

# Language, Stigma, Stories - Their Role in Mental Health and Wellbeing

Linden Lynn - Recovery Devon (revised August 2010)

Language matters. The language that people use to describe themselves and others, matters. This is true for every-one. Our perceptions and expectations are shaped by the words we hear and use. Words are part of the underpinning framework of our lives. Language is especially important for people who have had to overcome differences of some sort, particularly those who struggle to manage mental illness. Logically, we know that our mental health can vary throughout life and that mental ill health can occur to any-one, at any time. Yet people in the world around us can behave as though we are alien or 'other', should we experience these sorts of disturbances. The language that people use about emotional distress can portray this feeling of difference, or it can show compassion. It can paint a picture of hope, or of rejection and exclusion, or it can fall somewhere in between. As some-one who has experience of a mood disorder and has had to work at keeping my mood upbeat and stable, I often find myself thinking about this. Seeing people as people first, is key to the recovery movement. But 'person-first' language has yet to be universally adopted. The following is partly a plea for that, but also a contribution to the broader issues of the role of language in challenging stigma in its many forms.

## Why Language Matters

The language people use matters because it conveys both hidden and explicit messages. People who experience mental distress can be very sensitive to the world. Sometimes it seems we are like the canaries in the coal mines, able to detect when the space or place is becoming toxic. People are seen in many different ways and usually through a partial lens to suit a particular relationship or connection. Language serves to help construct our social and personal reality. Our perceptions of ourselves are mirrors of the way that others perceive and describe us. How we see ourselves can affect whether or not we remain 'stuck' when things go wrong. This affects our ability to recover and to fulfil our potential.

The importance of recovery focussed language and how it affects attitudes was one of the key topics identified by Recovery Devon, in several workshops, following visits to Devon in 2008 by Mary O'Hagan, Commissioner for Mental Health for New Zealand, and Mike Slade, Consultant Clinical Psychologist in Rehabilitation, Maudsley Hospital, and their subsequent reports on the organisational progress toward recovery working in Devon.

Most people who have lived through experiences of mental distress have many stories to tell. Chimamanda Adichie talks on the website TED about, 'The Danger of the Single Story'<sup>1</sup>. This resonated with me, as I imagine it does with many who have found themselves as minorities at different times. As a Nigerian, Chimamanda has had to overcome western attitudes to the continent of Africa. She gives examples of the way a single story is built in the minds of others. She says,

*"To create a single story, show a people as one thing, as only one thing, over and over again and that is what they become".*

The examples she gives demonstrate how type casting and stereotypes are created. Her argument reminds us that this simplified perception frequently affects those who experience stigma because of mental health problems. She also says that it is impossible to talk about the single story without talking about power.

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<sup>1</sup> [http://www.ted.com/talks/chimamanda\\_adichie\\_the\\_danger\\_of\\_a\\_single\\_story.html](http://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story.html)

Chimamanda reminds us that the way stories are told depends on power dynamics. She says, *“How they are told, who tells them, when they are told, how many stories are told, are really dependent on power. Power is the ability not just to tell the story of another person but to make it the **definitive story** of another person”*. [my emphasis]

Immediately there is a resonance for those who struggle to overcome prejudice around mental health issues. It emphasises the need for people to express their own story in their own words and to be empowered to do so. Finally, she explores how stories can alter perceptions and show people as whole, thus challenging stigma. Chimamanda says, *“Stories have been used to dispossess and malign, but stories can also be used to empower and to humanize”*.

### **Who Tells These Stories and What We Tell Ourselves**

We tell ourselves different stories according to our connection or disconnection, to our integration or disintegration. Our stories relate to our connectedness to the here and now, and to our hopes for the future; to our good sensations or to the spinning chaos of time distortion, isolation and dysfunction. Each of the latter will be a partial truth for a time, like having too much to drink, with slurred speech and wobbly walks. Many may have been there: but hopefully, it is a mode of being that people act quickly to overcome!

So how we tell our own stories, how others share our personal stories, matters. Who tells and how, can alter our perceptions and our actions and those of others. When people reflect on or tell our stories with hope, then we can start to regain belief in ourselves. We become more able to find inner resources to recognise and activate our own strengths and regain a focus on the future. Then we can challenge any temptation we have, to hide or shield behind what seems like fate, the behaviour of others, or a sense of weakness.

Personal stories of recovery are precious. Their value lies in their capacity to transform, to show people as complex, living, changing beings. They can and do challenge stigma.

