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Outcomes assessment for people with long-term neurological conditions: a qualitative approach to developing and testing a checklist in integrated care

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People with long-term neurological conditions (LTNCs) argue that receiving integrated services improves their quality of life. Our study explored current approaches to service integration and the outcomes that people with LTNCs want to achieve. We identified three groups of outcomes. We developed these outcomes into a checklist for staff to use during their assessment of a client's needs. We monitored how five community-based neuro-rehabilitation teams used the checklist to see if it changed the way they worked.



Key findings

- People with LTNCs described three groups of outcomes: personal comfort outcomes, social and economic participation outcomes and autonomy outcomes.
- Teams working in an interdisciplinary way were better able to use the outcomes in their everyday practice.
- Organisation and service-based pressures affected whether and how teams used the outcomes checklist.
- Developing and maintaining professional relationships are essential for successful integration but when organisations and services are restructured these relationships can become fragmented.
- People with LTNCs reported that the outcomes checklist covered the issues important to them.

Background

Despite policy stressing the importance of integration, there is little clarity about what integration means and what it should achieve. This makes it difficult to measure the effects of integration for service users. As a result, there is limited evidence about the effectiveness of integration for service users and their families or carers. This research starts to fill the gap in evidence by exploring how the outcomes that are important to service users can be included in assessment processes in community neurology services.

Findings

What helps or impedes the development of innovative approaches to health and social care integration?

Commissioners, managers and practitioners were positive about integrated service provision and saw it as a priority. However, in all our case sites, even those with integrated services and commissioning arrangements, staff felt that integration was not widespread enough. They identified several factors that affected integration including different finance and IT systems. Practitioners often instigated and maintained integration at the service level, but this needed to be supported by robust organisational processes that encouraged bottom-up innovation and integration.

Developing and maintaining professional relationships was essential for making integration work but this was difficult in a time of major restructuring of health and social care organisations. At this time, practitioners, service managers and commissioners found it particularly difficult to develop new ways to increase integration.

What outcomes do people with long-term conditions want from integrated health and social care?

People with LTNCs described a wide range of issues that were important to them. These ranged from those specifically related to their condition, to wider social outcomes concerned with everyday aspects of their life.

We identified 20 outcomes that we put into three groups: 'personal comfort', 'economic and social participation' and 'autonomy'. We then worked with the teams to develop these outcomes into a checklist that they could use in their usual assessment process.

Outcome groups and outcomes included on the checklist

| Personal comfort outcome group | Social and economic participation outcome group |
|--|--|
| <ul style="list-style-type: none">• Personal hygiene & care• Safety/security• Desired level of household cleanliness & maintenance• Emotional well-being• Physical health & functioning• Cognitive skills | <ul style="list-style-type: none">• Access to:<ul style="list-style-type: none">• paid employment as desired• training or new skills• further/higher education• Establishing and maintaining social and recreational activities• Developing and/or maintaining:<ul style="list-style-type: none">• intimate personal relationships and roles• family relationships and roles• social relationships and roles• Access to advocacy & peer support• Contributing to wider community/ies |
| Autonomy outcome group | |
| <ul style="list-style-type: none">• Access to all areas of the home• Access to locality and wider environment• Being able to communicate• Financial security• Personal decision-making | |

Can these outcomes be assessed in everyday service delivery?

This research showed that community-based neuro-rehabilitation teams could assess these outcomes as part of everyday practice. All the teams were enthusiastic about the fact that the outcomes had come directly from service users' views.

Some teams already included some of our outcomes in their assessments. However, using the checklist encouraged them to discuss outcomes in more detail with their clients. Some of our outcomes added value to existing assessment practices. In particular, some teams felt that *personal decision-making*, *access to advocacy and support*, and *developing and/or maintaining intimate personal relationships and roles* extended their current assessment practice.

Some outcomes proved difficult for some teams to broach in client assessments, particularly *financial security, emotional wellbeing and developing and/or maintaining intimate personal relationships and roles*. This was partly accounted for by staff feeling that these outcomes were too sensitive to raise or were not within their professional remit. Those teams who had a wide-remit were better able to interpret and assess the outcomes in their everyday practice. Lack of services to support clients also made staff reluctant to raise some of the outcomes. Staffing and caseload pressures, changes to service structures and remit, and competing demands of other compulsory paperwork added to the challenges of using the outcomes in their work.

