

Briefing Paper: Destigmatising Services

An introductory guide to removing stigma as a barrier to engagement for people who would or do use services.

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Explanatory Note

This Briefing Paper is designed to stimulate discussion in services and systems of care about the way people who use services feel about belonging in services, how they feel about the validation of their own experiences. It is offered in the context of transforming services and systems towards more trauma informed approaches. It is intentionally provocative and designed to question tacitly accepted practices and the relations of power between professionals and people who use services. Stigma doesn't just affect people who use services, it also affects professionals, many of whom have their own "lived experience" of various sorts and many of whom don't feel in a position to share that in their professional lives. The hope is that by using this guide in discussion in services and systems people will be able to make a difference in reducing stigma and making services and systems more inclusive.

What is stigma?

Stigma describes a devaluing of social status and identity which can be based on visible or invisible attributes. It works through a process of labelling, stereotyping, separating off and discriminating. Stigma sits on a spectrum which includes ignorance, irrational fear, and prejudice. If left unchecked it can become self-perpetuating, oppressive, and corrosive. It has played a part in the systematic dehumanisation and oppression of groups of people throughout history, enabling social inequalities to persist.

Where has it come from?

The concept of Stigma was made popular by Erving Goffman's work on 'the spoiled identity' (1968) although it was described much earlier by voices of prominent black writers such as Fanon (1965) and Du Bois (1903). The word itself dates back to classical Greece and the act of physically branding a member of an outcast group, thus rendering their status visible. This practice was still being recorded in Britain in the sixteenth century. In the nineteenth century the notion of stigma was inscribed in Poor Law policy by making charitable relief so unappealing that only those truly desperate would take it. This proved that they were genuine, but also marked them off with "the stigma of pauperism". The notion of the deserving and undeserving poor are still prevalent today.

The stigmatisation of people who experience poverty, homelessness, mental illness, addictions, and/or who have involvement with the criminal justice system has very deep roots in history, social structures, and the public consciousness. When considering "destigmatising" elements of society we have to view stigma in this context and see the person who is stigmatised as a "body totally imprinted by history" (Foucault, 1991, 83).

How does it function?

It is useful to see stigma as something that functions. It is a productive force that creates and reflects social inequalities.

While stigma might be experienced as emanating from the body of the stigmatised, in fact stigma describes a relation between normal and stigmatised persons...people acquire stigma in their exchanges with other people – be this a look, a glance, a comment or a more overt form of discrimination.

Goffman's understanding of stigma, as something produced in social settings, pivots on the existence of a social consensus about 'what is normal'. For Goffman, society 'works' and 'coheres' to the extent that members of society implicitly understand and share, or at least accept, the norms in operation in a given social context. (Tyler, 2018; see also Goffman, 1963).

Stigma is tangled up in power relations within society as well as webs of knowledge that surround certain groups. It is not just a negative attribute which leads to stigma, it is the particular stereotypes that surround particular negative attributes, and the historically embedded understanding within those stereotypes.

The stigma which surrounds poverty, disadvantage, and complex needs is underpinned by a belief that the people facing these experiences cannot be trusted to behave in responsible ways and therefore must be treated and managed in certain ways.

Evidence coalesces around this overarching belief into something which then appears watertight and truthful. This includes the particular type of data we seek to know about certain groups - such as their drug taking habits, their Adverse Childhood Experiences scores, or all the different needs they have.

Everyday policies and practices are rooted in this evidence: benefit sanctions, incarceration practices, foodbank vouchers, anti-begging policy, formal exclusion from services for bad behaviour or from hostels for rule breaking, drug testing of street homeless people. These policies and practices have massive impacts on those individuals and their life chances and affect how they are able to be in the world.

There is inequality in whose health and vitality is promoted and whose are not, whether this is through inaction or as a result of harmful action. The morbidity and mortality of people experiencing homelessness, for example, is starkly lower to those who are white, British, well-educated, taxpayers. And society, to some degree, simply accepts it.

Goffman wrote that the "psychological price" of stigmatisation is "living a life that can be collapsed at any moment" (1963, p. 108). Many studies have shown the myriad effects of chronic stress that is common amongst people living in poverty, including from a cognitive functioning perspective and a disease indicator perspective (McMannus et al, 2013, Blair and Raver, 2016).

