

REVIEW

Recovery tools in Mental Health Services: Are they adaptable for Deaf people?

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ABSTRACT

The concept of recovery has emerged as a significant paradigm in the field of public mental health services¹. A number of recovery tools have been developed and are increasingly being used to support recovery-focused practice and person-centred care. Fundamentally these recovery tools are rooted in a personal recovery model and founded on a philosophy of individual self-determination. It is a misconception by many that the use of sign language is a mixture of signs and gestures created from spoken language. In fact sign language is a language with its own vocabulary and grammatical structure. Yet it appears that Deaf mental health service users and staff are expected to use existing recovery tools that use the concepts and language created for a hearing society with English as a common shared language. This paper will explain the concept of recovery and discuss this in relation to Deaf service users. The use of recovery tools within Deaf in-patient and community Services around the UK, Europe and Australia will be explored through discussion of the use of a questionnaire sent to known Deaf mental health services. The results indicated that the term "Recovery" within Deaf mental health services and recovery tools were relatively unknown outside of the UK. Recovery tools appear to be rarely used in Deaf services, especially those in the community. The overall consensus of respondents was the need for a recovery tool that is specific to the Deaf community. However, consultation is required with Deaf service users and their involvement in developing such a tool is crucial.

KEYWORDS

Deaf, mental health, recovery, tools

Introduction – What is Recovery

The concept of recovery in mental health has increasingly become a key feature of UK Government policy and guidance^{2,3,4,5} and support for a recovery approach is evident in the literature of the main professional bodies^{6,7,8}. The follow up to the National Service Framework for Mental Health⁹, No Health without Mental Health¹⁰, again placed great emphasis on the importance of recovery. A commitment to achieving the objectives outlined in the strategy from a wide range of professional bodies was summarised in a shared statement, No health without mental health: A Call to Action¹¹, in which they pledged to work together to make change happen. It appears that recovery, in principle at least, is identified as being of real importance.

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But what is meant by the term ‘recovery’ in the context of mental health? The notion of recovery can be considered from a variety of perspectives, for example social, historical, psychological, and political. A further consideration arises from the distinction between medical or clinical recovery and personal recovery. A recovery approach is not without its concerns or its critics, as is evident in arguments and counter-arguments highlighted in the literature^{12,13}. Indeed in some quarters the very concept of recovery itself is contested¹⁴. Consequently a host of potential challenges arise from both definition and interpretation. Whilst it is not within the scope of this paper to explore all aspects of recovery of particular relevance is the concept of personal recovery as it is around this principle that the majority of recovery tools have been developed.

Personal Recovery and Clinical recovery

In a medical or clinical model of mental illness the approach taken is professionally determined, symptom and diagnostically driven, and tends to view a person as an illness first – a victim of circumstance over which they have no control – and a person second. Recovery is determined on the basis of removal or absence of symptoms, a term given to which is clinical recovery¹⁵. Using a clinical definition of recovery few people with severe mental health problems would recover. Whitwell¹⁶ argued that recovery from mental illness is a myth, stating that ‘recovery can act as a mirage leading onto something that is not really there’.

In contrast personal recovery is built around the values, experiences and beliefs of service users and found in narratives characterised by examples of people living a full and meaningful life in spite of symptoms or diagnosis¹⁷. The approach to recovery emphasises the importance of hope, personal values and responsibility, has a focus on goals, strengths and aspirations, and advocates self-determination and self-management¹³.

Although it appears there is no consensus on a single definition of recovery¹⁸ one broadly accepted and commonly used definition is that put forward by Anthony in the 1990’s:

‘a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness’¹⁹.

This definition is widely cited in the recovery literature^{13,20,21} and also, increasingly, in Government policy and guidance^{6,22,23}.

A definition of recovery is important because it provides a basis for any approach that aims to support recovery and also because it provides standards (goals/outcomes) against which the success or failure of recovery could be determined and measured²⁴. An additional consideration is presented by Lakeman²⁵ who highlights the potential difficulties arising from the measurement of something that is defined by some as an endpoint and others as a process.