### **Language, Recovery Principles and Changing Power Relationships**

As a member of Recovery Devon and a keen enthusiast of the document “Putting Recovery at the Heart of All We Do”<sup>2</sup>, I support the focus on mutual respect and the values and principles that are its basis. It enables people who provide services and those receiving help, to each better identify their roles and responsibilities when moving toward recovery focussed support and language. These ‘Daisy Pages’ clear up much of the confusion that arises over putting recovery principles into practice. The document has been described as a conceptual compass. It helps steer the way through many untold complications, about delivery of services to support people with very real needs. It also asserts the importance of supportive relationships, trust and reflective practices. Implicit within it too, is the belief that those receiving services, will feel encouraged to engage in respectful and considered ways with those who support them, as far as they are able within their own health circumstances. So this advisory leaflet encapsulates a humanistic approach for workers within the health service and points a direction for those of us who receive support. It specifically states:

*“Words are important. The language we use and the stories we tell have great significance to all involved. They can carry a sense of hope and possibility, or be associated with a sense of pessimism and low expectations, both of which can influence personal outcomes”*.

This leads me to welcome changes within the ‘New Horizons’ document<sup>3</sup>, which values wellbeing as well as mental health. It helps create the idea of wellness as an achievable aim for living. I also

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<sup>2</sup> [http://www.recoverydevon.co.uk/download/Putting\\_Recovery\\_At\\_The\\_Heart\\_of\\_All\\_We\\_Do.pdf](http://www.recoverydevon.co.uk/download/Putting_Recovery_At_The_Heart_of_All_We_Do.pdf)

<sup>3</sup> [http://www.recoverydevon.co.uk/download/2010-02-04-299060\\_NewHorizons\\_acc2.pdf](http://www.recoverydevon.co.uk/download/2010-02-04-299060_NewHorizons_acc2.pdf)

welcome the proposal of a multi-agency approach to tackle the root causes of mental ill health, if this has the necessary teeth and resources to challenge poverty and exclusion. There is a shift toward 'we' rather than 'them' and compared to previous policy, the document talks more about individuals, effectively seeing them as people experiencing mental distress. Yet it still retains the term, 'service user'. I along with many, hold the view that people who use services are people first – a person who uses or receives services, is so much more than a 'service user'. Being seen as a unique person rather than solely through a diagnostic lens or by a connection to services, gives a fuller picture and suggests a dynamic relationship with those who provide services. It feels demeaning in some way, to be seen and defined in a singular way, as someone engaged with services rather than a person living their life and striving to overcome the hurdles within it.

### **Challenging Stigma - People First**

The Recovery movement seeks to see people as separate from any illness, and more than any intermittent or enduring disquiet within the mind. The words people use, and the respect and dignity with which they convey messages, can make a person feel hopeful or can hinder progress. Thus we need to be more vociferous about the terminology used and the attitudes adopted by others. I defend my right to be seen as a person first and foremost and remain uncomfortable with naming/labelling which sees me as a 'service user' or other such labels. We need to look beyond the label and avoid seeing people through a single frame. These terms can make a person feel less equal. They can reduce the likelihood that people experiencing mental distress, will take on new ventures, such as new learning, or applying for jobs, because of the stigma that inappropriate language provokes. Thus we can limit our potential and we are less likely to be successful in undertakings, because we feel ourselves stigmatised by people and organisations around us.

### **Choosing Appropriate Language**

Although I believe that the language lies at the heart of the matter, the issues are also complex. There is a need to recognise the context, and at different times people can be and are described, in different ways. It is hard to convey the complexity of how people feel about the language that is used around their lives. When very unwell, many people find that paradoxically every single thing matters and almost at the same time, nothing matters at all. This fractured vision can leave a person acutely fragile and sensitive to how they are seen and spoken of. Ideally, a description of a person's relationship to mental health services should be agreed with the person themselves where ever possible. So on one occasion, some-one might be viewed as a person receiving services, or on another as a mental health activist or campaigner, a supporter, carer or friend, according to the services they receive or the contribution they make.

### **Language and Progress**

As times change and we find ourselves in a new situation, we need new words to offer new hope. The recovery movement recognises that people have the capacity to get well. This requires a changing relationship with the world in general and mental health services in particular (see Box 1: 10 key organisational challenges, Sainsbury Centre Final Policy Paper, 'Implementing Recovery - A methodology for organisational change', 2009).<sup>4</sup>

When each person is encouraged to step forward, to take back control, through expressing their own preferences, needs and strengths, they are able to establish their potential ability. They are then more likely to be able to move the situation forward. Being offered a choice about how to

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<sup>4</sup> [http://www.recoverydevon.co.uk/download/implementing\\_recovery\\_paper\\_\(SCMH\\_2009\).pdf](http://www.recoverydevon.co.uk/download/implementing_recovery_paper_(SCMH_2009).pdf)

describe ourselves can encourage us to regain a meaningful life away from mental health services. Such life opportunities should include the right to involvement in community, and to contribution through volunteering, connection and work, according to individual needs.

