Developments in Community Based Support for People with a Learning Disability leaving Restrictive Settings

Important and Positive Steps in 'Bringing People Back Home'.

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Background

It is 38 years since I started supporting people to leave restrictive settings such as long stay hospitals and Assessment and Treatment Units. My work started at Darenth Park Hospital, near Dartford in Kent. It seemed to me that those who lived there had found their own ways of making life manageable and tolerable. Professional interventions to stop certain behaviours and start others were rarely understood in terms of the coping strategies that people had adopted to survive harmful, adverse experiences. Progress towards a better understanding of what 'good' personalised support looks like in the presence of people who reject others and express their distress and confusion in harmful ways continues. Our work goes on to close the gap between how such individuals have come to perceive the world, and the way the world perceives them, acting in their interests, or with indifference.

Introduction

The question of where people at risk of harming themselves or rejecting others should live has been debated for years. In my area the closure of the long stay hospital all those years ago led authorities to create campus style bungalows. Others built alternative accommodation and specialised 'units' whilst a few adopted dispersed community housing.

The South East Regional Health Authority (SETRHA) at the time did much to develop a values based strategy called 'Bringing People Back Home' supported by expertise from a 'Special Development Team' based at the University of Kent who helped to build community based supports and create an evidence base around practice.

This strategy embodied, inter-connecting and complementary approaches:

1. Programmes and events bringing together academics, practitioners, educators, and families from across the region
2. The development of cross sector partnerships, sharing of resources and good practice
3. Information and publications that included an international perspective
4. A drive towards values-based commissioning and practice including PASS and PASSING training to teach normalization (and then Social Role Valorization), and to assess the SRV quality of human services
5. A Trainers Development Programme to develop skills in developing staff at a local level and local leadership
6. On site support and consultancy through the Special Development Team
7. The development and widespread use of support guides and materials based on real life stories generated locally.

I was fortunate enough to be part of 'Bringing People Back Home'. This, and other, initiatives are part of our history, they provided the foundations of our community services, and a legacy. We now have many years of practical experience to draw upon to help us take the next steps in bringing people home from mental health hospitals and Assessment and Treatment Centres based on the best of what we know and insights on what we now need to do.

Reorganisations and national transformation plans can chart progress over the short term however we need to look back further to really understand what has changed for people and why. It is time to reflect on what has been learnt over the last 30 years and tease out key lessons to inform a new generation of supports.

On my travels I have found a strong desire amongst staff to learn more about human healing for those who have experienced trauma in their lives. I have discovered a great interest in, and use of, massage, aroma therapy, singing, and the arts more generally. In fact, I am currently exploring how we might fund Positive Behavioural Support (PBS) training with community arts organisations/freelancers so they might reach out to people, with us alongside, to those most distanced from the arts, but for whom they bring significant joy and a means of expression and communication. I have known people who have been able to sing complete songs but who struggle with spoken language. This is one area that I think offers some exciting opportunity but where developmental

and supportive scaffolding for communities themselves is yet to be put in place.

Here are some of the things that I consider would support our journey towards a new generation of community-based support. In no way do I assume that these things are absent entirely in our practice, rather, that they need further development, and to be rolled out everywhere. They are not an exhaustive list but some practical things that I think would make a big difference to those we support.

Celebrating Achievement

There is now a better understanding of the importance of learning how a person wants to live and how support should be organised. PBS has been widely rolled out but there is little national information available on the quality of its delivery. Saying this, we have come a long way to understand what is needed to support people well in local communities. This includes those who may place themselves, or others, in jeopardy or limit their access to mainstream community resources. Incredible work has been done to support people to live positive, dignified lives who would otherwise have languished in institutional care.

I am inspired by the commitment of our staff and the numbers of young people who come to us wanting to make a difference. Young people still want to change the world, so we need their voices perhaps now more than ever. Recruitment of motivated staff remains critical but should sit alongside the recommendations in this paper that will (a) Improve the quality of life of those we support, and (b) support the retention of a skilled workforce and help to reduce levels of 'internal churn' where staff move between support teams sometimes due to tiredness or 'burnout'.