Clearly then discussion, open communication, collaboration and agreement upon what recovery means to the individual is of crucial importance and consequently any plan to support the individual in recovery should reflect their wishes and preferences^{26,27,28}. Therefore it would be of real value and benefit to use recovery tools that enable involvement, communication and understanding.

Why are Deaf community specific recovery tools important?

By its very nature the notion of recovery, underpinned by a personal recovery model, is driven and determined by the individual. Recovery tools developed specifically for the Deaf community are important not least because of the existing challenges of effective and enabling communication with the hearing population generally. A common misunderstanding that words used by the hearing population have the same meanings for Deaf people compounds difficulties in communication and understanding.

There are approximately 100,000 Deaf British Sign Language users (BSL) in the U.K.²⁹. Deaf (with a capital D) refers to those who primarily use British Sign Language and actively participate in the Deaf community. This is in contrast to the term deaf (with a lower case d), which refers to individuals who prefer to use speech and do not identify themselves as a member of the Deaf community (e.g. those who have lost their hearing after acquiring speech)³⁰. BSL users often identify themselves as being a cultural and linguistic minority rather than disabled³¹.

In contrast with the average reading age of school leavers (11 years old^{32,33}), a Deaf school leaver’s reading age is approximately 9 years old³⁴. This is because BSL is different linguistically and structurally to English. BSL is not a written language and, therefore, English is a second language.

Therefore, complexly worded questions may be misinterpreted by a Deaf person, who may respond to key words rather than the intended question in full³⁵. The low level of English literacy means that the Deaf community is often unable to access written leaflets, information and contribute to service user questionnaires, as summarised by a Deaf worker:

“Most information is impossible for a deaf person to read. There is jargon, terminology; sentence structure and Deaf people just can’t access this generally”³⁶.

Some concepts may also be difficult for Deaf people to understand as they may not have knowledge of them as this may not be a usual part of Deaf culture³⁷. For example, the use of timelines and rating scales are not advisable as they may not be readily understood by the Deaf community.

A number of recovery tools have been developed with the purpose of supporting someone to explore, plan and manage their personal journey. These include: Back in the Saddle³⁸, Wellness Recovery Action Planning (WRAP)³⁹ and The Recovery Star⁴⁰. Whilst there is no single, universally accepted and commonly used recovery tool across all mental health services, possibly the most commonly used tool globally is the Wellness Recovery Action Planning (WRAP).

Each of the aforementioned models appear to be predominantly English language based and unless delivered through some form of peer support or ‘study buddy’ approach rely on a person having literacy skills. This therefore presents a significant challenge for the population generally due to the levels of poor literacy skills reported nationally, one finding of which, as identified earlier, is that the average school leaver’s reading age is 11 years old^{32,33}. In 2006 a Government sponsored review into basic skills, the Leitch Review⁴¹ found that more than five million adults lack functional literacy skills at the level considered necessary to get by in life and at work.

This means that the available recovery tools may not be accessible to the Deaf community as some words that are commonly used within the hearing community may not be often used in the Deaf community. For example, terms such as ‘wellness’ and ‘crisis’ may not be easily translatable. In addition, timelines and rating scales can be misunderstood. Also, the stigma of Deafness and challenges this may present may make recovery more difficult. This may mean that the person needs ‘habilitation’ in order to support their recovery dependent on their life experience.

Recovery is a term used by professionals and the service users who come into contact with services who promote recovery. Within the Deaf community, it is not a term that

is used on a regular basis. As identified above, it is also a concept that has many different definitions, and can, therefore, easily be misunderstood, not only by professionals but by service users themselves. To illustrate the challenges of discussing recovery and recovery tools with Deaf people, there is not one sign used by all signers across the UK that encompasses recovery and all aspects linked with this.