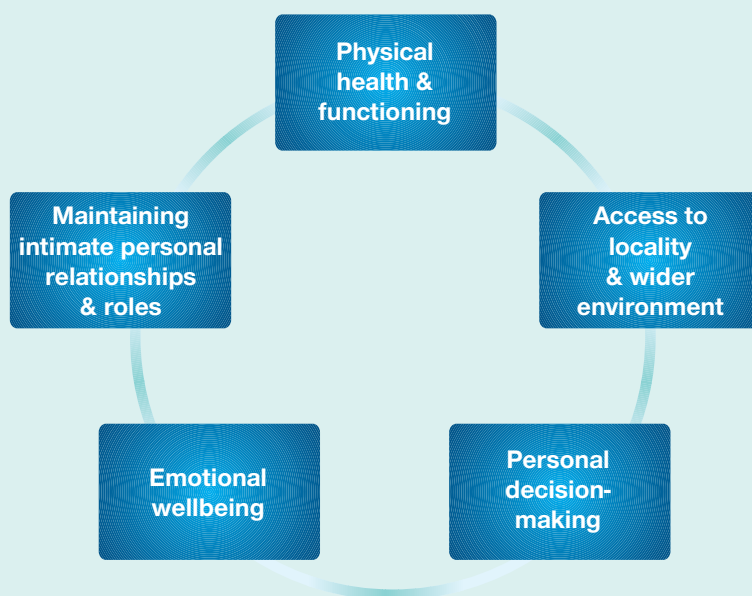
Service users felt the outcomes checklist could be a useful way of assessing their care needs because it covered the things that were important to them. However, they noted that changes in their condition or circumstances could affect the importance they placed on individual outcomes over time. Some service users expressed hesitancy in talking about some of the issues, such as intimate relationships and finances. This was primarily because these issues were seen as being outside the remit or expertise of the team. Despite this, service users thought it was useful for teams to ask about all of the outcomes to make sure that everyone's key issues were covered and to reflect that achieving one outcome could be dependent on achieving another.

Inter-relationships between outcomes: a case example

A man with multiple sclerosis explained that he had lost his ability to walk so he could no longer get to his local shops. This meant that he had to rely on others to shop for him and was not always able to choose what he wanted to buy. This upset him and affected his confidence. He was particularly upset that he was no longer able to choose, and surprise, his wife with cards and gifts.

The neuro-rehabilitation team offered several solutions for him to consider to assist with getting out and about. After some time, and with the team's guidance, he bought a mobility scooter. Using the mobility scooter, he was able to get out of the house independently and go to the shops as and when he wanted. He was then able to choose and buy presents for his wife, which made him feel that he was regaining his role as a husband. This, in turn, improved his emotional wellbeing and helped him start to come to terms with his mobility limitations.

The diagram illustrates the different outcomes that affect each other in this example.



How can different models of integrated health and social care affect outcomes?

There are three ways that integrated care can affect outcomes: the way outcomes are interpreted, how outcomes are assessed and, ultimately, how outcomes are achieved.

The way that teams interpreted and assessed outcomes reflected their priorities and their approach to practice. Neuro-rehabilitation teams that focused on functioning and medication issues interpreted and assessed the outcomes in more limited ways. In teams with a more inter-disciplinary and holistic approach, professional boundaries were more blurred and practitioners were willing to explore outcomes outside their immediate expertise. This gave them more scope to interpret, assess, and potentially achieve the outcomes because they worked together and shared expertise.

Implications for policy & practice

Our research suggests that maintaining professional relationships is central to integrated working and service provision and that practitioners' ability to work in an integrated way was inhibited by service reorganisations. This service disruption, meant it could be difficult to assess and address the range of outcomes important to people with LTNCs.

We also found that many of the outcomes that were identified as important by people with a LTNC were not addressed in validated 'outcome measures' being used by the teams. This has implications for service users' experiences of the type and quality of care delivered and for identifying priorities by those commissioning care.

Methods

This research was funded by the National Institute for Health Research Health Services and Delivery Research programme (project number 09/1816/1004) and was conducted by SPRU between 2010 and 2013.

In-depth case studies were conducted in four English PCT areas which had at least one community-based, neuro-rehabilitation team. The research was undertaken in three stages:

Stage 1 Understanding the service context and identifying outcomes

We interviewed practitioners (n=28) and other health and social care staff (n=15) about local services and organisational structure. Thirty-five people with a LTNC were interviewed about the range of outcomes that were important to them. Carers of people with LTNCs (n=13) were interviewed about their role in integrated service provision.

Stage 2 Developing and implementing an outcome checklist for use in practice

Data from service user interviews in Stage 1 were analysed to identify the range of outcomes important to people with a LTNC. With the teams, we developed a checklist of outcomes that they could use in practice. Teams implemented the outcomes checklist as part of their usual assessment processes and we audited its use (n=24).

Stage 3 Evaluating the use of the checklist

We conducted team focus groups or individual interviews with practitioners to establish their views on the checklist and its utility in practice (n=21). We undertook interviews with service users to explore their experiences of the checklist being used in their assessment (n=12).

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

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Further details about the study can be found on this web page: bit.ly/LTNCoutcomes

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