Understandings, Meanings and Connections

Medical and case notes record important things from the professional perspective but will not convey the story from a personal and/or family standpoint. The professional account will not capture how it felt, an important issue in understanding better why things happened the way they did. Understanding the story well and valuing the past is the first step to seeing a person as whole and complete. The story will convey the struggles of that person, and their family, and serve to underpin a strong sense of purpose, commitment, and solidarity with them. It can mean that a person's own destructive or harmful behaviours are better understood as strategies with meaning rather than aggression without motive. Where there is no story available a search for it can be incredibly rewarding and revealing for all involved.

A core element of Person-Centred Planning (PCP) is the creation of a person's lifeline. The story itself is always revealed in different ways and represents the twists, turns and spontaneity of life. It is these detours that lead to the greatest of understandings between people and enable connections being made between what might appear to be disparate, unrelated events. In my experience an over simplistic emphasis on individualism can limit our understanding of the interplay of many different influences and inadvertently reinforce many of the unhelpful experiences a person has had in their past. It can also unintentionally provide help that is experienced as unhelpful by the person.

The practice of PCP as a facilitated process of learning and discovery should be available to all people leaving restricted settings.

Recommendation 1

Life story work is further developed and used to (a) support stronger mental health and feelings of resilience and (b) create a deeper understanding of the life journey of a person, and their family, where connections and meanings become clearer.

Trauma Informed Care and Practice (TICP)

For over two decades I have been interested in work with people who have significant life complexity and who reveal to us their considerable distress. This came through supporting a young woman who had left a long stay hospital with high stress levels triggering seizures so significant they demanded frequent emergency care. Her story is told in some detail in my book 'Life Nourishment: the potent effects of life nutrients on human wellness, in community health and social care'.

Work on Post Traumatic Stress Disorder (PTSD) has advanced significantly over recent years. The NHS defines PTSD as an anxiety disorder caused by very frightening or distressing events. For some people with a learning disability distressing events might arise from involvement with violence or abuse or being exposed to an environment where such events have been witnessed. Some people may have been exposed to intimidation or violence by other people living with them, or through people in positions of power over them. This does not just mean staff.

People with learning disabilities who display significant behavioural challenges often find themselves subject to multiple transitions and don't have the chance to get rooted in both people and place. Too much

transition, too much confusion and too much loss can further compound the difficulties they experience.

Research suggests that one in three people who experience a significant stressful situation may go on to show symptoms of PTSD that may be mistaken for other things. The effects may show within weeks but may not manifest for years. Factors that prevent easy detection of PTSD for people with learning disabilities include the person's inability to vocalise what has happened to them, or understand the places, or people that trigger anger, rejection, or harmful behaviours. I have encountered many people who have had multiple serious violent episodes in their lives and for whom our current practice is inadequate. A deeper and more expansive understanding is necessary. We can draw much from allied professions and the people they support in creating this. It may also be the case that Social Care will need to embrace new job roles and pay grades bench marked against such important therapeutic roles elsewhere.

Some people who have experienced significant periods of solitude through seclusion, medicalisation and/or restrictive practice have learned that human contact is to be avoided. Further, that our very presence can, and usually does, signal the onset of demand. The obvious way to deal with this is to avoid it. Rejection of our presence is not uncommon and is an issue faced by many support staff. In all sorts of situations support workers must be able to convey that being near is rewarding and that relationships can be safe and kind when the person may understand them as contingent, fleeting, or unsafe.

At the core of our work with people who present significant behaviour challenges is an evolving relationship. Tasks or activities are merely vehicle through which reciprocal relationships can be built and from which the value of participation is found. PBS embraces the importance and opportunity in all interactions but my experience in recent times suggests that staff can easily fall back into traditional demand based and contingent teaching.