In addition, a literature search of Deafness and recovery highlighted a dearth of papers regarding this topic.

Aims and Objectives of the Study

The study was undertaken on behalf of the International Nurse Specialist Forum (INSF). Its aim is to establish what is happening internationally in relation to the use of recovery tools with mental health service users who are Deaf. Professionals who work within the specialism of mental health and Deafness were consulted in relation to the aims and objectives of the study. These included;

- Are recovery tools being used?
- Were the existing recovery tools adapted to make them accessible?
- Was adaptation successful in making the tool fully accessible?
- Was one recovery tool used more than another due to accessibility?
- To explore professional’s views in relation to a specific recovery tool to be created for the Deaf community?

Methods

The authors who undertook the study are registered mental health nurses with a combined total of over 20 years working in the specialist field of mental health and Deafness. Will Hough works as a Clinical Nurse Specialist and Lecture Practitioner, and Rebecca Walls works as a Community Psychiatric Nurse (CPN) in South Yorkshire. They created a structured questionnaire which was distributed to professionals working in specialist adult inpatient and community Deaf services.

A list of contacts was created from the membership of the INSF, membership from the National Deaf Clinical Governance Group and members of the European Society for Mental Health and Deafness. A questionnaire was created (appendix 1) to establish professional’s views within adult inpatient and

community services to answer the above aims and objectives.

The questionnaire was structured to receive a mixture of qualitative and quantitative data. In order to meet the aims and objectives, the authors wanted to know not only what tools were being used within Deaf Services but also their effectiveness and how, if at all, they had been adapted.

The questionnaire was sent via email to 16 contacts within adult Deaf mental health inpatient and community services. It was decided to use a questionnaire rather than interviewing due to the distances between services, time restrictions and cost. E-mail questionnaires were selected over postal questionnaires to eliminate costs. It was also felt that the response rate would be greater if electronically based rather than via the postal system. There was also the facility that the authors were notified when the email was delivered and read. After the deadline date the questionnaire was emailed again to the list of people who had not yet responded and another deadline set.

The questionnaire was also presented by one of the authors (Rebecca Walls) to the European Society for Mental Health & Deafness (ESMHD) European Special Interest Group Conference in Lisbon Portugal, where the author was able to present the concept of recovery and recovery tools within Deaf mental health services and discuss this with professionals. A multi-method approach was chosen as it was felt it would yield an increased number of responses⁴².

Results / Findings

From the questionnaires returned 69% (n=11) of the inpatient and community services in the UK and Ireland and Australia responded. The responses from Europe and other international Deaf Service providers obtained via the ESMHD Conference was that they had not heard of the concept of recovery being used in Mental Health. Therefore only the responses from the questionnaires will be used as part of the findings and discussed further.

As stated, the overall response rate was 11. Of these, 82% (n=9) were from Deaf mental health community services, and 18% from Deaf Mental Health Inpatient services. There are seven inpatient services for Deaf people with mental health problems. Therefore, those that did not respond to the questionnaire were all inpatient services.

From the 11 respondents, only 36% (n=4) (fig. 2) used any or a standardised recovery tool. The remaining 64% (n=7) used none and from these 64% (n=7) were from services based in the community.