Such health inequalities are intersectional, too. Racial stigma cannot be separated from the stigma of poverty or disadvantage. For example, the risk of severe mental illness is viewed as an inherent risk of being a black Caribbean man. So, the problem is reduced to racialised understanding which removes structural causation from consideration and this perpetuates stigma. This view could be reframed by questioning how constituting a group as threatening and dangerous then influences the risk of their exposure to racism, of their experiencing and being diagnosed with illness, and their adverse treatment for that illness. (Synergi, 2018)

Destigmatising Services: sites of 'intervention'

It is not possible to commission destigmatisation. Destigmatisation is relational. However, it is possible to commission enabling environments in which people have the time to care. That this has been designed out is itself a result of stigma.

This table suggests some interpersonal, service level, and systemic levels of destigmatising care.

| Stage of care | Trauma Informed Principles | Worker (interpersonal) | Service | System (e.g. government, policy) |
|---------------|----------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Reception | Safety Cultural consideration Choice | Trauma Informed training Has time and desire to engage relationally not transactionally Meets people where they are at. Does not insist upon engagement | Premises are suitable, and designed thoughtfully within principles of Psychologically Informed Environments and ideally co-produced with lived experience | 'No wrong door' to access services Funding is not siloed. Multiple forms of care on offer enables greater choice and remove assertive engagement / requirement |
| Assessment | Trust Choice Cultural consideration | Has time and desire to engage relationally not transactionally. Works diligently to identify types of support wanted and/ or needed Identifies assets and capabilities | Assessments are not predicated on recording deficits and extracting negative causal pathways Flexibility in assessment criteria Assessment coproduced with lived experience | Outcome measurement requirements are transformed |
| Intervention | Choice Collaboration | Works holistically, relationally and with a focus that builds on assets and wishes | Broader notion of what 'intervention' and 'work' entails because outcome measurement | Outcome measurement requirements are transformed |

| Safety Empowerment | Flexibility in terms of engagement. Long term working relationship enables trust to form | requirements are enabling Broad scope of therapeutic options available | Funding increased and not restricted, resources can be deployed more flexibly and in a personalised way |
|---------------------------|----------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | Scope for individual to mould activity | Workers not given large caseloads | Multi agency working is the norm |
| | | Workers provided with ample training and support | |
| | | Service provision co-produced with lived experience | |
| Collaboration Safety | Monitoring is conducted alongside individual with journeys defined and reflected upon in their language and on their terms | Outcome and monitoring requirements are dropped or transformed | Outcome measurement requirements are transformed |
| Empowerment | | Any overall standard monitoring is co-produced with lived experience | Quality Standards are appropriate and are not used restrictively |
| Empowerment Collaboration | Exit is by mutual agreement and not as a result of missed appointments | Outcome and monitoring requirements are dropped or transformed | Outcome measurement requirements are transformed |
| Safety | Capacity in workload to meet individuals who have exited | Open door for individuals to return | Capacity is retained to support re-entry into treatment |
| Trust Choice | | | |
| | Empowerment Collaboration Safety Empowerment Collaboration Safety | Empowerment Collaboration Safety Empowerment Monitoring is conducted alongside individual with journeys defined and reflected upon in their language and on their terms Empowerment Empowerment Empowerment Exit is by mutual agreement and not as a result of missed appointments Collaboration Safety Capacity in workload to meet individuals who have exited | Empowerment Empowerment Empowerment Empowerment Scope for individual to mould activity Scope for individual to mould activity Workers not given large caseloads Workers provided with ample training and support Service provision co-produced with lived experience Collaboration Safety Empowerment Empowerment Empowerment Exit is by mutual agreement and not as a result of missed appointments Collaboration Exit is by mutual agreement and not as a result of missed appointments Capacity in workload to meet individuals who have exited Trust Broad scope of therapeutic options available Workers not given large caseloads Workers provided with merapeutic appoint near and monitoring requirements are dropped or transformed Outcome and monitoring requirements are dropped or transformed Outcome and monitoring requirements are dropped or transformed Outcome and monitoring requirements are dropped or transformed Open door for individuals to return |

| Community | Safety | Is also engaged in meaningful work in the community alongside | Provides space for community groups to flourish | Public investment in community programmes which |
|-----------|------------------------|---------------------------------------------------------------|-------------------------------------------------|------------------------------------------------------------|
| | Choice | their professional role | | provide people with places to go, belong, and have purpose |
| | Cultural consideration | | | |

The antonym of the word "stigma" is "belonging". At every level, while people are with us as workers, as managers and at a system level we must do our utmost to make them feel that they belong.

