



Caring for the Carers:

Carers Experience of Reablement Services

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Background

Reablement is a short-term approach focusing on supporting individuals to regain their independence and skills after a period of illness.

Reablement services are delivered in the person's home by a team of social care professionals¹. Unlike traditional home care, which typically involves doing tasks for the person, reablement follows a 'doing with' model, encouraging individuals to actively participate in their own care and do for themselves rather than have someone do things for them.

The aim of this project was to understand the experience of the reablement service from a carer's perspective. In doing so, we explored how the reablement service could better support carers. Although carers play a crucial role in helping people regain their independence, there is limited information on their experience within the context of Greenwich reablement services.

Ten interviews were conducted with carers to understand what worked well and any challenges faced. Carers were largely unpaid, close family members responsible for supporting loved ones through the reablement process. Four interviews were conducted with Reablement staff to provide additional insight.

Summary

Carers were positive about the principles of reablement, and grateful for the support and resources to enable, or maintain, loved-one's independence at home. Witnessing the gradual regaining of skills and

¹ Reablement consists of a variety of roles such as Independent Living Assessors (who assess the level of independence and the extent to which this can be improved), Occupational Therapists (who assist with physical rehabilitation) Support Workers (who help with everyday tasks and practical support) and managers (who plan and monitor service delivery).

abilities was a source of immense satisfaction and relief for carers, and often reduced concerns about the need for institutional care.

Carers confidence to support relatives grew as a result of guidance provided by reablement staff, enabling them to effectively assist the reablement process. Carers shifted from being passive observers to active participants to aid loved ones.

Communication was a challenge and carers did not always receive the information they needed. Information was not always provided prior to the service starting – for example at hospital discharge. Not having clear information created a mismatch between expectations and what was delivered, leading to frustration and confusion.

Cultural and religious sensitivity could be strengthened. Providing a culturally sensitive approach, tailoring services to align with a person's preferences, is a key feature of person-centered care. Greater cultural sensitivity creates better understanding of an individual's needs, preferences, and potential challenges, supporting more effective reablement planning and delivery. Moreover, demonstrating cultural and religious sensitivity fosters trust between carers and health and care professionals – which is critical for the reablement process.

Once the short-term reablement process has finished, carers still need ongoing support, guidance, or resources to continue assisting their loved one to maintain the gains made. However, follow-up was inconsistent and patchy.

About

Healthwatch Greenwich (HWG) is an independent, statutory organisation representing people who use NHS and publicly funded health and care services in Greenwich. We collect patient and public feedback and use these experiences as evidence to drive change, and influence

commissioners and providers to ensure the design and delivery of services is equitable for all. Our vision is for Greenwich to have high quality services, consistent levels of public engagement and an excellent service user experience that meets patient needs and preferences. To achieve our vision we listen, we act, and we influence.

Acknowledgements

We would like to thank the relatives/carers who participated in this study for sharing their experiences with us. We are grateful for the support of the Royal Borough of Greenwich Reablement Team for commissioning this project. Special thanks goes to Jess Hurn, Marco Silvestri, and Rajkarun Masina for facilitating this project. Their appreciation of carers as integral participants in the reablement journey served as a catalyst in driving forward the objectives of this project.

Aim

To explore the experience of reablement from the perspective of unpaid carers.

Methodology

At Healthwatch Greenwich we gather people's experiences of services using interviews, focus groups or small surveys, rather than conducting large scale quantitative research. In comparison to quantitative research, we focus on words rather than numbers, and depth rather than breadth. Our method is exploratory; we seek to unearth experiences, opinions, thoughts, and feelings. We have found this method to be the most

effective and efficient method of capturing insight and engaging with communities and service users.

Recruitment

Reablement staff were responsible for recruitment of carers into this project. Once consent had been obtained, contact details were passed on to the Healthwatch Greenwich (HWG) team.