Figure 1: Breakdown of Respondents - Inpatient & Community Service

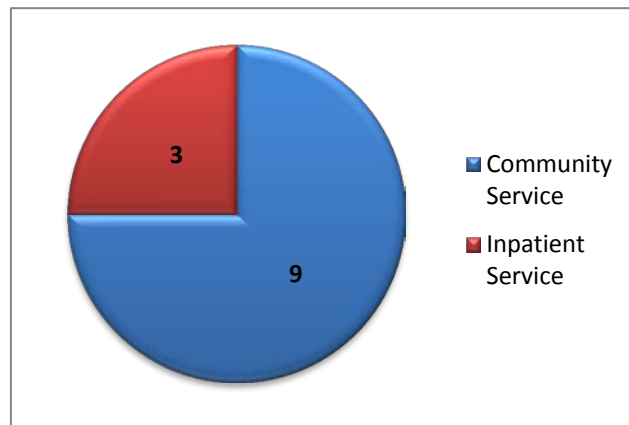
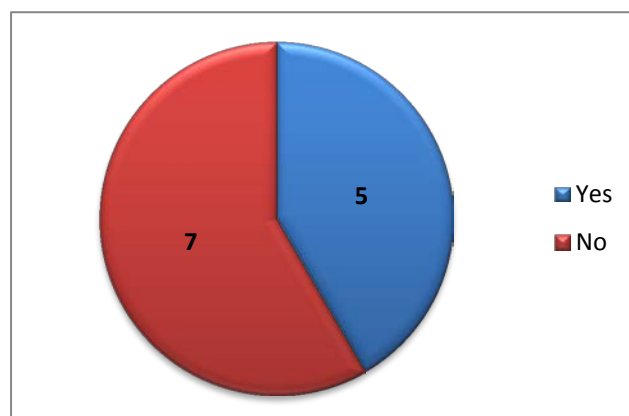


Figure 2: Do you use a standardised recovery tool?



From the 4 respondents who used recovery tools, half used WRAP. However, it was found that despite different recovery tools being used, the services that used them found that the tools were only partially accessible and had to adapt the format of the English and convert it to BSL in order to improve accessibility. Even with the adaptations the tools were still only partially understood and beneficial for the clients. Comments regarding the adaptations can be found in box 1.

Box 1. Comments about making adaptations to the recovery tools

“...this depends on individual clients. Some find useful and require no adaptation. Others don't like it at all and alternative tools or formats are used or extracted from the booklets.

We will also include various techniques to empower and gather evidence for the booklets such as

1. collaborative note writing
2. patient journey
3. social network map
4. strengths list
5. weekly activity plan
6. personal goals etc

Users' narratives are recorded in writing and on video as required.

Carers are also introduced their own recovery plan.

Recovery outcome star model, personalisation and physical healthcare agenda have been included.

The work has been delivered during 1 to 1 and group settings. Some users have attended our trustwide recovery meetings and conferences and shared their stories.”

“We are not allowed to adapt the tool so we have started to use the philosophy and principles of the tools to create individual recovery based tools e.g. recovery books that are visual ,BSL based and created with the involvement of the service user so that it meets their cognitive and linguistic needs and to make it as accessible as possible”

“The wording of the tool was simplified to some degree, with pictures added. However, out patient population have varied language and communication skills, so all required support to attempt this tool. For BSL users especially, this required talking them through the items.”

“We have tried to simplify the tool by adding images but ultimately, have had to resort to staff going through it and explaining the language in BSL.”

From the services that responded to the questionnaire, 82% (n=9; fig. 3) agreed that some work should be undertaken to develop a recovery tool that was specific and accessible to the Deaf people. 9% (n=1) did not respond and 9% (n=1) believed that there was no need as they felt “It is not about the tools or documentation but how they are implemented”.

Further comments about whether a specific tool should be created can be found in box 2.

Discussion

The overall response rate was pleasing with 69% of services contacted responding to the questionnaire.

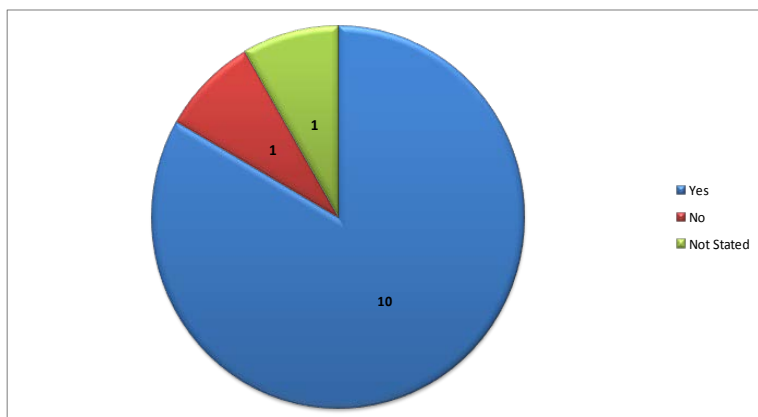
However, the authors were disappointed that there was not a greater response from the Deaf inpatient services where the authors believe recovery tools are more likely to be used than in the community setting. This may have given a clearer picture of the types of recovery tools used in practice and the adaptations Deaf services are undertaking to make them accessible.