Going Deeper: How does stigma manifest?

- People experience stigma in exchanges.
- Stigma within services and access to services.
- Self-stigmatisation (shame).

People experience stigma from service providers in exchanges.

'Deficit-based' models of service provision - that are predicated on narratives surrounding 'fixing' a person's 'needs' - lead to interactions that make the individual feel worthless; experience isolation and loneliness within services; and face social stigma from service providers and other members of the public (e.g. Mayday Trust, 2018; Sanders and Brianna, 2015). WY-FI co-production champions noted "the familiar reality of stigma across all services around multiple and complex needs" including negative perceptions from staff.

Labelling is tied to stigma. Stigma has been associated with the acquisition of psychiatric diagnosis (Fraser, 2000), in being labelled as a 'problem user' or drug addict - even when in recovery (McPhee, 2013).

if you're on methadone It's like you are looked at in a different way when you're on methadone eh. you're a dirty person. And less of a person. Because heroin's a dirty drug right, but like when you're on methadone you're not seen as people who are trying to get off drugs... The woman at the chemist as soon as she knew I was on methadone Boof. Nothing [she stopped being friendly toward him]. Next day, I was on time and I came in and-nothing. See I'm trying to better myself, I'm a better person than you hen (**Stevie, research participant**)

In spite of guidance surrounding the positive role pharmacists might play in the recovery of heroin users, persistent institutional stigma has been widely seen to reinforce addict identities, forcing methadone to be taken in view of the public thereby exposing the 'undeserving' customers to a public gaze, and encouraging clients to be passive recipients of treatment. These have poor implications for recovery (Harris and McElrath, 2012, Mill et al, 2010)

The label of 'vulnerable' also carries a stigma and can have exclusionary effects. When 'vulnerable' denotes difference - as opposed to those who are not vulnerable - it results in segregation and entrenching inequalities, since it rests on qualities that are deficient in relation to the non-vulnerable (Brown, 2011). Furthermore, there are issues of power at play in who gets to decide who is or is not vulnerable or in giving someone a diagnosis (and this is more likely for ethnic minorities) (Brown, 2014)

Stigma within services and access to services

People with poor Mental Health in Scotland are likely to die 20 years younger than those without due to physical illness. Relatedly they are likely to wait over 4 hours in accident and emergency compared to those without.

"What do you think an A&E department should be able to do?"

"Just listen to you, and instead of going in dictating what I want actually just listen to them as well, and listen back. Instead of going in with a mindset" (Alice and Terry, researcher and participant)

People who experience multiple needs are often excluded from appropriate psychotherapeutic support, despite frequent and cyclical traumatic experiences being commonplace (Dowding et al, 2022). Evidence shows how those who do get psychotherapeutic support were more likely to engage in positive developmental contact with external support services, and less likely to require reactive, negative contacts. (This is also buttressed by Sandhu et al 2019, WY-FI, 2020).

Within services stigmatised people will face inequality in the way their behaviour is perceived and punished. It is well documented that certain people may be formally excluded from services for "challenging behaviour", which may lead to an entrenchment of their problems, inequality in access to healthcare and treatment, and a further entrenchment of distrust of services (WY-FI, 2019).

20% of WY-FI beneficiaries have been banned from services. Firstly, this means people don't receive the care they desperately need and secondly, they become further excluded. Psychologically, this feeds a person's belief that they cannot be helped making it less likely they will engage in the future. And thus, the cycle continues.

A particularly high degree of stigma is thought to attach to people caught up in the homelessness, substance misuse or criminal justice systems owing to perceived behavioural 'deviance' or 'transgression (Shelton et al, 2010, Fitzpatrick and Stevens, 2013, McNaughton, 2009)'.