Carers referred by Reablement service to HWG	Carers agreed to participate.	Conversion rate - referrals to interview	Reason for not participating
23	10	43%	Lack of time/availability (13)

We interviewed carers to assess:

- Their experience of the reablement service
- How the reablement service meets the needs of service users and carers
- What works well and any challenges.

Profile of participants

The ten carers were all relatives of service users receiving reablement - daughters, sons, husbands, wives, and a niece. Of these ten, seven were White British and three were people of colour from an ethnic minority background, - Indian, Burmese and British Pakistani.

All were unpaid carers supporting their relative through the reablement process. Nine of the ten carers were primary carers² and one was a secondary carer³. All carers either live with service users in the same accommodation and/or are responsible for liaison with the reablement service and coordinating support through this service.

We spoke with 4 members of the reablement team, one from each of the following roles:

- Manager
- Physiotherapist
- Independent Living Assessor
- Support Worker

Data collection methods

Ten in depth audio recorded interviews took place with carers, through a mixture of phone calls and in-person meetings. Interviews took up to 90 minutes. Carers received a £30 shopping voucher as a thank you.

Staff interviews took up to one hour and were video recorded online via Teams.

² Primary carer is the main caregiver for the person receiving reablement. They are responsible for providing most of the care or support needed.

³ Secondary carer has a supportive and supplementary role helping the primary carer and is not as deeply involved in providing care or support to the person receiving reablement.

Findings

We present our findings as they relate to the reablement journey:

- Communication - information sharing and decision-making at discharge, at home, and during the assessment process.
- Support - the extent to which carers felt supported and involved in their relative's reablement journey.
- Benefit - impact on the health and well-being of carers.
- Challenge - barriers or difficulties experienced by carers before, during, and end of reablement service.

1. Communication

Information sharing and decision-making

Carers first hear about reablement shortly before discharge from hospital. They describe this phase as one filled with anxiety and confusion. Carers are typically told by hospital discharge staff that reablement will be provided once the patient is back home. Conversations about reablement are often brief and lacking in detail, leaving carers unsure of what to expect from reablement, such as – how long it will operate for, any financial implications, and the specific nature of the support provided. Without written information to refer to, carers told us it was hard to remember any meaningful detail from the short conversations with hospital discharge staff.

While the reablement service began within a couple of days of arriving back home, carers shared that understanding the reablement service, before it begins, is important for them so they know what to expect and can then make decisions with regards to broader care arrangements. Moreover, they would also then know who to contact with queries or in the case of changing circumstances in the first few days. The absence of this information created a sense of unpreparedness, uncertainty, and anxiety for carers.

The arrival of the Independent Living Assessor, within a couple of days of discharge, provided the first opportunity for carers to ask questions and receive detailed information on reablement. At this stage the assessor, service user and carers discuss what support will be made available to them to work towards their independence and how therapists will later set goals to achieve this.

Some carers found the process of assessment positive and helpful, and assessors were described as knowledgeable. Assessors explained to

carers how frequently and which staff members would be involved, which in turn helped carers to understand how the reablement process would move forward. Carers noted that staff were kind and friendly during the assessment.

However, this experience was not consistent among all carers. Some felt they weren't given enough information or actively involved in decision making. Additionally, with multiple services and health/care professionals coming in and out - all involved in the care of their relative, carers found it difficult to distinguish between various services/roles and their respective purposes.

Some carers were able to gather information through their own research or had access to information from other (non-reablement) health or care professionals. Carers with access to adequate information felt more assured and less anxious during the early stages of reablement.

"I was very stressed, but she didn't give me any information. It was just about how many hours I wanted, what time, male or female. She didn't tell me that the OT or physio would be involved."

-Participant 2

"I felt assured because I knew that the care she would get from the reablement team would be suitable for her."

- Participant 6

2. Support during and post-reablement service

Types of support

Carers felt supported by reablement staff and were grateful for their friendliness and compassion during a difficult time for their family. Carers appreciated how considerate staff were, particularly those who did not live with their relative who said staff made extra efforts to keep them informed and updated.

