

'All About Me' Deaf Recovery Package Guidance Book



Introduction

Welcome to 'All About Me', a recovery package developed by groups of Deaf people to help support Deaf people with mental health problems. This booklet describes the reasons for creating "All About Me" and how it was developed. It includes a practical step by step guide in its use and guidance notes for each domain. The domains are as follows:

- 1. Communication
- 2. Identity
- 3. Understanding my Mental Health
- 4. Problems
- 5. Rights
- 6. Services
- 7. Information
- 8. Healthy Living
- 9. Activities
- 10. Relationships

Background

'All About Me' is the result of hours of discussion and reflection in local Deaf wellbeing groups or forums and in meetings with representatives from Deaf mental health services in England.

'All About Me' will be used to structure recovery planning, within Community, Inpatient and Secure settings, and should become a focal point in Care Planning meetings and Reviews of Care between Deaf service users and Deaf and hearing professionals/workers, interpreters, family and carers.



Understanding Deaf Culture

Understanding Deaf people – important things to know when working with Deaf people

Deaf people view themselves as a cultural and linguistic minority and are as a distinct group but, not a 'sub culture' because the word sub has negative connotations. Deaf people celebrate themselves as a vibrant and diverse group.

How do Deaf people behave differently from hearing people?

To get other Deaf peoples' attention, Deaf people will:

- Stamp on the floor to create vibrations
- Wave their hands
- Turn the lights on and off
- Touch each other's shoulders

In communicating with each other, Deaf people will also point at people, objects and directions – this is not considered rude in Deaf culture although it is in hearing culture.

Eye contact is necessary for Deaf people to communicate with each other and hearing people. Regardless of it being undertaken through British Sign Language or communicating with their voices.

Common experiences

Deaf people have pride in their community and do not feel 'disabled'.

Deaf people sometimes find that they have problems with attending appointments – due to their name being called via a tannoy system, for example. Deaf people will share experiences with each other where they have had a crosscultural misunderstanding with hearing people, with humour, knowing that other Deaf people have more than likely been through similar experiences.

Deaf people's education

Every Deaf person has a different story of how they learnt language and how they were able (or not able) to access and understand education.

Deaf people go to a range of schools which vary widely in meeting their communication needs, even within Deaf schools. Deaf people, as children, may have gone to a mainstream hearing school that offers support from a resource centre/unit for Deaf/ hearing impaired children. Specialist Deaf schools vary in how they meet the communication needs of their pupilsthrough oralism/spoken language, total communication or British Sign Language.

Ouite often Teachers of the Deaf were not specially trained in Sign Language and as a result pupils' language development and hence language acquisition has been further delayed. The longer term impact has been that upon leaving school literacy levels have been historically low for the majority of Deaf people. To further compound the low literacy levels, is the fact that 90% of Deaf children are born to hearing parents. The majority of whom cannot (many choosing not to learn BSL) use sign language that is sophisticated enough to enable their child to learn through incidental learning and shared conversation just as a hearing child would within the family. However, there are some Deaf children born to exceptional hearing parents who understand/appreciate how crucial Sign Language for their child's development.

The advantageous group are those Deaf and hearing children that are born to Deaf parents. These children's development generally progresses as a hearing child would, within a hearing family.

How can hearing people ensure they meet the needs of Deaf people?

Helping Deaf people to feel less marginalised and therefore, less disenfranchised is easily achieved by making reasonable adjustments.



Bear in mind that the Deaf person may communicate through a variety of ways:

- Booking a qualified British Sign Language Interpreter (yellow badge holder)
- Ensure you have eye contact
- Pen and paper
- Lip-reading
- Gestures
- Pointing
- Make sure that there are alternatives to intercoms or anything that could be a barrier for the Deaf person accessing your service
- Ensure your letters to them are in plain English
- Do not state, 'if unable to attend please ring this number'. Provide a text number for Deaf people to contact your service.

Deaf peoples' general life

Deafness has a lot of stigma attached to it – which has impacted Deaf peoples' lives historically. They may have missed out on promotions at work, for example. Or, have been late for work (yet again) because the announcement over the tannoy at the train station, notifying a platform change, was not heard. Most Deaf people are stoical about life and given that it is difficult to access jokes from a hearing spoken culture, tend to create their own jokes which are largely drawn from the negative but sometimes funny, experiences they have had being misunderstood, marginalised and disenfranchised.

Deaf peoples' social life

For various reasons, some Deaf people may not have met Deaf people growing up; and were therefore socially isolated from their peers. Often, their parents were hearing and didn't want the Deaf person to learn sign language (because of the stigma).

