NHS

PERSONAL HEALTH BUDGETS GUIDE

Ensuring equal access

DH Department of Health

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Contents

Personal health budgets

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

What are the essential parts of a personal health budget?

The person with the personal health budget (or their representative) will:

- be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a health care professional
- know how much money they have for their health care and support
- be enabled to create their own care plan, with support if they want it
- be able to choose how their budget is held and managed, including the right to ask for a direct payment
- be able to spend the money in ways and at times that make sense to them, as agreed in their plan.

How can a personal health budget be managed?

Personal health budgets can be managed in three ways, or a combination of them:

- notional budget: the money is held by the NHS
- third party budget: the money is paid to an organisation that holds the money on the person's behalf
- direct payment for health care: the money is paid to the person or their representative.

The NHS already has the necessary powers to offer personal health budgets, although only approved pilot sites can currently make direct payments for health care.

What are the stages of the personal health budgets process?

- Making contact and getting clear information.
- Understanding the person's health and wellbeing needs.
- Working out the amount of money available.
- Making a care plan.
- Organising care and support.
- Monitoring and review.

1 Introduction

The government's aim is that in future, everyone in England who could benefit will have the option of a personal health budget. This commitment includes parents of children with special educational needs and disabilities. By April 2014, people eligible for NHS Continuing Healthcare will have the right to ask for a personal health budget, including a direct payment for health care. The NHS will also be able to offer personal health budgets beyond NHS Continuing Healthcare – for example to people with long term health conditions or those with mental health problems.

Personal health budgets have been piloted in over 70 locations in England. An in-depth evaluation of 20 sites, published in November 2012, supports the planned national roll out.[1]

This guide focuses on how the NHS can ensure equal access to personal health budgets for people from all sections of the population. It includes relevant findings from the evaluation as well as practical examples from pilot sites.

Personalisation and equalities

Personalisation means thinking about care and support services in an entirely different way ... The traditional service-led approach has often meant that people have not received the right help at the right time and have been unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives in all social care settings and is far wider than simply giving personal budgets.

Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that everyone has a wider choice in how their needs are met and can access universal services such as transport, leisure and education, housing, health and opportunities for employment.[2]

Rather than treating everybody in a uniform way which ignores difference, commissioners, providers and practitioners should be aiming to treat every individual with the same level of dignity and respect. This means listening, understanding and responding to their unique needs and is at the heart of personalisation. Good care and support is about considering a person's circumstances, life history, their family, partners, friends and those caring for them, as well as their experiences of discrimination.[3]

– Social Care Institute for Excellence

Personal health budgets are aimed largely at those with the worst health status, and so provide an opportunity to address health inequalities and improve outcomes for sections of the population who are not well served by conventional services. People taking up personal health budgets include those eligible for NHS Continuing Healthcare, those with mental health problems, and those with long term conditions. This includes older people and people with disabilities. The government's mandate to the NHS includes commitments to make personal health budgets available to all people who could benefit, including children with special educational needs and disabilities.[4]

Personal health budgets have the potential to help the NHS become much more tailored to individual needs, with the creation of highly individualised support arrangements that reflect each person's background, preferences and specific needs.

Under the Equality Act 2010, the NHS has legal duties to eliminate discrimination and advance equality of opportunity for specific groups with protected characteristics (see box on page 5). In short, the law means the NHS must ensure services are fair and meet the needs of everyone, regardless of background and circumstances. These duties also apply to councils and other organisations performing public functions.

Clinical commissioning groups must take care to ensure their populations have equal access to personal health budgets. This will include groups such as people with learning disabilities and people with mental health problems. Commissioners must not simply assume that some groups or sections of the population cannot benefit from a personal health budget – for example, people who lack mental capacity. Once a personal health budget is provided, clinical commissioning groups should provide everyone with an appropriate level of support based on their background, circumstances and individual needs. The equality duty also applies to NHS provider trusts and other public bodies.

The public sector equality duty[5]

The public sector equality duty consists of a general equality duty, which is set out in section 149 of the Equality Act 2010 itself, and the specific duties which are imposed by secondary legislation.

