

PERSONAL HEALTH BUDGETS GUIDE

Co-production – changing the relationship between people and practitioners



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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

A central element of personal health budgets is a different relationship between those who receive support and those from whom they receive it. This idea has been written and talked about over the past 40 years – a concept called co-production.

This good practice guide describes the ideas behind co-production and offers suggestions for how they can be used to make sure personal health budgets work well for people in your local area.

A note about language

Language is powerful. Much of the language that has grown up around health and social care perpetuates the notion that there are people and organisations who give care and support and people who need care and support. Co-production fundamentally challenges this notion. Throughout this guide we have chosen to use certain words:

■ Why are we using “we”?

This is about all of us having some responsibility for how things are – services, society, individuals, the media.

■ People who need extra support

All of us receive some support in our lives (unless you can fix your own car, boiler, TV or broken ankle). We talk about “people” or “people who need extra support” as shorthand for people who live with an illness or long term condition, are disabled or older, or use any health or social care services.

■ Families

We use the word to mean the people who are in our lives because they care about us and don't have a paid role. This is usually our blood relatives, but might include other people who are close to us.

2 Managing health and wellbeing

Most NHS spending is on long term conditions such as diabetes, arthritis, chronic obstructive pulmonary disease (COPD) and mental health problems. These are all conditions that can't be cured, but that people live with and manage from day to day. We also know that, with an ageing population, the cost of long term conditions to the NHS can only rise.

Effective management of long term conditions falls more to people and their families than to health care professionals. The average person with a long term condition in the UK spends no more than three or four out of the 8,760 hours in a year with a health professional. Even a person receiving intensive treatment, for example from an assertive outreach team, would see that team for no more than three hours a week – less than 2 percent of the hours in the year.

There is a strong argument for enabling people to play an equal role, alongside clinicians and other practitioners, in managing their care. Several initiatives over the past 10 years have focused on greater choice and control for people using health services and on changing the role of health care professionals, including the following.

Expert Patients Programme

Participants attend six group sessions, led by trained non-professionals who also live with one or more long term conditions. The programme is not condition-specific but looks at self-care issues that are commonly faced by people living with an ongoing health condition, such as dealing with pain and extreme tiredness and communicating with family, friends and professionals.¹

Shared Decision Making (Right Care)

Shared decision making starts from the reality that there are very few areas of health care where there is only one treatment option. In the vast majority of cases there are several possibilities, each with different risks, side effects and likelihood of success. Shared decision making aims to bring together clinical evidence and the informed preferences of the person who needs treatment. It can apply to any aspect of care where the situation is not immediately life threatening and the person has the mental capacity to make a decision. This includes decisions about tests, treatment options and the ongoing management of conditions. People and clinicians act together to make decisions, each recognising each other's expertise. Decisions are based on both clinical evidence and the person's informed preferences.²



Year of Care

Year of Care was initially a pilot project launched in 2007 in three primary care trusts: Tower Hamlets, Calderdale and Kirklees, and NHS North of Tyne (North Tyneside and West Northumberland). Its aim was to improve the care of people with diabetes by giving them more control through personalised care planning, a collaborative relationship with their clinician, and effective local commissioning. Year of Care introduced a two-step process for people with diabetes, involving an information-gathering session with a health care assistant followed by a review with a GP. This gave people more chance to think through their goals and priorities and discuss them with family members before meeting with their GP to agree their goals and action plan.

The Year of Care pilot found that effective care planning consultations rely on three interdependent elements:

- an engaged, empowered person
- working with health care professionals committed to a partnership approach
- supported by appropriate/robust organisational systems.