But viewed a different way, challenging behaviour has also been shown as a *consequence* of material disadvantage and previous traumas (Maguire et al, 2010), as a consequence of acquired brain injuries - highly prevalent in homelessness and those who are incarcerated and which for women are usually linked to domestic violence and abuse - which affect cognitive functioning (Disabilities Trust, 2015); or even as a side-effect of prescription medication (Healy et al, 2006, Golebiewski et al, 2020).

We will never prove our way out of this sort of stigma, no matter the evidence. It requires a shift in founding assumptions of the client.

Self-stigmatisation (shame)

Public stigma is the most prominent form observed and studied, as it represents the prejudice and discrimination directed at a group by the larger population. Self-stigma occurs when people internalise these public attitudes and suffer numerous negative consequences as a result.

It has been noted that experiences of stigma and discrimination affect engagement with services, making it less likely people will engage. Moreover, stigma is 'additive' and when someone perceives one form of discrimination, they are more likely to perceive other forms of discrimination too, increasing the risk of negative consequences. Research has also noted that some people stigmatise others in their group in order to absolve themselves of their stigma (i.e. by distinguishing themselves as 'genuine' rather than 'scroungers').

The experience of stigma is closely related to feelings of shame.

Shame is experienced when one sees oneself as lacking in some way and can result in low self-esteem, social withdrawal, and avoidance. However, shame is not only a psychological construct, but should be seen as a technology for political oppression. Shame is produced through a complex assemblage of social and institutional discursive practices that erase the structural causes of poverty and hunger, reducing them to individual problems. Shaming discourses represent political and communicative power – the power to produce negative differences to oppress populations. (de Souza, 2022)

The Internalised Stigma Mental Illness Inventory-29 (ISMI-29) measures self-stigma using four categories:

- Alienation: Feeling embarrassed, ashamed, inferior or disappointed in yourself for being ill. Feeling that your illness is your fault. Believing mental illness has ruined your life. Feeling like others are incapable of understanding you.
- Stereotype endorsement: Applying stereotypes to yourself, such as people with mental illness are violent, can't live good or rewarding life, can't do certain typical things (e.g., get married, work a steady job, contribute to society) and can't make decisions for themselves.
- **Discrimination experience**: Feeling discriminated against, patronised, ignored or not taken seriously; believing others would not want a relationship with you; feeling incapable of achieving much.
- Social withdrawal: Avoiding getting close to people who don't have mental illness, socialising or talking about yourself because you feel like a burden, out of place or inadequate, like a potential embarrassment to loved ones.
 (Boyd et al, 2014)

The "why try" effect describes the self-stigmatisation which interferes with life goal achievement. Self-stigma functions as a barrier to achieving life goals. Diminished self-esteem leads to a sense of being less worthy of opportunities that undermine efforts at independence like obtaining a competitive job (Corrigan et al, 2009).

When people perceive devaluation, they may avoid situations where public disrespect is anticipated.

Going Deeper: Destigmatising services

Stigma is acknowledged in policies and by service providers but destigmatisation is rarely defined and strategised. It is quite often mentioned in a list of experiences, as if stigma is an unavoidable part of the experience.

Whilst the APPG on Social Action and Complex Needs (2015) suggested that peer mentors were invaluable in combating stigma based on their shared experiences, there was no pause to ask why the solution to stigma was only for stigmatised groups to work with each other? Why wasn't it asked: what is it about the current forms of care that continue to perpetuate stigma for this group? What role can all individuals play in destigmatisation?

If stigma is about the dehumanisation of particular groups, in which they experience inequalities across their life-course as well as in the various daily interactions, then destigmatisation is about valuing those groups as equal, treating them with humanity and within a framework of universal needs.

Of course the solution is you have to get rid of the whole thing and start over...and operate as if we were all human beings (Mel Reeves, in Davis & Beckstrom, 2021).

Starting again isn't viable for most. But an important first step for services is to ask: will this service destigmatise, or will this service perpetuate stigma in order to meet other aims (such as monitoring and evaluation requirements, resourcing)?