In summary, those subject to the equality duty must, in the exercise of their functions, have due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
- advance equality of opportunity between people who share a protected characteristic and those who do not
- foster good relations between people who share a protected characteristic and those who do not.

These are sometimes referred to as the three aims, or arms, of the general equality duty. The Act helpfully explains that having due regard for advancing equality involves:

- removing or minimising disadvantages suffered by people due to their protected characteristics
- taking steps to meet the needs of people from protected groups where these are different from the needs of other people
- encouraging people from protected groups to participate in public life or in other activities where their participation is disproportionately low.

The Act states that meeting different needs involves taking steps to take account of disabled people's disabilities. It describes fostering good relations as tackling prejudice and promoting understanding between people from different groups. It states that compliance with the duty may involve treating some people more favourably than others.

The new duty covers the following eight protected characteristics: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. Public authorities also need to have due regard to the need to eliminate unlawful discrimination against a person because of their marriage or civil partnership status. This means the first arm of the duty applies to this characteristic, but the other arms (advancing equality and fostering good relations) do not apply.

See section 5 for more information and resources regarding the public sector equality duty.

2 The personal health budgets pilot programme

The pilot programme's approach to equalities

The law does not require specific documentation for equality analyses (or equality impact assessments). However, assessment of the potential impact of policies on equality is inherent in the public sector equality duty in s149 of the Equality Act 2010. An equality analysis (or equality impact assessment) can provide the framework for a coherent approach to achieving this, but it is just one of many ways of demonstrating compliance with the public sector equality duty.

The Department of Health published an impact assessment and equality impact assessment at the start of the pilot programme. This has been updated in the light of learning from the programme and published as part of the consultation on the new regulations that will allow the NHS to make direct payments for health care.[6]

Pilot sites carried out a local equality impact assessment as part of the process for applying to take part in the programme, and were offered feedback.

Evidence from social care

As the pilot programme has developed, the Department of Health has adapted the approach based on both early learning from the pilot sites and evidence from the implementation of personal budgets in social care.

This showed that self-directed support could lead to better outcomes for some groups whose needs have been poorly served by conventional health and social care services, including people from black and minority ethnic (BME) backgrounds, people with learning disabilities, and people with mental health problems.

Some groups were less likely to be offered personal budgets in social care (and particularly the option of a direct payment), with higher uptake for people with physical disabilities than for people with mental health problems or people with learning disabilities. People aged over 65 were also much less likely to be offered a direct payment. The process of getting a personal budget could be overcomplicated, and in some cases inflexible rules limited choice and control, leading to worse outcomes.[7]

There is also a risk that groups who have not been well served by conventional services might miss out on the benefits of personal budgets. The Social Care Institute for Excellence has published information and examples of good practice on personalisation and equalities.[2,3] This highlights the need to improve access for seldom-heard groups including:

- asylum seekers and refugees
- people from BME backgrounds
- young people leaving care
- gypsies and travellers
- lesbian, gay, bisexual and transgender (LGBT) people
- people living in rural communities.[8]

Research carried out by the Equalities and Human Rights Commission (EHRC) has looked at the experience of a number of groups including:

- LGBT people
- young people with mental health problems
- gypsies and travellers.[9]

People in these groups reported difficulty in accessing any help or services, and that information was often irrelevant to them or hard to understand. Services often had a systematic lack of understanding of these groups, or sometimes stereotypical attitudes towards them. For example, LGBT people experienced barriers and discrimination in health and social care services.

There is a risk that these issues will continue, which could prevent people in these groups from gaining the benefits from personal budgets and personal health budgets.

The research concluded that to implement personal budgets and meet the equality duty, organisations should:

- use robust local evidence
- assess the impact of local implementation on all users
- develop better information
- improve access to advocacy and brokerage
- consider targeted outreach work.

Evaluation of the personal health budgets pilot

The Department of Health commissioned an independent evaluation, which focused mainly on 20 in-depth pilot sites.[1]

The approach taken by the programme and the evaluation was informed by previous experience from social care. The evaluation therefore focused on the areas and protected characteristics where there appeared to be most risk. This included age, sexuality, ethnicity, health condition and disability. Socioeconomic status was also included because, as with all choice initiatives, there is a risk that personal health budgets become a tool only for affluent, articulate people.