At the start of the pilot, most health care professionals were not used to working in partnership, and an extensive training programme was put in place to win them over to this philosophy of care. Partnership is now firmly embedded in the three pilot areas, and the Year of Care approach has been

extended to COPD and to long term conditions more broadly, recognising that a significant number of people have more than one condition.³

Co-creating Health

Co-creating Health was a large-scale demonstration programme (2007–12) developed by the Health Foundation to enable people with a long term condition to “improve their health and have a better quality of life by taking a more active role in their own care. The programme distilled the evidence about what works in enabling self-management into a set of skills and practices that can be taught to both people with long term conditions (self-management programme) and clinicians (advanced development programme). Both programmes were spread over a number of sessions and co-facilitated by a person who was successfully managing their long term condition along with a clinician. Both programmes focused on three enablers: goal-setting, shared agenda-setting and goal follow-up. Support was provided to demonstration sites to improve the design and operation of their services to support self-management.⁴

We have now started to see a real shift in thinking from a disease-focused NHS to one that looks proactively at health and wellbeing. The New Economics Foundation (NEF) has developed a set of evidence-based public health messages aimed at improving the health and wellbeing of the whole population (see box on page 6).

Five ways to wellbeing⁵

■ Connect...

With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

■ Be active...

Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.

■ Take notice...

Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

■ Keep learning...

Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

■ Give...

Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

These ways to wellbeing begin to challenge the relationship between people who need extra support and practitioners. The ideas behind co-production offer a framework for taking this a step further.

The evaluation of the personal health budgets pilot programme⁶ demonstrates that personal health budgets really do have a positive impact on people's care-related quality of life and on their psychological wellbeing. Particularly, how personal health budgets were offered was found to be important, specifically that people:

- know how much their personal health budget is
- have genuine choice and flexibility about how to spend their budget, and what on
- have genuine choice about how to manage their budget.

A clear theme of the evaluation was that personal health budgets offer additional opportunities for health care professionals and people to work together in partnership, making shared decisions and actively co-designing services and support.

3 What's different about co-production?

Co-production is a concept that applies across all public services. Its heart is in community development and tackling social injustice. It is based on the idea that health and social “problems” can’t be resolved by either government, or public service professionals, or individual citizens alone, but are best tackled in genuine partnership, with each party contributing their particular skills and knowledge.

The term “co-production” was first used by Elinor Ostrom⁷ and her team from Indiana University in the late 1970s as she conducted a series of studies on the effect of delivering services from a large centralised institution. Her example showed how moving police officers from patrolling the community on foot to working predominantly in patrol cars had a negative effect both on crime and on how people viewed the police. She identified the elusive missing ingredient (that she called co-production) – police officers on the beat build relationships with local people who share information that helps keep crime down. Simply put, the police needed the community as much as the community needed the police.

Edgar Cahn turned his work on timebanks and the core economy into a challenging but practical agenda for social change in his book ‘No more throw-away people: the co-

production imperative’. While working to promote the timebanking model, he began to notice what felt like a universal public service issue, felt by everyone he spoke to regardless of their profession, the service they were offering, the client group they served, or the neighbourhood they worked in:

It’s really difficult to get the people we are trying to help to participate.⁸

We hear versions of this from many professionals across health and social care:

I’ve given them all the information about stopping smoking but they just don’t do it.

Some people just don’t seem to want to be helped.

We put on groups and they’re free but people still don’t always come.

If he just got some more exercise then his back would be so much better.

If she just lost some weight then her diabetes would stay under control.

Edgar Cahn called this the missing factor “the x-factor”, and recognised that what was critically missing was some form of endeavour from the consumer, so they were not a passive recipient. Hence his use of the word “co-production” (see box on page 9).

Co	The prefix literally means “with”, but defines some form of relationship or partnership – though intentionally not necessarily equal
Production	More than a passive consumer, directly involved in the production or creation or bringing into being of something

Or ... it's a bit like the difference between ordering take-out pizza and making one yourself with the kids! If you order out, you look at the menu and choose from the pizzas they have ... Margarita, Hawaiian, pepperoni. Really good take-out services will also give you the option of putting together your own flavour, from a list of toppings ... I bet you still order the same three pizzas every time?