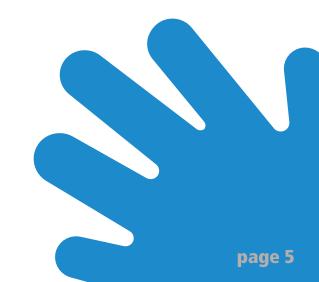
Deaf recovery

Effective communication is essential to begin developing a relationship with a Deaf person. Where communication meets the Deaf person's needs, the Deaf person feels equal and respected. Without communication, it is not possible for the Deaf person to express their needs or wishes or understand what other people want or intend. The Deaf person's preferred communication may vary, and the effort to find out how they want to communicate is appreciated. The ideal standard of healthcare would be direct communication in their preferred language, that is – for the healthcare practitioner to be fluent in British Sign Language. If this is not possible, a gualified skilled experienced British Sign Language interpreter is the next best alternative

Also important to Deaf people's recovery is the attitude and expectations of people/support network around them – being Deaf is not something to mourn and struggle on through life; as with any person, Deaf people can do anything.

And remember to smile...!

Deaf people are 'experts' on reading people's body language and facial expressions. It is one of many gains from being Deaf and a visual communicator. Deaf people appreciate it when hearing people are friendly, understanding and showing some interests in their culture.



Working with BSL/English Interpreters and Deaf Professional Communication Specialists (DPCS) in Mental Health Services

Essential Standards:

All communication providers need to be qualified and registered with a professional body such as NRCPD (The National Registers of Communication Professionals working with Deaf and Deafblind people) or similar. They need to have professional indemnity insurance and an up to date DBS.

Best Practice Guidelines

Interpreters and DCS (Deaf Communication Specialist) will not only interpret spoken or signed language but will also include relevant cultural and contextual variables to ensure that meaning is accurately conveyed between all parties.

The Interpreter/DPCS

- Needs to have a minimum 3 years post qualification.
- Needs to be experienced in a wide variety of clinical settings and therapeutic sessions.
- Have a clear understanding of the different clinical roles in a multidisciplinary team.
- Be familiar with psychiatric terminology and medication.

The Service

- Books the same Interpreter/DPCS on a regular basis to allow rapport and trust to build within the triadic relationship, essential for ongoing therapy sessions.
- Include preparation and debrief into session time.
- Ensure the wellbeing of the Interpreter/DPCS and be able to offer support and supervision if necessary.

For further information please refer to the Communication domain appendix.

Including the 'lived Deaf experience' into service provision

To be part of a culturally Deaf community, Paddy Ladd suggests 9 factors that indicate a Deaf person's acknowledgement of their identity, culture and community¹.

- Using BSL and sharing the culture that surrounds the Deaf Community.
- Having a shared experience of Deaf education (oral/BSL).
- The shared experience of oralism and its effect on self worth.
- The shared experience of being audiologically Deaf in a hearing world.
- Having the knowledge of Deaf social organisation and informal Deaf history and traditions, Deaf clubs, parties, games.

¹Understanding Deaf Culture, In Search of Deaf hood, 2003.



- Monolingualism not having a second language that is of benefit, lack of English written or reading skills (only understand BSL not lip-reading or writing).
- Socialising within the Deaf Community

 local, national, sports, parties, caravan club, LGBT etc.
- Deaf Arts, social events, volunteering to be a Deaf role model.
- Embracing the D position and being proud of Deaf heritage, community, culture and language.

For people who identify as a member of the Deaf community this can be summed up as 'the Deaf Way', 'Deaf Heart', 'Deaf World'. "Deaf Hood encompasses the total sum of all the positive meanings of the word 'Deaf', past, present and future".

Paddy Ladd – Understanding Deaf culture-in search of Deaf Hood 1983.

"I came out from a cave in which the shadows of meanings had flickered, I came out into the bright day of true communication, where meanings were as plain as the hand in front of your face, where a message is no sooner expressed than understood".

> Laurent Clerc, cofounder of The American School for the Deaf 1785 – 1869

What is Recovery?

Users of mental health services have identified three key principles:

- 1. The continuing presence of hope that it is possible to pursue one's personal goals and ambitions.
- 2. The need to maintain a sense of control over one's life and one's symptoms.
- 3. The importance of having the opportunity to build a life beyond illness.

This means moving away from a focus on illness and symptoms. It is about looking at the positives and building on those. This can be difficult for mental health services which are used to defining patients by their diagnosis. It can also be difficult for people who might be used to seeing themselves defined by their diagnosis/label. For deaf people as well, with or without mental health issues, they may have been negatively affected by hearing people's expectations of them. For deaf people in the deaf community, it is about recognising that their isolation is not unique to them; that other deaf people within hearing communities are just as isolated as them too. Also importantly, that this isolation does not have to continue.