The sites that took part included urban and rural areas across England. The evaluation showed that personal health budgets were offered to people from a wide range of backgrounds.

Results of the evaluation

The evaluation looked at the effects of personal health budgets for people participating in the pilot programme, including the impact of having a personal health budget on health status, quality of life and use of health services. Across the whole of the group taking part, there were positive results – personal health budgets led to better quality of life and less use of health services. Health status did not improve, but it did not deteriorate:

During the study period, and after controlling for baseline differences and health conditions, personal health budgets had a significant positive impact on care-related quality of life, psychological wellbeing and subjective wellbeing compared to individuals in the control group ... By contrast, personal health budgets had very little impact on health status.

Key findings regarding the cost analysis were ... services such as primary and secondary care, not covered by personal health budgets (hence "indirect"), were found to be significantly lower for the personal health budget group compared to the control group after accounting for baseline differences.

Personal health budgets are best offered to people with greater need, to act as a substitute for conventional service delivery.[1]

The qualitative findings showed the central role of information, advice and support. The people who benefited most were those who felt they had enough information; those who had a less positive experience felt they lacked information.

The evaluation also looked at how well personal health budgets worked for different groups.

- There was some weak evidence that personal health budgets may have been more beneficial for people aged under 75. But this does not mean that older people cannot benefit from a personal health budget – there is some evidence from social care that older people may be less likely to be offered as much choice and flexibility, including the option of a direct payment.[10]
- People with mental health problems and those receiving NHS Continuing Healthcare (usually those with the most significant disabilities) tended to report the most improvement in outcomes.
- People who had a university or college education, or who were not in receipt of benefits, tended to report improved outcomes.

- Personal health budgets were more cost effective for people over 75. A possible explanation was that personal health budgets led to reduced overall costs, in particular from hospital admissions, without worsening outcomes.
- No other differences in cost effectiveness were found via analyses looking at gender and socioeconomic status.
- No differences were found in outcomes or cost effectiveness based on ethnicity; however, the numbers were too low to give robust results.

The evaluation indicates that personal health budgets have been taken up widely and can benefit everyone, regardless of background. There was no conclusive evidence to show that any groups were systematically excluded from taking up personal health budgets, or had worse outcomes. However, for some groups the numbers taking part were too small for this analysis to give clear results. For example, people who identified themselves as LGBT made up fewer than 5 percent of those taking up a personal health budget. Only around 1 percent of personal health budget holders were identified as people with a learning disability. There are some suggestions of differences that are inconclusive at this stage, where more work may be required.

Personal health budgets toolkit

In addition to the independent evaluation, the Department of Health has also worked closely with the pilot sites and the national peer network to gather learning throughout the pilot. Peer networks are made up of people taking up personal health budgets and family members. The section on co-production and peer support (page 13) explains more about the role of peer networks in developing personal health budgets.

This work is published as a series of good practice guides, which make up the personal health budgets toolkit.[11] The toolkit shows how personal health budgets can be implemented well for people from different backgrounds.

The toolkit demonstrates how equalities issues are addressed by core aspects of the programme. It includes a national information leaflet on personal health budgets, also available in easy read format.[12] Pilot sites can tailor this leaflet to local circumstances and produce it in other languages and formats. Information is also available on the NHS Choices website.[13]

The toolkit was developed keeping in mind those groups that might need a more targeted approach. Within the pilot programme, pilot sites were encouraged to offer personal health budgets to people with mental health problems, and were supported by an action learning network led by people with direct experience of mental health services.

The aim was to identify and understand the reasons why implementation in mental health services might be more difficult, and to support sites to overcome these barriers.

There has also been a major focus on supporting sites to implement personal health budgets for people eligible for NHS Continuing Healthcare, who include substantial numbers of older people. This has involved improving access to information and advice, better support planning, and offering all options including direct payments.