If you make pizzas at home with the kids then it is likely to involve quite a lot of flour on the floor, some constructive discussion (argument) about how many different toppings it is possible to get on one pizza and whether pineapple and pepperoni really do go together. The pizzas might not be round, they're likely not to be the same size and they certainly won't correspond to anything you might find on a take-out menu. But, there's something about the experience of making them together – fun, frustration, finding out things about your kids that you didn't know just because you are spending time together

creating something. And if you decide that pineapple and pepperoni really don't go, you won't try it again (but you could find a combination that changes your pizza eating experience for ever!).

Edgar Cahn framed four core values that define co-production:

- recognising people as assets
- valuing work differently
- promoting reciprocity
- building social networks.⁸

This guide aims to:

- explore what each of the four core values means
- expose the traps we fall into and the myths we perpetuate as we design and deliver care and support
- offer ways to challenge these myths through the framework of personal health budgets.

4 Co-production – the core values

Core value 1 – recognising people as assets

The real wealth of a society is its people – we need to celebrate and use the skills and strengths they bring. This is about how the NHS sees people who receive extra support in their lives from services. Often, when a person needs extra support, their illness or impairment becomes all we see. We forget that a person with a long term condition that means they need help to get up in the morning, prepare food and get around is also a daughter to a mother living with dementia; a friend who makes great chocolate cake; and an avid campaigner for the Green Party.

The traps we fall into and the myths we perpetuate

- We think and talk about people who need extra support as patients, service users, clients, customers – “problems”.
- We believe we are the experts in delivering our service.
- We consider the person’s diagnosis as the first and often the most important thing when planning their support.

Or ...

Our patients are all very vulnerable so we have to be careful about what we can let them do.

We try really hard to give our patients the support they need but some people just don’t want to be helped.

We only work with people with dementia – that’s our specialism.

Challenging the myths

Recognise that people really do know what they need

Central to personal health budgets is the idea that people are experts through experience. While professionals have a great deal of clinical expertise about diagnosis and treatment, people are experts in understanding how a particular condition affects their life and the things that matter most to them – going to work, being a parent, getting involved in the local community.

Recognising people as partners alongside professionals is relatively new in the NHS, which has tended to prioritise clinical expertise. There remains a tendency to question the validity of decisions that people make or to restrict their choices in certain ways, for example by allowing people to purchase only traditional NHS services with a personal health budget, or by creating a menu of choices from which they must choose.

A Health Foundation animation,⁹ 'Behind closed doors', shows two different conversations between doctor and patient, highlighting the power of different ways of asking and answering questions.

Personal health budgets will make the biggest contribution to improving the efficiency of the NHS if people are allowed to be as creative as possible, unencumbered by restricted menus, and if they are recognised as experts through experience, whose decisions should not be second-guessed.

Listen to what people say about what works for them

There should be a range of formal processes for people to contribute to how care and support is designed and delivered – such as patients' forums, planning events, and using information from review processes.

It is important to take an asset-based approach when asking people to contribute to service design and delivery. One way of doing this is to find out more about people's skills, knowledge and experience (not just their illness or impairment) when asking them to be part of a formal planning process.

Sarah's story

In one area, a woman living with a long term mental health condition was invited to join the personalisation board as a service-user representative. At the first meeting she attended, they were discussing the back-office systems – some of the software was getting in the way of practitioners recording and sharing information from people's care and support plans. Sarah plucked up the courage to tell the board that she had a master's degree in computer science and would be happy to help them look at what needed to change ... and write the programs if necessary.

Give practitioners the opportunity to hear it how it is

NHS staff training programmes should include people talking about their lives and experiences.

Core value 2 – valuing work differently

This is about radically changing how we define work. We usually think about work as something we do that earns money. Co-production helps us think about work as any activity we need to carry out – looking after children or older people; running a home; being part of Neighbourhood Watch are all activities that we need, but none of them is rewarded with a wage. We can also think of these activities as part of the core economy (see box).