It was Freud who identified three things we need to be happy; relationships, occupation and recreation; we can simplify this as love, work and play. Mental health problems should not mean that people miss out on these chances for happiness, or become anchored to the past, because they have been through a bad patch. On the contrary, all should be valued for their current and potential strengths and should have plenty of opportunities to make helpful choices. When we are seen as 'people first' then it flows more logically, that we can better re-engage with life.

### **The Evolving Story, the Historical Context and Continued Inequality**

Historically, society has always found mental ill health conditions and experiences difficult to confront or think about. Even quite recently people were abused, subjected to un-anaesthetised electric shock treatment and lobotomised, because of attitudes of 'doctors', toward powerless minorities. Currently, there are many with mental health difficulties who languish in prison for minor crimes, and there are a disproportionately high percentage of people who are homeless, jobless, financially poor and lacking in secure and trusting relationships.

These disadvantages are so profound that in America, in 2006, a person diagnosed with a serious mental illness died on average twenty five years earlier than a person without such illness. ("The Roots of the Recovery Movement in Psychiatry", Davidson, Rakfeldt and Strauss; Wiley-Blackwell, 2010, page 2). This situation worsened from twelve years difference in 1986. It may be that 'Care in the Community', and the increased freedom and vulnerability of people when faced with difficulties accessing support, are partly responsible. Almost certainly stigma and exclusion are another part of the picture. It is a deplorable fact and we need to discover the statistics relating to discrepancies in the age of death in Britain and to highlight them and campaign for improvements.

### **Empowerment, Language and Identity**

As attitudes have changed over time, words have expressed the prevailing views of society. These words, which were often associated with behaviours linked to conditions, took on their own stigma, eg. 'lunatic', 'psychotic', 'neurotic'. Later the language used related to the diagnosis, e.g. 'schizophrenic', 'manic depressive'; later again it described the relationship with services, 'mental health patient', 'mental health client', 'service user', etc. As each word or phrase has picked up social stigma and become unacceptable, a new term is needed to replace the tarnished one.

It is easy to see why people who experienced mental distress sought the use of a more neutral phrase like 'service user', to replace the dramatic and often condition-specific language of the past. And though I am uncomfortable with it, others may feel that it describes a helpful relationship at particular times. The nature of prejudice is that we are blind to our own.

Today, people who use services are more empowered and are beginning to have their voices heard, partly due to the efforts of people who have been through the mental health care system and found it wanting. The relationships that we have with ourselves and others raise questions of identity. Most people have the chance to grow into their identity and become secure in their own minds of their own values. They are not encumbered by the catastrophe of mental health breakdown and inpatient experiences. Most are fortunate and are not labelled by incidents of emotional collapse, although equally, many people will experience this at some time in their lives. Others receive labels, as a result of getting too close to the edge, when circumstances are such that there is no-one to help them back at a time of crisis.

## **Are we really just Service Users?’**

The term ‘service user’ can suggest both a static and a passive view of the individual, some-one who has an ongoing relationship with mental health provision. It can potentially act to retain that person in a set role and also focuses the views of people around them. It suggests no sense of movement forward from the position of being a passive consumer of services, towards gaining / regaining a sense of agency, identity and empowerment.

In the same way that Chimamanda Adichie identifies how a single story develops, we build images of a person as a ‘service user’ and this can create the same sort of stigma. As long as a person identifies her/him self primarily in this way, s/he is potentially less likely to develop an active personal and social role, moving beyond the 'catastrophic effects of mental illness'. While people can adopt different roles in different circumstances, the identity of 'having a mental illness' or 'being a service user' can all too easily become that which pushes out more positive identities.

Most people today would probably not choose to adopt the term 'service user', ‘mental health client’ etc, to describe themselves, for the above reasons. But they ‘accept’ that they are seen as such, by an organisation, Mental Health facility, government etc. It still often suits organisations to describe people thus. In my experience, this is not the best way forward. When people who provide services see those they support holistically, they stop seeing a person solely through a medical model. As a result, instead of disempowering that person, they can offer hope and encouragement. In turn this enhances recovery, and reduces stigma and a sense of 'them and us'.