The Department of Health also has links with other programmes that involve people with specialist expertise:

- it has funded work from the Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations (LGBT Consortium), which is carrying out a 3-year programme on health care and personalisation that is directly relevant to personal health budgets[14]
- it has commissioned work from the Foundation for People with Learning Disabilities to produce information on NHS Continuing Healthcare and personal health budgets for people with learning disabilities.[15]

3 Ensuring personal health budgets benefit everyone

Understanding need

As a starting point for thinking about personal health budgets and equalities, clinical commissioning groups should ensure they have accurate information about the needs of their populations. The NHS and local councils are responsible for carrying out joint strategic needs assessments and developing joint health and wellbeing strategies.[16]

It is important to spend time building links and relationships with a wide range of organisations and groups, and to work with them to understand needs and identify groups for which targeted action may be needed.

Investment in equalities and inclusion at early planning stages is valuable as it will save costly changes being made after people have experienced unsatisfactory outcomes.

This is not a one-off process – it is about starting a conversation. This includes listening to people and speaking to them about personal health budgets. This should include, but not be limited to, people who already use services, carers, community groups, user-led organisations and other voluntary sector organisations, local racial equality councils, GPs, service providers, Healthwatch and health and social care staff directly involved in providing care. It is important to consider how to build links with seldom-heard groups who are much less likely to be included using conventional methods of consultation. The EHRC has produced guidance on engagement that gives examples of alternative methods.[17]

Early discussions will also help to provide information about how attitudes to personal budgets vary between different people, and why. Patterns can be analysed with regard to individuals' gender, age, socioeconomic status, ethnicity, sexual orientation, religion, disability, urban or rural location, etc. As part of this process, it is important to identify groups who may be excluded from, or have a poor experience of, health and social care services, and for whom specific action may be needed. It is particularly important to consider how to include people who lack mental capacity, but who could benefit from a personal health budget. Section 4 has more information about mental capacity and personal health budgets.

As part of the work to understand needs, carrying out an equality analysis (or equality impact assessment) can be useful – though it is important to keep the focus on meeting the duty and avoid the assessment becoming an end in itself. The Department of Health has

Merseyside – working with the voluntary sector[18]

In Merseyside, the NHS worked closely with the voluntary sector in the pilot programme. A manager from Imagine, a mental health provider, played a lead role in developing the programme, and Imagine also provided advice and brokerage. This helped to increase uptake of personal health budgets by people with mental health problems. People were able to use their budgets in ways very different from conventional services, tailoring their support to suit their background and circumstances.

developed an equalities and inclusion thinking tool for use by personal health budgets pilot sites (Appendix 1).

Leadership of the programme

It's also important to ensure there is a clear governance structure for the programme of work to introduce personal health budgets, which is clearly linked to other structures such as the clinical commissioning group board and the local health and wellbeing board(s).

Governance arrangements should involve people from a range of groups, and have a clear remit to ensure equal access. Including in governance people with experience of using services, and voluntary sector organisations, can help to ensure a wider range of experience, build connections with groups that are less likely to be in contact with statutory services, and keep the focus on issues that matter to people who use services and their carers. It is important to review the membership of decision making groups such as risk enablement panels.

People's stories

Stories showing how personal health budgets can make a difference to individuals are a powerful way to win over health professionals, and to encourage people to take up budgets.

The Department of Health has developed a wide range of film and written stories showing people from very different backgrounds, including people from BME groups, older people, people with learning disabilities, and people with complex long term health conditions and disabilities. The stories show how care and support can be tailored to each person's situation.

Several personal health budget sites have produced films locally, and people taking up personal health budgets have told their stories in person at national and local events. Local stories help to show that personal health budgets are relevant for the local population. The personal health budgets website has film and print versions of stories, which are also available on DVD.[20]

Razia's story

Razia, aged 32 and from Merseyside, was fleeing an abusive relationship and was isolated and traumatised.

Razia used her personal health budget to purchase a computer, enabling her to study at home and to maintain supportive email contact with her family in Pakistan. A bus/train pass ensured she could get to college and attend vital appointments with an Urdu-speaking counsellor.[19]

Co-production and peer support

As part of the pilot programme, the Department of Health has worked closely with people taking up personal health budgets to co-produce the approach through developing a national peer network. This has helped to ensure personal health budgets focus on what matters to people who use services and their families, and that a wide range of people have taken part in their development.