The results indicate that despite recovery tools being a common feature of government policy and guidance, the majority of Deaf community services are not using any recognised recovery tools. This may be due to the general feeling that the tools are inaccessible to the Deaf community. Anecdotally, the authors are aware that recovery strategies and philosophies are being used but not the tools.

From the services using the tools, it was clear that adaptations needed to be made from their original written formats so they were partially accessible. However, even with adaptations, there was still only partial understanding and partial benefit for the services users. The authors recognise that as a result of this study, it would have been of benefit for service users who have experience of using recovery tools to have been involved in the study in order to get a clearer picture of how true their understanding of the tools really are.

It was noted that WRAP was used more than other recovery tools (although by only 2 services). This could possibly be due to commissioners requesting that services demonstrate recovery by using this tool. It appears that recovery tools were used more in England than in other areas. However, this may be due to the varying service provision provided by individual Deaf services, especially community-based services. For example, some teams (Scotland

Figure 3: Is there a need for a specific Deaf recovery tool?



and Republic of Ireland) provide assessment services and do not use recovery tools although recovery is embedded into their philosophies of care.

Box 2 – Comments regarding whether a specific recovery tool needs creating for the Deaf community

“Mainstream Secondary services are introducing recovery plans within this Trust and as we work in partnership with them, we will get involved as and when. I am aware this Trust is using the Recovery Star and WRAP. I have only been involved with one patient using WRAP with a CMHT”

“It is not only about the tools or documents but how they are implemented.”

“Yes-BSL based DVD .

Any English based tool will need to be adapted to meet individual need and this should be supported.”

“A general point, but I think it’s important to be clear what ‘recovery’ means, especially for those deaf adults with longstanding mental disorders (e.g. personality disorder; developmental disorders; specific learning difficulties). For some, it can be more a process of discovering than recovering, and we should be honest about that.

Given the range of communication skills of the adult deaf inpatient population we work with, any recovery tool will need to allow sufficient flexibility of approach. For those who need support, my preference is for a semi-structured format / interview, with some guidance for interviewers / support workers to ensure consistency of approach.”

“This is an important piece of work which requires all of the deaf services to work together. My shared pathway is not really appropriate for our patients and we would like to collaborate on designing a deaf friendly, specific tool.”

European services appeared to have minimal awareness of the concept of recovery, particularly with its definition as individual recovery rather than the medical model of recovery.

In relation to the creation of a Deaf recovery tool, the majority of professionals called for the prospect of one being created to be explored. It was felt by the authors that although they agree with the comments made by one professional that a specific Deaf recovery tool was not required, that consideration of a specific tool that is culturally appropriate and accessible to Deaf service users is recommended. It may be that the tool does not need to be in a written format but in a visual form (such as a DVD in BSL or pictures). This idea may not be unique to the Deaf community but also other ethnic minority groups whose first language is not English.

Recommendations

The authors recommend that research is undertaken with Deaf mental health service users who have experience of recovery tools being used as part of their care and treatment. Service user involvement is integral to ensuring any tools being used are meaningful and accessible⁴³.

It may be beneficial for authors of a pre-existing tool to work with the Deaf community and professionals working in the field of Deafness and mental health to research and adapt specific culturally appropriate tools.

It is hoped that publishing this article will raise the concept of recovery and the challenges in relation to working with Deaf mental health service users in recovery.

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