Carers commented that therapy staff were thorough in assessing the home and making suggestions and orders, for any needed adjustments. Therapy staff also helped with physical rehabilitation, practising exercises with the service user whilst also involving carers to understand and encourage the process.

Support workers assisted with more practical tasks, taking recipients through the process of learning how to do day-to-day activities again after their illness or injury. Carers told us this helped to build their relative's independence and confidence.

“And what I found the most helpful thing from them was the fact that the nurse would sit there with Joyce and encourage her to eat her food, which she did, whereas with me up to that point. She found me a bit pushy with it, you know. And so with a total stranger, She was less liable to flare up about. So I found that very useful”

– Participant 1

– “So it was, It's nice to know that somebody's coming in to help him with his food and someone was there for the exercises, which is very important and they were doing it properly”

Length of support

Reablement services can extend for up to six weeks, based on the level of need. While carers were aware of the six-week duration, they were not always aware of the conditional nature of this timeframe. As a result, some carers felt the service was unjustly curtailed or that their loved-one was entitled to more support than they received, leading to dissatisfaction. In addition, carers were confused and worried about support arrangements once the reablement service had finished.

Role of staff

In our interviews with reablement staff it was clear that the knowledge and support carers provide is valued. Staff acknowledged the importance of building trust and rapport and their role in supporting carers as well as service recipients.

Staff are aware of the lack of understanding amongst carers and service users regarding the reablement service. While staff do their best to explain, carers are often still confused as to how or why reablement is distinct and separate from conventional care packages.

Moreover, staff can find it challenging to address the nature of free/not free- for the same service. While reablement (of up to six weeks, depending on need) is not subject to a financial contribution from those receiving it, where an ongoing package of care is required, those who can afford to do so are expected to pay.

“We involve the family members and the support network in that so that they can also help and contribute towards working towards a goal for the patient to achieve.”

- Staff member 2

“You can see the confusion in people's faces. We do have to explain that quite a bit and also explain our service quite a bit, not just our role, but the service in general, because they do think that we are a care package, you know, and we are there to do domestic work and Hoover.”

-Staff member 4

3. Benefits of reablement service

The approach and attitude of reablement staff created an open and relaxed atmosphere throughout the reablement journey. Carers told us that the care and support given by reablement staff had made a huge difference to their loved one's health and wellbeing. As a result, service recipients were more mobile than previously and more confident in their ability to carry out everyday tasks. As a result, most carers felt satisfied with reablement services and positive about the health and well-being of their loved one.

Carers spoke of the importance of being able to 'take a break' whilst reablement staff were in their home. They were relieved to be able to use this time knowing that their loved one would be safe. This 'momentary break' was highly valued.

“They went far beyond what they should have when they were trying to help me settle him, even when he was going ballistic and walking and slinging stuff around the bedroom. They would sit there and try to talk to him so calmly, peacefully, even when they were worried for their own safety, they managed it. I can't fault them in any way.”

-Participant 3

“That gives me a break knowing that there is health care professionals there to take care of my wife, a knowing that there is somebody that is looking after my wife's means that I'm not tethered to her all the time. It also gives her a chance to talk to somebody else rather than me, so it helped her.”

- Participant 9

4. Challenges during reablement journey

Before the reablement service

Lack of information or misinformation meant that carers were unclear about the type and level of support provided by the reablement service. This led to gaps between what was expected and what was delivered. For example – some carers were told (by hospital discharge staff) the service was free for six weeks, only to be later told by reablement staff that the service is available free of charge for up to six weeks, based on need. This caused confusion and disappointment for service users and carers.

During the reablement service

Some carers experienced challenges related to cultural considerations and consistency such as a lack of sensitivity and their cultural identity not being respected or not being offered translation services.

The flexible timing of the service was also a problem. Carers are told that reablement staff can't provide specific times for their visits. This creates inconvenience and disruption to daily routines.

Additionally, some carers were confused about the role of reablement support workers, believing them to be able to carry out personal care and housework tasks.