It has also proved valuable to develop local peer networks that bring together people with personal health budgets.[21] This creates the foundation for the local development of personal health budgets, co-produced with people who have direct experience of using services and their families, and working with professionals as equal partners. This helps to ensure personal health budgets will be easy to access and work well for everyone.

Peer networks help people move from being passive recipients of services to being able to play a leadership role. This can include becoming involved in the oversight of the programme, and supporting efforts to make personal health budgets available to all sections of the local population. Members of peer networks are able to act as experts by virtue of their experience, providing peer support, advice and encouragement to people who are new to personal health budgets. This can in turn support efforts to reach out to people who might not otherwise be aware of, or feel confident to take up, personal health budgets. The membership of peer networks should be reviewed regularly to check that the group is actively including and welcoming people from a range of backgrounds.

The personal health budget peer network plays a central role in helping us get the policy and delivery of personal health budgets right. Their targeted involvement in our work ensures that what we develop is grounded in real experience. As a group, the network has a wealth of knowledge and experience and they offer real challenge when we need it. They are also essential allies in helping to explain to NHS professionals and others what personal health budgets mean in practice and helping to get people on board.

– Alison Austin, personal health budgets policy lead, Department of Health

Information, advice and advocacy

It is essential that information and advice about personal health budgets is easily available, and that people who need it can access support and advocacy. Good information is an important building block in making personal health budgets available to groups who are at risk of being excluded.

Information needs to be tailored to the needs of different groups. Information on websites and in printed leaflets, and other written material in plain English, is a good start. Directing people to information on local websites and NHS Choices gives them a chance to read information at their own pace.

However, many people do not have internet access and can find written material hard to understand, or irrelevant to their situation. For some people it will work better to get information through personal contact from trusted people, peer support, and the chance to hear directly from people who already have a personal health budget.

Working with a local peer network at an early stage can help to build understanding about how people want to obtain information.

Working with local councils and voluntary organisations is also an important way to build information and awareness of personal health budgets. Many voluntary organisations run telephone helplines, and can answer initial queries and direct people to more information. Direct payment support services are also a good source of advice. It's also helpful to build links with people and organisations with expertise and knowledge of working with particular groups – such as self-advocacy groups for people with learning disabilities.

People within groups also have an individual and unique set of needs. In the same way that personal health budgets are offering choice and control around the services a person receives, people will also need tailored information and advice to be able to make the best possible choices.

Some personal health budget sites have commissioned advice and brokerage services from voluntary organisations and user-led organisations. External brokers bring a wealth of experience of working with diverse populations. Links may also be built with other sources of information including GP surgeries, community centres, Citizens Advice Bureaux, mosques and libraries.

It is also important to consider how to include people who lack mental capacity. The personal health budget guide 'Advice, advocacy and brokerage' provides more detail on how pilot sites have developed information and advice services locally, and about requirements regarding mental capacity.[22]

Making information widely available

A number of pilot sites have gathered feedback on their personal health budgets information and used it to improve leaflets and tailor information to specific groups – for example, providing easy read versions with pictures. Sites have also made information available in a range of formats and languages on request.

In Oxfordshire, Age UK has worked closely with the NHS to develop personal health budget information that will be useful for older people as they become eligible for NHS Continuing Healthcare.

In Cheshire, the Centre for Independent Living employs a broker who works closely with the NHS Continuing Healthcare team, providing information and support to develop a care plan.

In the West Midlands, the NHS produces a roadshow. A bus visits travellers' sites, areas with high BME populations and areas with high levels of deprivation, providing information about NHS services including personal health budgets. GPs and health visitors travel on the bus to offer services.

Care planning – developing flexible and tailored support

At the heart of a personal health budget is a care plan. The care plan sets out how an individual's budget will be spent to enable them to reach their health and wellbeing goals.

The ability to use a budget in ways that are flexible and tailored to the person's background and needs provides a huge opportunity to make the NHS more responsive to the needs of the whole population. Rather than fitting people into existing services, each person can choose the arrangements that work for them. For example, a person can choose who to employ as a personal assistant, or choose a service provider that is more likely to understand their background and meet their needs. Some people with a personal health budget have chosen friends and family members to provide support. This has been particularly important for people who have experienced prejudice and discrimination in the past, or where mainstream services are hard to access or not geared up to meet the person's needs.