Destigmatisation is a whole system process and requires out of the box thinking. It is disruptive and transformative and actually very simple, **rooting in human connection and universalism**. If you simply collect less data and connect more to the individual you're already destigmatising.

Out of the box thinking.

1 Reframe the individual within concepts that are universal

The challenge mounted by transformative approaches to providing care asks: if what we all need is a sense of purpose, belonging, trusting relationships, and a feeling of safety and security then do we really need to know about the detailed life experiences of the individual asking for help? Do their deficiencies really need to be recorded and monitored? Does it help that person to have their childhood adversities held under a microscope?

As an example of how certain groups are judged differently to others, the "recreational use" of cocaine in Britain (noted amongst high-income earners in finance, for example) is no different to the "misuse" of heroin. They are both illegal drugs. There is no routine drugtesting of the general population, even though it is evidenced that the UK illegal drugs market is worth millions and that the global drugs market is devastating socially and environmentally. The evidence gathered surrounding the 'substance misuse' of people sleeping rough, for example, serves to reinforce a negative stereotype of people sleeping rough as drug addicts, and in some way responsible for their situation. Only people experiencing disadvantage are targeted and responsibilised in this way. Instead, we could ask why use drugs at all? For pleasure, for pain management, to soothe, to distract, to forget. There are universal needs which we all meet in varied ways including illegal drugs, shopping, eating, even social media. Only some people's pain management is held under the microscope and pathologised.

A transformative approach would drop the need to learn about drug taking habits. Or would see drug use as a coping mechanism and be able to refer that person towards long term therapeutic support.

Transformative approaches have shared humanity as their foundation.

The May Day Trust provides a person experiencing tough times with a Coach who works with their hopes and ambitions to create opportunities in which they can feel better about themselves in the world. The May Day Trust does not collect any data about the individuals they work with that reinforce stigma or highlight negative stereotypes.

The **Poverty Truth Commissions** and **Wandsworth Empowerment Networks** bring together people experiencing poverty or otherwise disadvantage with those in policy and politics to create long-term, vulnerable and trusting relationships as a basis for working together to ensure mutual trust and understanding.

L'Arche creates communities in which people with and without learning disabilities live together and give reciprocally.

2 Focus on authentic relationships

Service providers need the time and space to build a trusting relationship with the person experiencing tough times and in need of some help. Big case-loads which diminish time with beneficiaries is detrimental to everyone, leading to negative feelings from service user to provider, and burn out amongst providers.

I don't think Community Psychiatric Nurses are given enough time...they've changed. I used to have a CPN that used to drive and sit with me for an hour and we used to talk about anything and have coffee and it was great. Now a CPN gets fifteen minutes! They're not given enough time to do anything... [my new one] said sorry I'm not that kind of CPN I've just been drafted in to give you your maintenance script! (Craig, research participant)

The WY-FI and Fulfilling lives approaches centre this approach using navigators who work long term and flexibly with people in order to develop trust and improve access to sustained therapeutic support.

Because relationships are not quantifiable in economic/efficiency terms, they are often discounted as important or as 'valuable work'. But relationships are the foundation to all of our wellbeing. Practices such as "gathering, listening and tending" to another should be seen as radically ordinary, with "revolutionary political significance" (Hauerwas, 2011)

3 Encourage reciprocity

When a person is unable to reciprocate, they are tied into a "bondage" of gratitude which puts them at a disadvantage in relation to the giver (Simmel, 1950, 393). It is good for our sense of self, purpose and belonging to be able to give and give back.

Though we might operate within a society that focuses on individual endeavours, societies are created and sustained through networks of interdependencies, and we are all always caught up in networks of care. The interdependent nature of society and social action means that "we owe one another a certain measure of reciprocal care" (Young, 2011, 9).

We promote the benefits of volunteering and peer mentorship to service users, but we don't consider how service providers can receive. Within a transactional paradigm of service provision, in which there is no room for relationships, the helper is never able to be helped in some way. Such a lopsided relationship will maintain divisions.

4 Create spaces for belonging and community

People need places to go to be and connect with others. People want to feel equal to the other people around them, and people don't like to feel judged.