End of the reablement service

Post-service transition can be challenging. Carers felt unprepared and uninformed about further support and what the financial implications might be.

"I would have to be there and say [explain] to my dad because they said to me "we're not here to wash him. We're not carers, we're reablement". But this where I didn't know what reablement was. I just thought it was about his mobility helping his mobility Yeah. And he obviously didn't understand with his dementia, he kept swearing and shouting at them.

"- Participant 2

"I think the biggest problem, I think was the timing. If they'd been here at certain times before I'd actually done it. It may have been better"

- Participant 1

"A bit stressful for me because I've got male carers now all the time and because I'm a Muslim and I have to wear a scarf and cover

myself because sometimes they're here four times [a day] and there's no specific time that they'll come. it's difficult..."

- Participant 2

Conclusion

The benefits of the reablement service are evident in the improved health and well-being of service recipients. Carers spoke highly of the positive impact on their loved ones' mobility and confidence, and carers valued the brief respite some of these visits from reablement staff offered them. The reablement experience was positive for carers. The rapid nature of support for their relative was welcomed and carers operated alongside reablement staff as key partners in ensuring progress is made and maintained.

The quality of the relationships built between reablement staff and carers plays a vital role in the success of the reablement service. Carers appreciated the compassion and friendliness of reablement staff, and most felt respected and involved in the decision-making process.

Effective communication is pivotal. The initial phase of pre-reablement often leaves carers feeling anxious and confused due to the lack of detailed information provided by hospital discharge staff. Clear and comprehensive information before the reablement service begins, would prepare them for what to expect and reduce the mismatch between expectations and service delivery. While the duration of reablement services is known to be up to six weeks, carers sometimes misunderstood the conditional nature of this timeframe, leading to dissatisfaction. In addition, there remains a challenge in clarifying the distinction between

reablement and conventional care packages, as well as addressing support arrangements once the reablement service has ended.

Recommendations

Before Reablement Service Begins:

- Provide written pre-reablement information at hospital discharge that includes a description of the reablement service, the conditionality of the service, an explanation of the multiple roles – such as support workers, ILA’s and therapy staff and what they are responsible for.

During Reablement Service:

- Regular check-ins with carers to review shared understanding of goals and expectations and address concerns or queries.
- Identify specific needs and preferences during initial assessment, such as cultural beliefs and practices, timings of visit, and other factors that may affect the delivery of reablement.

Post-Reablement:

- Consistent follow-up and provision of information on post-reablement support and services.
- Proactively seek carer feedback.

Provider's Response to Recommendations

- We will ensure that the HIDT team and Hospitals are provided with information that describes the Reablement team and Service to be provided. This can be given to the service user and carers prior to [hospital] discharge.
- We will ensure that the allocated Independent Living Assessor carries out regular check ins with service users and carers to review goals and expectations and address any queries or concerns that they may have.
- EDI training to be procured via learning and development and subsequently provided for all staff. The team will also identify an EDI champion. This will help ensure that specific cultural needs and preferences are consistently adhered to as part of all Reablement interventions.
- On discharge from Reablement the Support Worker leaves the service user and their carer information which is taken from the Client Information document. Specifically, this includes helpful telephone numbers (such as CACT/Live Well Greenwich/ District Nurses/Welfare Rights), food and fluid (fortified advice) information and the Reablement brochure.
- We will review and add additional information pertaining to carers services. We will also reinforce with the ILA's that they need to pass on the CACT telephone number at the end of the intervention.

Responses provided by:

Marco Silvestri. Short Term Service Manager, Health and Adult Services, Royal Borough of Greenwich. Dated: 16/1/24

Limitations

- The sample was recruited by reablement staff. We do not know how many carers (in total) were asked and refused, or if there is a pattern with regards to those who agreed to take part and those who did not.
- Only three out of ten carers came from an ethnic minority background. This limited our understanding of how the reablement service is experienced by those from diverse ethnic and cultural backgrounds.

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