Economists estimate that at least 40 percent of economic activity takes place in the core

economy and is not reflected in the gross domestic product. This means that people who stay at home to raise their children, look after older people and run their homes are technically unoccupied. If we want to make co-production work, we need to find ways to recognise and reward activity that is part of the core economy.

The principles of co-production remind us that we need to see and use the skills and experience people have to offer. We also need to find ways to reward this work in ways that are not just about paying people in cash.

The traps we fall into and the myths we perpetuate

- We don't have any way of recognising contributions people bring to the organisation, other than through the formal payroll.
- We believe people are too ill or too vulnerable to contribute.

We have two economic systems:

Money drives activity: This is all the private and public sector organisations that do things in exchange for money. It includes the services and support provided through health or social care.

Family, neighbourhood, community drive activity: This is all the unpaid activity that is driven by our hearts and minds, our care and compassion and love for people close to us. It is the work we do to bring up our children and look after our wider families and older people. It is the things that build communities. It is the core economy.

- We believe only clinicians can understand the evidence base for a treatment.
- We don't create any flexibility in how we run services to enable either staff or people who use the service to recognise their other roles – as parents, family carers, community leaders.

Or ...

*We have to make sure that there are **clear boundaries** between staff and clients and that includes our volunteers.*

*You have to remember that **these people really can't do very much for themselves.***

*People are **placed in our service** because of the support they need – **our job is to make sure that they get that support.***

*We like to find opportunities for people to do some volunteering **but only if they are capable.***

Challenging the myths

Set up formal ways for people to have their time and expertise valued

Jane's story

Jane is part of a group of parents whose sons and daughters have complex health care needs and receive support through a personal health budget. They help families new to personal health budgets by sharing their stories and experiences.

This is not paid work, but NHS managers recognise how important it is and reward the group with places on training sessions, free meeting rooms and venues for events, and some office space to work from. Members of the group can also have their experience formally referenced on their CV by practitioners, helping people who want to look for paid work in this field.

Peer support

The idea of peer support isn't new, and is a very ordinary way of thinking about people supporting each other. It's based on the notion that sometimes we need people to support us who really do understand what we're going through, or how the world looks from our perspective. In everyday life, that might mean chatting to a person who has recently been to Australia as you plan your trip of a lifetime. In health, it might be receiving informal support at a carers' coffee morning; having the chance to talk to a person who lives with MS when you've been recently diagnosed; or putting together a support plan alongside a person who works for a user-led organisation.

peoplehub

The national peer network¹⁰ promotes the voices of people with direct experience of having a personal health budget, either themselves or as a family carer. Jo Fitzgerald, Mum to Mitchell, who is 20 years old and has a personal health budget, is co-founder of the network. She talks about the importance of local networks:

Local peer networks are a great way to involve people in shaping the way that personal health budgets are delivered. Working in partnership with people with direct experience will enable local NHS organisations to offer personal health budgets in a way that makes sense to individuals, and provide a place where organisations can “try out” processes and get honest feedback on what is working and things that may need to be changed locally.

Use the principles of timebanking (page 8) to develop a strong basis of peer support

Timebanking¹¹ is one way to formally reward people for work they do if they don't want to be paid in cash, or if that is difficult to do

without affecting their benefits. The currency of pay is hours. An hour of whatever you offer – cooking a meal, fixing a dripping tap, accountancy or computer support – has equal value. You earn and bank your hours, and you can take hours out of the timebank to get things you need.

Pete's story

I've lived with diabetes since I was 15, and I'm 45 now. Over the years I've got a good understanding of my condition and how best to manage it – my priority is to live life without diabetes getting in the way. I get support from the diabetes clinic and recently I've joined a scheme where I give support to someone who has recently been diagnosed. It's great – I can tell it like it really is and also offer very practical and emotional support. I've even started playing golf with one of the guys I've met.