So empowering people to speak up is only a part of the value of person centred strategies. When each person is seen as a person, rather than primarily within a diagnostic framework, and is offered a range of support and encouraged to take back control, they can begin to make headway. But inclusive opportunities need to be in place to support re-engagement with communities. People with mental health issues need the same entitlements to general health care, healthy activities and involvement as others. Then they can assert their own needs and strengths and develop potency and hope. We know that other people, including health workers, ultimately can't ‘recover’ us. They can help through the words they choose and the support they offer, and by appropriate medical care, but ultimately we have to find for ourselves, the inner resolve and resilience needed. This is most possible when the social context is vibrant and hopeful and the access to help appropriate.

## **Finding Ourselves and Developing a Personal Identity**

Receiving a diagnosis can also be self stigmatising. A mental health label can be disquieting in itself. Recognising that we are all more the same than different can help. For everyone has some sort of baggage they carry, a personality difficulty at some time, whether it's panic about having locked the door, or trying to juggle too much work and having a poor work-life balance. Guilt, anxiety, anger: we all have personalities that are less than perfect at some point. Being able to choose our preferred form of words to describe a relationship to services can make a difference.

We also need to challenge whether a diagnosis is fixed, definite and accurate. If we describe ourselves according to a diagnostic category, then it can appear to be set in tablets of stone. In reality nothing is as constant as change and people can grow through spiritual transformation such as a mental illness, improve their wellbeing and return to more fulfilling lives.

When we think back to the international impact of the New Zealand recovery movement we can reflect on their debates on language. I believe that there isn't a Maori word for ‘patient’, but the word that is nearest, translates as ‘seekers after wellness’. This emphasises the active role and engagement of the person themselves in their own recovery, in the same way that we are seeking.

## **What Do We Call Ourselves?**

While I will continue to argue for person centred language, putting the person first in any description, I know there are others, who would favour the word 'patient'. Then a person is seen as like any-one else with a physical problem, and seeking help. It is worth noting that the term 'patient' has a specific context. It recognises reciprocal roles and contracts. The 'patient' occupies one axis of the 'doctor-patient relationship'. The designation of 'patient status' also provides rights and responsibilities. As a 'patient', one is supported by the art and science of a doctor's medical care, legal responsibilities and interventions. Perhaps in the light of major changes predicted for the National Health Service, we need to re-emphasise the paramount nature of this caring role. Although personally I find it hard to see the term 'patient' encapsulating the recovery dynamic, I accept that there may be good reasons to support its use.

## **Does Stoicism have a Place?**

There is another way of looking at this. As each person begins to build resilience following an episode of illness and gains a renewed sense of personhood, it becomes possible to see language for what it is, a single part of a bigger story. With improved insight we can challenge any self identification with being a 'service user', 'vulnerable', or 'ill'. We can start to avoid seeing ourselves negatively, as disabled. That way we can also question the temptation to believe that 'my life problems are just to do with what has happened to me.' Regaining resilience, courage, and hope, it becomes possible to see oneself as a person first, with personal roles and responsibilities, including towards one's own health and wellbeing. This feels like a crucial forward step.

## **People in Recovery**

But if language and stigma matter to one person, they probably matter to many. And the respect that is shown in exploring these aspects is partly as important as the outcome. People should have a right in general situations to describe themselves in words of their own choosing. "The Roots of the Recovery Movement in Psychiatry", Davidson, et al; Wiley-Blackwell, 2010, (page 5), contains the following comment, which succinctly sums up the importance of person-centred language.

*"We believe strongly in and adhere to person-first language in our work.... We thus refer to individuals with serious mental health illnesses as people with serious mental illnesses, or people in recovery rather than as 'the mentally ill' or any one of the historical epithets used to refer to such individuals ( e.g. 'mental patients', 'schizophrenics', 'manic depressives', etc). It is as we will repeatedly stress, a foundation of the recovery movement to view people with serious mental illness as people first and foremost, and only secondarily as people who have happened to develop a mental illness. The illness or diagnosis can no longer be viewed as subsuming the person."*

The real danger in the single story, for people with mental health issues, is that in showing a partial view, it distorts perceptions and creates a society fearful to engage with people who are seen as different. When we share our stories and are seen through a human lens as distinctive, fallible beings, striving to manage our lives, then we as 'people in recovery' are likely to regain our sense of purpose and hope for the future. If we can be viewed across the nation as people first, people, in our communities, overcoming difficulties in much the same way as every-one else, then we can regain a sense of normality and potential in the lives we live.

The story of improving relationships and language, and of challenging stigma, is part of the journey to encouraging communities to address mental health and wellbeing as a normal aspect of life. A healthy society will value and nurture the growth and diversity of its people. My hope is that others will continue this exploration of these issues.