The Grassmarket community Project in Edinburgh hosts courses and activities which are open to everyone. Although the offerings - including free lunches - are best served by people who are homeless and experiencing tough times, everyone who attends is referred to as a member, and everyone has opportunity to give as well as receive.

Some recovery movements create spaces of belonging for people of a certain stigmatised groups, such as sober gyms. For example,

The Phoenix ("Phoenix") is a sober active community that provides free, active and engaging programming - such as rock climbing, CrossFit, yoga, dance classes and social events - to anyone in recovery from a substance use disorder or who chooses to live a sober lifestyle. Phoenix is not a replacement for treatment, nor is it simply a "sober gym." Instead, Phoenix picks up where treatment services leave off by offering a welcoming, safe and supportive community to recover and heal, free to anyone with at least 48 hours of continuous sobriety. Recognizing the interpersonal trauma and social isolation are at the core of many people's addiction, all programming is aimed at bringing individuals into a community that instils hope instead of fear and fosters personal growth without judgement. Phoenix instructors are peers who have lived experiences through their own recovery journey or personal connection to the mission, which promotes trust, hope and emotional safety. (Wyker and Hilios, 2020,3)

5 Work together

We must rethink participation, what counts as knowledge, and who gets to create it. You cannot dismantle the master's house with the master's tools. Neither can we destigmatise services by using traditional methods of evidence generation/ gathering which continue to silence people who use services.

Research makes knowledge, and it buttresses the systems we already take for granted. It is not just the concepts that need deconstructing but our methods of creating knowledge.

There are world making practices at play when conducting research, or co-producing services. By co-producing knowledge with people who bear the brunt of stigma we create opportunities for transformation: both of their own sense of self, *and* the systems of inequality which surround them.

6 Assets and journeys

The underlying deficit inherent in the word 'recovery' results in a situation whereby recovery presents barriers to social and political participation. This can be seen as extending the stigmatisation of the identified group as well as narrowly defining what 'recovery' looks like (Fraser, 2000, see also Rose, 2014).

Empowering individuals seems to be an effective way of reducing self-stigmatisation. Encouraging people to believe they can achieve their life goals and circumvent further negative consequences that result from self-stigmatizations.

Empowerment is, in a sense, the flip side of stigma, involving power, control, activism, righteous indignation, and optimism. Investigations have shown empowerment to be associated with high self-esteem, better quality of life, increased social support, and increased satisfaction with mutual-help programs (Corrigan and Roe, 2012)

It's key to believe in one's role in the wider community and society.

Journeys can be supported through finding roles which are meaningful to an individual: this could be things like service user involvement or removing barriers to employment (Revolving Doors Agency, 2018).

"Employment that's actually spiritually good for you...Doctors were saying they're happy if you were working but it's how you're treated. It needs to be helping you a little bit. Why should people with disabilities do the crappiest and most physical jobs?" (Esther, research participant)

Autonomy is key. There is a difference between abstinence that is required of a person experiencing homelessness, and abstinence as a goal that an individual sets themselves. Or the requirement for compliance with treatment, or rules, or a service versus engagement with that service.

"It's funny if i could just see a physio and get some therapy I'd get much better" (Esther, research participant)

"Not aiming for completely level, just aiming for small ups and downs, not big ups and downs (gesticulates big wave motions)" (Stevie, research participant)

7 Language

Destigmatising language can help change the way stigma is experienced to a degree. Not referring to drug taking as "misuse", not labelling someone with deficiencies such as vulnerability, or with complex needs, or at least not leading with those identifiers. These practices go a long way, as do the subtle shifts from homeless person to person experiencing homelessness.

Yet language itself does not dissolve stigma. Stigma sticks to the person; it is not stuck to the concept. Moving from "multiple and complex needs" to "severe and multiple disadvantage" implies a shift in emphasis from individual to environment, yet the individual is still subject to similar systems and processes in which stigma is involved.

8 Monitoring

Only record what is absolutely necessary (this requires a systemic shift in what we define as necessary!). Would you collect this data about yourself? How would you hold up to it? Collecting 108 data points at quarterly intervals is a 'dividing practice' which ensures the service user remains the Other (Foucault, 1976).

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