Recommendation 2

Training on Trauma Informed Care and Practice (TICP) should be available to support staff in order that events, experiences, and effects for people are understood and inform all aspects of our work.

Recommendation 3

The practice of PBS should be universal, subject to ongoing evaluation and sit alongside other healing and restorative approaches that may currently be missing.

The goal of building a respectful and rewarding relationship with people who have had exposure to highly stressful, volatile, and violent situations can be long and scary- often for both parties.

On occasions I have found myself back tracking or reflect upon how poorly I have understood the issues presented to me.

I have come to understand that a healthy human relationship is 'therapeutic'. Therapeutic exchanges occur naturally in everyday life, they are valuing, nurturing, and strengthening.

I also recognise the vital role of 'therapy' as an area of work that deserves a wider audience and further investment and recognition. Much important work has been done with people who have a learning disability that has both inspired and informed my own professional practice over the years.

There is scope in our psychological services to further develop support and training for staff where they can learn more about their own potential for therapeutic work and receiving therapeutic support. This is particularly so for staff who may be the subject of aggression, or violence in the support of people who understand that this as a powerful and legitimate way to interact with others.

Recommendation 4

Therapeutic support should be sewn into the fabric of community support for both people who received and deliver it.

Vision and Values

As an educator I am passionate about people championing their own ideas. My work with many teams has taught me that much of what we encounter is spontaneous and requires critical thinking skills, strong leadership and a willingness to embrace fallibility. It is only by 'asking' that we address seemingly intractable problems. Bringing teams together to ask of each other, and construct a compelling vision of a desirable future, to facilitate discussions, problem-solving and action setting is an essential part of learning what 'good' looks like. Having the time to build a compelling vision of the future creates a sense of hope and possibility for both the individual and the team. It can serve to bring

support staff to life, fire up their motivation, and channel collective energy.

Recommendation 5

Support teams should have access to skilled independent facilitation to support creative thinking and collaborative work with individuals, families, and other allies.

Envisioning the Community Place

Community spaces are quite often spontaneous, even chaotic, and can be daunting for many people returning from restricted settings. Some may find themselves either in 'special' activities unable to find ways into community life. They are betwixt and between. They are in the community, but not part of it.

Mapping community spaces that provide safety, and freedom, yet a sense of connection to others is an essential part of gently and deliberately opening life. It can take ingenuity, creativity and patience.

This work taps into local placemaking initiatives that aim to understand how the public space might be better used. It has been said that a 'place' is a space with meaning. Part of our role is to support people to find that meaning in the communities where they live. Social care providers need to have the capacity to work with their local Councils and other partners in transforming the communities where they support people.

Matt was 21 and had lived in a variety of residential schools when I met him. He was impulsive, found it difficult to relate to others and would withdraw from the world or attempt to harm people around him. No planned transition had been in place as he left the residential school that had been his home for several years. His family were unable to support him at home and social services had to make rapid plans for his housing.

In his new home Matt had journeys out in the car and often went for long walks. He enjoyed listening to music and rarely used the communal rooms of his home. The kitchen and dining room were locked for safety reasons and his access to the garden was restricted. He struggled with understanding beginnings and endings of events and activities.

That summer we introduced Matt to the local tennis courts. On the first visit he and his support staff arrived without suitable footwear. The support staff had not considered that they would be playing. We gave them permission to have a go and enjoy this time. We had brought a folding chair for Matt to sit and watch and use the hour to invite him to join in. Sometimes he would and other times he preferred to watch. There was no pressure for him to participate only that he experienced the joy of being around people in a happy and free place. The staff at first were unsure about this as they wondered whether 'activities' needed to demonstrate things. It frustrated them when Matt decided not to play ball with them.