Recovery is about people living their life empowered by the three principles above; for deaf people it is additionally about coping with the barriers that they face as deaf people in a hearing world, and also thriving despite them.

When a recovery approach is taken, the relationship between staff and patients may change. Staff are no longer the 'experts' who make the decisions. Instead, the patient and the clinician are partners on a journey with equal importance which will lead to shared decision making at all levels. Both will learn from each other as they travel along this journey. In a recovery approach the personal qualities of staff become more important than qualifications: are they compassionate, respectful and supporting?

A service which uses a recovery approach creates an environment where people can begin to create a new story about themselves. They can decide on what they want from life, what they need to achieve their goals, and how they want to manage their mental health. As part of this they might try to identify triggers which cause their health to get worse. They might also identify things they can do to stay healthy. Importantly, this means everyone's recovery is personal to them and they are in control of it. Evidence has shown that the best support people can get comes from others with a similar lived experience of mental health problems.

When embarking on a journey of recovery the following key principles should be followed:

- The Deaf person should be at the centre of the care at all times.
 Recovery journeys should be personal to the Deaf person involved. The focus is holistic and should not focus on symptoms only.
- Recovery is a journey and as with any journey, this takes time.
- From the start, all people involved in the recovery pathway should have a belief that the Deaf individual concerned can become well in recovering from their mental health problem and empowered in managing the issues in their lives that occur due to their deafness.

- Recovery can be affected by Deaf individuals' mental health problems and also by their environment.
- Support from family, friends and professionals/staff is an important factor, and their understanding of 'Deaf awareness' considered.
- A successful recovery journey provides hope, acceptance, control, basic needs and meaningful activity from the start of the journey.

Within the 'All about me' film you will see an example of Sarah's Recovery journey.

Social Inclusion as Part of Recovery

Social inclusion can increase a sense of belonging and wellbeing, thus having a positive effect on an individual's recovery. It is important to recognise that lots of communities don't understand the deaf person's experience. During recovery a Deaf individual is empowered to 'get their life back on track', this may involve them getting into a Deaf community. A key role for services is to support people who want to regain their role in the communities where they live. Taking part in social, educational, training, volunteering and employment activities are all ways in which the person concerned can:

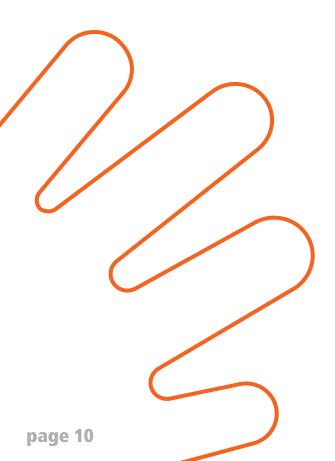
- Take back the control of their life and become self-dependent.
- Feel accepted by their communities.
- Stay well and become a productive citizen and family member.

In certain circumstances useful resources to aid this kind of activity are personal budget and/or personal health budget allocations that can be provided to Deaf individuals.



'All About Me' Tool Explained

This tool has been developed to assist the Deaf individual's recovery from mental health problems by following a simple process to gain an understanding of what recovery means to an individual and to help to identify their individual outcomes / goals. Once identified each goal can be rated at agreed intervals to track and review progress.



Prior to using the tool ensure you have a good understanding of:

- 1. Deaf culture you can do this by reading 'Understanding Deaf Culture' on page three.
- 2. Recovery in mental health you can do this by reading 'What is Recovery?' on page eight.
- 3. NHS England Accessible information standards - The following film explains this standard: www.youtube.comwatch?v=1k8CM2Q93k&feature=player embedded

Once the healthcare professional has a good understanding of Deaf Culture, Recovery and accessible information standards they can proceed by arranging to meet the service user and start to use the 'All about Me' package. It may be useful to arrange to view the DVD together as some of the terminology within the film may need to be explained until individuals feel more familiar with it.

Who may need access to the 'All About Me' package?

- Deaf Service users
- Deaf & hearing staff
- Deaf and hearing carers, family and friends



What is a Domain?

'All About Me' is based around 10 domains, a domain is basically a subject heading or something to discuss. The domains within the tool were identified as key factors that are important to Deaf individuals throughout the recovery journey. By using the domains as a framework for discussions you can ensure that you have considered all aspects leading to a collaborative, individualised and holistic package of care to support recovery. The 10 domains are colour coded to make them easier to use.