People will often need support and advice when developing their support plan. To be fully engaged in the process, so that the care/support plan is a genuine collaboration between the patient and their health professional, people will require support, which may not always come from within the NHS. Having external brokers with knowledge and expertise in the needs of specific groups can be important. It is essential that people have the information and support they need to make informed decisions.

When developing and signing off the care plan, organisations must also take care to ensure a wide variety of available options. Pilot sites that had the most success were those that provided the most choice and flexibility in how the personal health budget could be used. Putting in place inflexible rules could lead to discrimination by preventing people from tailoring their support to suit their needs.

For more information on care planning, see the personal health budgets guide 'Implementing effective care planning'.[23]

Evaluation and review

It is important to monitor how personal health budgets are working. At the local level, this will mean having systems in place that enable the NHS to track access and outcomes for people across all the protected groups. At the individual level, a good system of reviews will help to show whether care plans are working and whether people achieve their outcomes. It will also provide evidence on how people are using their budget.

The Department of Health is working with personal health budgets pilot sites and In Control to develop ways to measure the uptake and outcomes of personal health budgets beyond the pilot programme. This aims to provide a system enabling sites to monitor who is taking up personal health budgets and to measure their experience of the process and the outcomes achieved. This is one way to make monitoring and evaluation part of normal practice beyond the pilot programme. The evaluation tools will enable progress to be reported both locally and nationally. Pilot sites are also developing local approaches to evaluation based on the local context and the groups targeted.

4 Personal health budgets and mental capacity

Who are people who lack mental capacity?

The Mental Capacity Act (MCA) is the Act that underpins all NHS care for people who lack capacity. The MCA sets out that people with a mental impairment must also be assessed as lacking capacity in relation to the specific decision to be made. So, for example, patients with a diagnosis of dementia, or learning disability, or brain injury must have had a capacity assessment that concludes they are not able to manage a personal budget – and then they will be deemed to lack mental capacity in relation to this decision.

There are some 2 million people who have mental impairments in England; some will have capacity to make the decision to have and manage a personal budget, and some will not.

Can people who lack mental capacity receive a personal health budget?

The NHS has to treat people equally. This means that those people who lack the capacity to manage personal health budgets can be assessed as to the benefits and risks in relation to having a personal health budget. The benefits are likely to be similar for people with and without capacity. The risks are likely to be different.

A person-centred risk assessment is required. For example, if a person has a number of family members already involved in their care; if they have a circle of support set up that meets regularly to review how arrangements are going; if the condition or health need is relatively constant, then these all may be indicators of low risk. If the person has no family or friends involved in their care; or if their condition can deteriorate very quickly, these are indicators of high risk.

Risk assessments have to be personal to the individual, and clearly recorded. Where risks are low, it may benefit a person who lacks capacity for their family to use a personal health budget to purchase and arrange their health care. Where risks are high, alternative ways of arranging health care should be sought.

The risk assessment should identify strategies for risk management, which include how often reviews should take place. Safeguarding issues should be identified and addressed. Reviews are very important for people who lack capacity and are receiving a personal health budget. Reviews need to be more frequent for people who lack capacity, and more frequent for those who are dependent on only one person to manage the health budget. Where there is a stable group of people involved, there is less risk.

5 Sources of advice and good practice

The Social Care Institute for Excellence has published a set of resources about personalisation and equalities, including several films.[24]

The EHRC provides information and guidance about the Equality Act 2010, including:

- a starter kit explaining the public sector equality duty[25]
- case studies showing how health services can meet the equality duty[26]
- guidance on engagement[17]
- guidance on reasonable adjustments (in chapter 7 of the Code of Practice).[27]

The Cabinet Office has produced advice on equalities and procurement.[28]

NHS Choices provides information for the public on NHS services, including the responsibility of the NHS to meet the needs of everyone, regardless of background and circumstances.[29]

The NHS Equality Delivery System has been developed as a tool to help commissioners and providers ensure the NHS provides good results for all sections of the population.[30]

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