, ‘inclusion’ and ‘respect’ often adds up to nothing more than generalised declarations of good intent: there is nothing to connect with. Whereas the human givens approach is concrete: it is concerned with the ‘what’ and the ‘how’. It is practical, meaningful and real. It allows us to recognise that a resident’s sense of general wellbeing owes much more to the kind of interactions that take place daily within their main community – their home – rather than the more infrequent excursions into the wider community. To me, visiting a garden centre once a week, when you are severely learning disabled, is *not* participation in the community. Sitting companionably alongside someone who is reading out snippets from the paper and sharing their enjoyment with you, even when you can’t speak and don’t understand much language – *that*, to me, is community participation. ■

REFERENCE

¹ Department of Health (2001). *Valuing People: a new strategy for learning disability for the 21st century*. Department of Health, London.