Core value 3 – promoting reciprocity

This is also known as “give and get” – people who access care and support have a chance to give as well as get support. It’s about making sure people are not just seen as, treated as, or expected to behave as “people who need help”.

Support that works in this way builds on people’s assets and expects everyone who receives support to (at some point) offer it to someone else. Everyone needs to be needed and valued – this builds our self-esteem and makes us stronger, and less likely to be a “problem” for the NHS to “sort out”.

The traps we fall into and the myths we perpetuate

- We hide behind “duty of care”, “client confidentiality” and “management of risk”, which stops us being able to encourage or enable people to support each other, or to support others in the community.
- We believe that only paid staff have the necessary skills and expertise to offer information, advice or support.
- We believe that reciprocal arrangements are unreliable and are bound to fall apart.

Or ...

*We have to remember that we have a **duty of care** towards our clients.*

*Our job is to help **patients with their problems** – we are the **professionals** and*

their needs are complex and require a professional response.

*Our **patients** are people who **need support**. We can’t ask too much of them or make too many demands.*

*We **don’t encourage** our clients to talk to each other – we **can’t be sure** they’d give accurate information and we do find it tends to make them more unwell or exacerbate their own problems.*

Challenging the myths

Harness people’s capacity to do it themselves and to share what they learn

Many people will be able to develop their support plan on their own – start from the assumption that people will be able to plan for themselves, and work backwards. If you start out by asking people whether or not they want support to plan, many will say they do, even if they are capable of planning alone.

Those people who do need support in developing a plan can receive this in many ways, including through family and friends, community members and peers. Much of this support can be provided reciprocally – a person who has received support offers it to others in return at a later date.

Professional brokers are an expensive option, and personal health budgets will not be financially sustainable beyond a pilot if everyone who is eligible for and wants a personal health budget is referred to a professional broker.

The system has a responsibility to enable people to lead their own planning by making the support planning process clear and straightforward, and by making clear information easily available. People who have planned their own care and support are also a very useful source of information. (See the “care and support planning” section of the personal health budgets toolkit.¹²)

Support and grow strong peer support

Routinely ask people if they are prepared to share their skills and experience. For example peer networks can be a useful way for people to share experiences and help each other to find solutions. This enables people to make a contribution through helping and encouraging others.

Core value 4 – building social networks

This is about remembering that people build and sustain communities. You have to be present to be included. Services need to play an active role in supporting people to become, or remain, part of their local community – not to cut them off from any but paid contact.

The traps we fall into and the myths we perpetuate

- We mistake behaving “professionally” for a need to keep clear boundaries between paid staff and people who use services.

Vera’s story

I’m 78, I have COPD, and I live in my own flat in an extra-care housing complex. I moved here three years ago when my daughter emigrated to Australia, and I was really worried about making new friends at my age. I needn’t have worried as I’ve probably got more friends now than I ever did! I have a small personal health budget to help me keep my lung function as good as possible and I use it to go to a singing group.

In the housing complex, we all sign up to doing something to help our local community – I help with the flowers in church every week, and help bake buns for the sale we have every week. We have a communal lounge that we open twice a week for local mums and dads to come with their toddlers – they really bring a breath of fresh air. I’ve got particularly close to one young woman and Mia her daughter – Mia’s like a grandchild to me, which is lovely as I miss my daughter so much. Because of my friendship with Mia’s mum, she now gives me a lift to my singing group, which means I don’t need to get a taxi. It’s made such a difference to my life.

Farid's story

Farid is part of a personal health budget support planning network in his local area. The long term conditions team has a process where, when a person's support plan is signed off, they are asked if they would be prepared to talk to one other person to help them with their support plan. This can be anything from an informal chat to working with the person to write their whole plan. The network is supported by a user-led organisation contracted to the NHS. Members of the network can support just one person, or may want to stay involved with the network and play a more active role in support planning locally.