On the third week a lady passing by stopped to say hello. We introduced Matt and she asked if he had a cap and sunglasses as it was such a warm day. The next week she came back and had purchased these items for him. A relationship struck up and every week from there these encounters would happen and whilst some played tennis this lady and Matt spent time together. He learnt her name was Teresa and started to ask for by name. The tennis session became part of the weekly plan and Teresa would come by and sometimes introduce others. On one occasion Paul the local Community Warden came and said he would arrange to call by the house.

We chose the local tennis court specifically. Firstly, it was a contained space offering a high level of safety from the main road. Secondly, the tennis court was seen by the locals as a relatively high-status place and the wire fencing rather than keeping people out was understood as necessary to keeping the tennis balls in.

The courts offered a large open space to walk, run and play team games such as throwing and catching that supported learning about turn taking, passing things, and helping each other. An important side effect of adult play such as this is that it changes the flow of energy and interactions between people, Even after a few minutes of play the staff team would be found smiling, laughing and having more open body language. Their interactions with Matt became more exuberant, light and valuing. The amount of gesture increased, and verbal instruction decreased. A lot of happy memories were created along with opportunities that arose out of what some thought as an unconventional approach.

Recommendation 6

Memory creation is understood as vital part of balancing a person's experience and exposure to situations that evoke happy feelings and safety. This includes capturing visual, auditory, and tactile reminders of people, places and activities that are recorded as part of a person's unfolding lifeline.

Social Responsibility

I met Luke after he had moved into a house with an extensive garden looking out onto rolling hillside. There was nothing remarkable about this neighbourhood, it was well kept, and quiet. However, within the first few month's issues bubbled up with the neighbours.

The front and rear garden had become overgrown as the contractor has not shown up and the garage scheduled to be redeveloped as an extra room had been left with an unsightly temporary door. As support workers came and went multiple cars would be parked on the front lawn and in the street. Meetings with the neighbours did not go well. They were frustrated that they did not know anything about their new neighbour being told that this was confidential and protected information.

When Luke had moved into his home no window dressings or curtains had been put up so people walking past could see indoors. A neighbour had observed him walking around with no clothes. This caused offense and had led to rumours about who had moved into their street.

In this situation the barriers to people knowing each other, helping each other, and co-existing in a peaceful way were real and significant. It clearly provides an illustration of the need to move away from a mindset of 'providing service' to one of supporting community and association. Paying attention to the context within which people are expected to live is critical to the individuals themselves, how they are perceived, self-image and to the development of good community relations. Social care has a critical role to play in supporting strong cohesive communities. We want people to have positive social roles in their communities, to be welcomed, and for different lives and histories to be better understood.

Recommendation 7

Further work needs to be undertaken on the theme of social responsibility, how introductions are made, connections sustained and different lives and histories understood. These should be widely shared.

Conclusion

It would not be right not to conclude without a mention of funding.

The funds provided to social care must be sufficient to build the infrastructure needed for long-term sustainability. Financial settlements must take account to community capacity building and developmental work to support the inclusion of people moving into communities where they have no natural connections. Funds should also be available to create a vibrant cross sector learning environment with social fairness, avoiding the waste of lives and social responsibility at its heart. The involvement of academic institutions to support an evidence base of what is working well and why is seems essential.

My experience of 'Bringing People Back Home' was that a centrally co-ordinated strategy led to a strong social movement, collaboration and sharing of resources. Additional benefits included, the development of new leaders as part of local succession planning, peer support across the region and a focus on interventions with a clear track record and evidence base. Person's leaving restricted environments who have few personal possessions should receive sufficient (transitional) financial support to equip their homes with essential items and provide contingencies. There should be some agreement about what things are deemed essential. For example, are televisions, digital devises and WiFi considered essential?

Recommendation 8

There should be a central furniture and household equipment repository in each region where essential good quality items can be loaned if needed.

Recommendation 9

'Bridging' contingency funds (not loans) should be in place wherever needed.

Recommendation 10

Funding should be available to support community capacity building, accessible placemaking and engagement with the arts. This work should be subject to evaluation and contribute further to a national evidence base on what works well and why.

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