A full explanation of each domain can be found on the domain description templates in 'All About Me' tool . Each domain has a separate page to collate comments and details of an individual's goals/preferred outcomes .

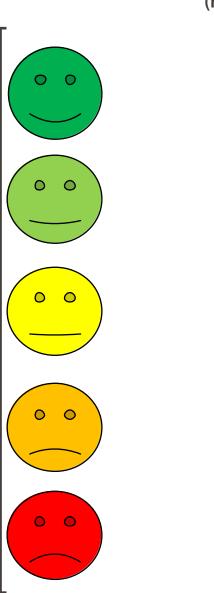
Once goals and outcomes have been agreed it is time to choose a rating scale.



Rating Scale Examples

What is a Rating Scale?

A rating scale is a way to monitor and review progress in achieving goals/desired outcomes identified in each domain. It is important that individuals either create or choose their own rating scale and this can be in any format including visual, numerical or narrative. A variety of simple visual measures are provided in the appendix. The example used in the film is shown here.

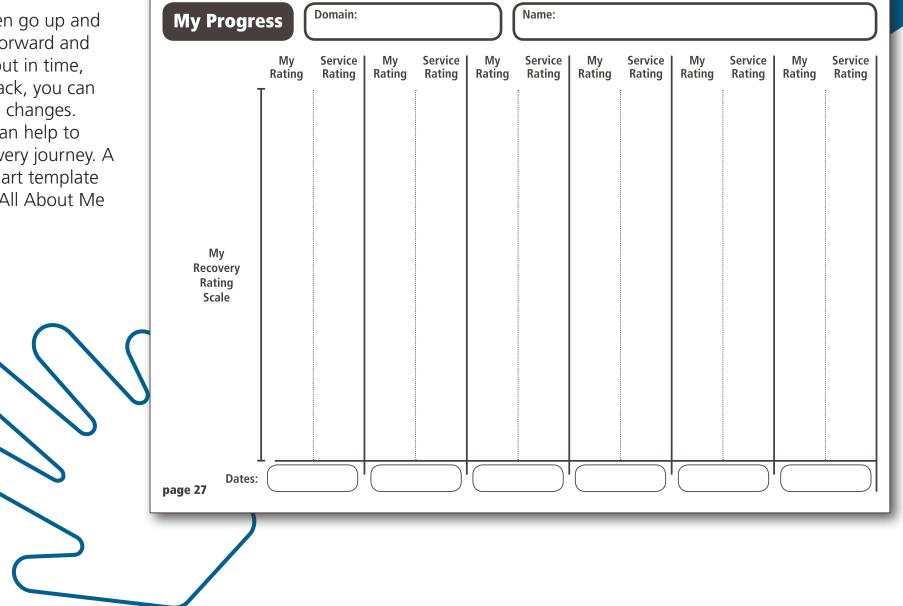


(High Rating/Good/Happy)



(Low Rating/Bad/Unhappy)

Progress chart

Recovery can often go up and down, one step forward and two steps back, but in time, when you look back, you can often see positive changes. Using this chart can help to visualise the recovery journey. A blank progress chart template can be found in 'All About Me Tool' booklet. 

Example of what details should be included on domain sheets:

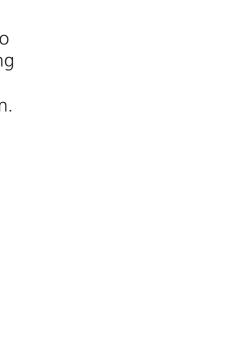
Comments: Please include notes from your discussions including strengths, progress, risks, issues, concerns

Goals/Outcomes Desired: Please

include details of the individual Goals / desired outcome that have been identified. Remember these are items that are important to the service user. Recovery can often feel overwhelming when starting at a low point or when feeling disempowered so professionals often ask service users to consider specific goals that they would like to achieve (ideally with them identifying these themselves). Goals can be identified in relation to each domain.

Guidance note

Deaf people often have had difficulty accessing information and knowledge in many areas of life. Therefore it may be difficult for non-specialist services to fully meet their needs. If this is the case, we recommend liaison/referral to specialist Deaf mental health services, which provide consultation.





Appendix

Useful information can be found on the following websites: www.signhealth.org.uk www.mind.org.uk www.rethink.org www.rcpsych.ac.uk

Organisations involved in developing All About Me



Birmingham and Solihull NHS Mental Health NHS Foundation Trust





THE DEAF HEALTH CHARITY SIGNHEALTH













St George Healthcare GROUP

Promoting independence and safety: maximising quality of life.