



## Improving Adult Rehabilitation Services

### The service user's experience of rehabilitation

- E1** Individuals express frustration with persuading professionals who have the power to refer them to rehabilitation services to listen to their needs and refer accordingly. There is a lack of understanding by primary care professionals and others, of the potential role of rehabilitation and what services an individual may benefit from. Perseverance and self belief are perceived as of greater influence in gaining a referral rather than objective need

*"Your GP knows all about you but they don't ask the questions that matter, [to decide you need rehab] he just stares at his computer"*

- E2** Patients want to be offered rehabilitation at a time when they feel they can make the most use of it. Many feel they had too little rehabilitation while an in-patient, poorly preparing them for their return to home. Others want access to rehabilitation once they feel they have recovered from an acute episode. However it is not always available at this point. Yet others are aware that their needs change over time and that even later interventions would help maximise their potential.

*"You're panicking when they're in hospital and when you first get home so it may not sink in at the start really, so it's picking the right time [for rehabilitation and information]"*

- E3** Individuals want their goals to be personalised to what matters to them. They and their families express the need to understand shorter term rehabilitation goals in the context of medium and long term personal objectives

*"One size fits all approach doesn't work, it's got to be tailored to the individual especially if services are trying to get that person back to normality because everybody's normality is different so it has to be tailored to the individual"*

- E4** Service users who have both mental health and physical needs wish to be supported in a holistic manner that takes account of all their needs, regardless of whether the service is predominantly for physical or mental health.

*"They arranged for me to go to tai chi classes, which helped me meet people [social exclusion], kept my motivation and helped me with my posture [curvature of the spine]"*

- E5** People value interaction with others who have similar health issues and benefit from rehabilitation that can be tailored to their needs but within a group environment

*"Because you're in a group, other people asked questions and you found out so much more. If you are with people who you know have experienced the same then you know they know a little about how you are feeling"*

- E6** At times of ill health, many express self-doubt and want the encouragement of those perceived to have expertise in rehabilitation. This may be no more than a phone call to check they are ok and to help them gauge if they are progressing as expected.

*"I feel that if someone from the hospital just followed up to see how I was progressing it would have been beneficial as I didn't really want to bother anyone and I didn't know what was normal or not"*

- E7** Some, but not all, service users want to take responsibility for finding their own means of rehabilitation at some point, without this choice excluding them from further contact with mainstream rehabilitation

*"Once I had recovered from the shock of the diagnosis [cancer] I took control. I continued to swim and put myself on a diet of 2000 calories because I knew people died from malnutrition and I ate it whatever I felt"*

- E8** Service users wish to be treated by individuals who are knowledgeable, skilled, supportive and empathetic. Their relationship with the individual(s) providing rehabilitation is important. Rapport and confidence in their judgement encourages engagement with rehabilitation, particularly in the longer term. Continuity of a trusted individual in their rehabilitation allowed individuals to gain confidence and focus on their objectives.

*"they talked to you, not down to you [and] if it was not for them I may have lost interest"*

- E9** People want service providers to understand that rehabilitation is one part of their daily life and to provide a co-ordinated pragmatic care plan that fits within it

*"You're like, do I still have a life or do I give up my life to do exercises.....I do volunteering..... which is important at my age"*

- E10** People want to be provided with care services that support their rehabilitation, not hinder it.

*"They [carers] came in, started to cook my meal. I had to get undressed and needed help as couldn't breathe. They said it wasn't in my care plan so they couldn't help. They gave me my meal but I had to sleep in my clothes"*

- E11** Service users (and families) have experienced early discharge where the needs of the individual have not been adequately assessed before discharge. Services, both rehabilitation and care have not been put in place in a timely fashion.

*"You go home after only ever doing the stairs once then you are at home on your own"*

- E12** Communication systems, including making appointments, should be easily used and responsive to service users' needs.

*"...until may I was seeing a podiatrist, and then in may they sent you an appointment at 48hrs notice which wasn't convenient, was unable to get hold of them, I called several numbers, left messages, but didn't hear back until October"*

- E13** Service users and their families want information to be given in a timely manner. They also need an opportunity to discuss any written materials at the time they receive it and later when they may have further queries.

*“I didn’t fully understand some of the things I was asked to do before and after the op, like the breathing exercises, I was told to cough up the stuff in my lungs and was given painkillers but it hurt a lot so I didn’t do it often, but maybe if I knew the purpose I could’ve prevent the collapsed lung- but maybe they thought I was educated enough to not need it, but I was weak, in lots of pain”*

- E14** Individuals can experience difficulties getting to the location of rehabilitation services due to their health or the availability of support to travel and wish to choose where they undertake rehabilitation as far as possible.

*“I had physio but had to go to the hospital so had to rely on people to get me there as I live alone and could not drive due to my arm. It would have been useful if a physio had come to my house”*

- E15** When moving onto self-management and reablement, people highly value community resources are if they are affordable and accessible.

*“Luckily not too far away there is a specialist rehab gym, which I use twice a week, its £5 per time, which I can afford. It is remarkable. I’ve seen other stroke survivors there and how they are improving. It’s not just a normal gym it is good if you are motivated as you can see you own recovery, you can control and see your own improvement”*

- E16** Service users and families, regardless of the problems that initiate the need for rehabilitation, may require timely access to psychological and or emotional support to make the best possible use of rehabilitation and cope with change.

*“I think when you got through something like this people don’t really give much attention to the psychological impact and there are definitely things around the loss of independence, and it’s a knock to your self confidence and ability to do things.”*

- E17** Family carers wish to be given the opportunity to be involved in the rehabilitation of their family member. They want help and information to support this process. They require involvement along the patient journey such as in the preparation for discharge.

*“... and you know that person best of all, the clinicians have no clue about their life before, you know their strengths, weaknesses, what that person is like”*

- E18** Where appropriate, people want to be able to access support to enter /return to work.

*“I didn’t know where to start, she didn’t just help me to get my job, but one that was sustainable”*

**E19** Individuals and their families, particularly those who have long periods of rehabilitation, wish to be better prepared for discharge from rehabilitation services. They want to have the confidence to take on responsibility for their own rehabilitation. They want better signposting to appropriate resources in the community including charities and support groups, a contact point for any concerns and a simple process for re-referral if required.

*“They all work together to see what you need, but after 12 weeks it’s cut off which I find disturbing because people with strokes are different, no one she fits all, everybody’s different, everybody’s stroke is different, but it’s just cut of and you’re left to fend for yourself.”*

**E20** People report they did not receive rehabilitation services and sourced rehabilitation at costs they could ill afford

*“I started these [hip and knee] classes before the op and then continued after but they were not offered or recommended by the treatment centre”*

**E21** People wish to be introduced to relevant charities and support groups at an early stage in their rehabilitation. They value the services, understanding and support (practical and emotional) that charities and voluntary groups offer. The information provided through these sources is respected and considered relevant and current.

*“She [independent advice service worker] wanted to hear what my concerns and needs were and ..... we worked as a team to help build my confidence in this new environment [shops, banks, public toilets]”*

**E22** Some service users’ experiences give them an appreciation of particularly the long term cost benefit such as a reduction in benefits payments and requirement for further services.

*“my point of view is I know it costs money for the early intervention but in the long run they would save millions because people don’t need as much help in the long run”*