A community exchange programme

Lehigh Valley Health Network in Philadelphia, USA runs a community exchange programme, where people can share skills and knowledge with other people in their neighbourhood and earn "time dollars".

As part of the programme, people who have been discharged from the hospital's medical wards are offered someone to come and visit them at home to check they have everything they need, offer help, and simply have a chat. This support is given by people who have also been patients in the hospital – on discharge, everyone is asked if they would like to be part of the programme in future. They are carefully matched so they live near the person they are visiting, and people often build new connections and friendships through the programme.¹³

- We hide behind risk, and believe that communities are essentially unreliable.
- We commission services and support that distance people from their wider community, rather than helping them keep and strengthen their connections.

Or ...

*Helping people make friends **isn't our job**. Our patients find it hard to make friends and they're very vulnerable to exploitation. Anyway, we have to be aware of data protection.*

*The most important thing for us is to recruit **staff who have the right clinical expertise** – nothing else is really important.*

Fred's story

Fred is 68 and lives on his own. He has unstable diabetes and needs to get to hospital for regular appointments, but has no-one to take him. He used to rely on hospital transport – now, through his personal health budget, he is able to pay his neighbour, John, to give him a lift. They quickly found out that they both like going to the cinema but hate going on their own, so the arrangement they have come to is that, once a week, Fred pays for them both to go to the cinema and have some lunch in the pub. Both Fred and John say the new friendship has made a real difference in their lives.

People in the local shopping centre don't understand our clients so its best to keep them doing activities within the day centre.

Challenging the myths

Remember it's not just about the money

Since it is new for people to control NHS money, there is a risk of reducing personal health budgets to "shopping for treatment". Money does bring control, but we know from social care that first we need to help people think about how they would like their lives to be different. Otherwise, people can end up with just more "stuff", without seeing any real transformation in their life.

We know money is just one asset that people have at their disposal – it is one component of our real wealth, alongside inner resilience, our strengths and talents, our family and friends and community connections. We can draw on all these to improve our health and change our lives for the better.

People should be encouraged to develop a support plan that draws on all their available assets and to see the money they have available as providing a way of developing assets in other areas. For example, there is a growing tendency for people to use their personal health budget to pay for a personal assistant (PA) to take them

shopping or to a community activity. This may be necessary initially if people are isolated. But the PA should act as a bridge to social connections and friendships that do not rely on payment.

Encouraging people to develop an initial support plan as if they have no access to money from a personal health budget can be helpful in identifying other assets.

Support creative community services to develop

Personal health budgets will change the pattern of services that are commissioned to reflect personal choices. With some support and encouragement, community-based services that have little to do with specialist health care could flourish through people's use of their personal health budgets.

Anya's story

Anya lives with a long term mental health problem, and often finds it hard to get out of the house to make or meet friends. As part of her personal health budget, she has employed a PA on a six-month contract. Part of the PA's job description is to support Anya to try out new things to do – going to the gym, joining a rambling group – and to help her get into conversations with people who share these interests, so that she has the confidence to go along on her own.

5 Conclusion

Personal health budgets can operate effectively only through a new type of relationship between people and health care professionals. This relationship has been described in terms of co-production – based on the concept of a genuine partnership, with each party contributing their own skills and knowledge to the process.

Money is just one component of our real wealth, alongside inner resilience, our strengths and talents, our family and friends and community connections. We can draw on all these to improve our health and change our lives for the better.

Personal health budgets will improve the efficiency of the NHS if people are allowed to be as creative as possible, unencumbered by restrictions, and if they are recognised as “experts through experience”.



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Personal health budgets team

Websites: www.personalhealthbudgets.dh.gov.uk/toolkit
www.nhs.uk/personalhealthbudgets

Email: personalhealthbudgets@dh.gsi.gov.uk

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