



Personal budgets – A lived experience

“Someone invites you to a wonderful party but they forget the food.”



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About Hestia

Hestia is a charity, working together with adults and children in crisis to change their lives at the times when they most need our help.

We have supported people with Personal Budgets for five years through our Personalisation services in Richmond, Newham and Wandsworth. We provide payroll, managed account and Personal Assistant recruitment

services. In 2015-16, we supported 691 people with their Personal Budgets.

Across our broad range of other services, we also help people to find a permanent home, manage their finances, take care of their health, and access work, training or education, as well as providing emotional and practical support to help people succeed in their daily lives.

In 2015-16,
we supported
people with
their Personal Budgets.

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Introduction

Over the past twenty years, individuals needing support to live independently have been increasingly involved in shaping the care and support they receive.

This transition marks a cultural change in social care – moving away from institution-led, one size fits all approaches towards individual packages of support designed around the needs and aspirations of the person involved.

The 2014 Care Act required Local Authorities to assign a Personal Budget to all people who are eligible for support. By law, Personal Budget holders can decide how, who with and where they wish to spend that budget in order to meet their needs and achieve the outcomes of their support plan.

In response to this growing service area, we wanted to co-produce a report which highlighted the strengths and challenges of holding a Personal Budget.

The people who use our services have agreed that the growing use of Personal Budgets has been a positive step in social care and told us that they value its core principles. They have highlighted that, to an extent, they are being given more choice and control and are able to access tailored care and support.

However, our research has found that these reforms have not always met expectations. A limited market, operational barriers and absent or conflicting information has prevented our clients from

consistently utilising all the opportunities Personal Budgets could offer.

Through the use of case studies, interviews, focus groups and survey data, our research has identified eight key findings, each with corresponding recommendations aimed at Local Authorities and third sector organisations similar to Hestia. Though our recommendations are directed by the people with lived experience, our research is hot off the press and we welcome opportunities to develop our findings.

Summary



82.76% of people with a Direct Payment and/or Managed Account valued having more choice and control over their care and support.



91.67% of people with a Direct Payment and/or Managed Account are either fully or partly aware that they have the option of being an employer when using a Personal Budget.



Of the people with a Direct Payment and/or Managed Account who knew where to look, 83.7% were able to find tailored care and support.



People with a Direct Payment and/or Managed Account are unclear on what a Personal Budget can be spent on.



Direct Payment users were less likely to fully utilise their whole budget as 26.5% had money left over at the end of the financial year.



If people experience a delay in payments due to reviews or administrative errors and receive the reimbursement back, the reimbursement is paid back as one lump sum. This amount can then be taken away again if it is not spent by the end of the financial year.



30.5% of people felt that the financial value of their Personal Budget did not meet their care and support needs.



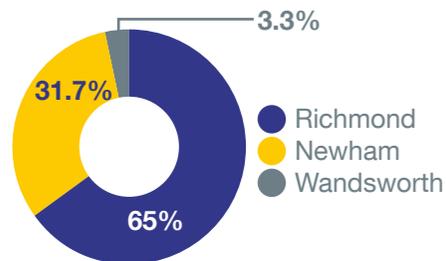
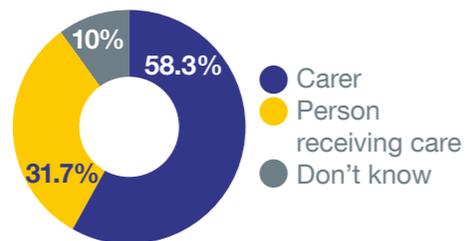
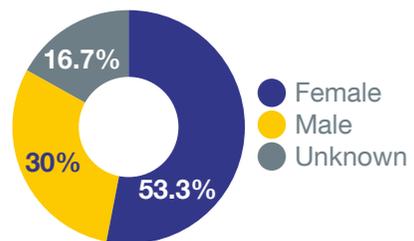
Young people and their families are facing difficulties transitioning from a Personal Budget in Children and Young People's Services onto a Personal Budget in Adult Social Care.

Methodology

We interviewed 23 clients individually, held two focus groups and received 60 completed surveys. In total, we consulted with 21% of people currently

using our Personalisation services. We also consulted with our staff so that the client feedback could be interpreted at an operational level.

Who responded to our survey?



Definitions

When completing our research, it became apparent that different professionals and Local Authorities operate under different definitions, which is an additional barrier to those attempting to navigate Self-Directed Support. For the sake of consistency, we have provided brief definitions of our relevant terminology.

- **Personal Budget** – The virtual amount of money allocated to meet a person’s assessed care and support needs
- **Direct Payments** – Cash payments given to people in lieu of community care services they have been assessed as needing
- **Managed Account** – The person’s Personal Budget is managed by a third party
- **Self-Directed Support (SDS)** – People using social care services are given choice and control over their support.

Key Findings

82.76%

of people with a Direct Payment and/or Managed Account valued having more choice and control over their care and support.



Carleene's Story

"What I would say about having the Personal Budget is that it's given me more choice so I can adapt my son's respite provision to his specific needs. When you're dealing with your children, you want the very best for them and to have the opportunity and the choice to make the right decisions. Being allowed to make those choices makes a big difference and my son has really benefitted.

His PA (Personal Assistant) is somebody that I have vetted and who I have seen around my son. My son gets to do things and take

part in activities that work for him. My other children also benefit by having a break from their brother. They also need to do fun things like every other child and this allows us to have time with them. It could be to sit down and read a book together, it could be to play a board game or puzzle or it could be to go out and do something.

I got really stressed in the beginning but since Hestia has managed my son's account there hasn't really been any hassle. I think that's important for a person like me as I haven't got time for any hassles, my son is my main issue."



POET's 2014 National Survey has highlighted that more than three quarters of Personal Budget holders reported their budget having a positive impact on dignity, independence, arranging support, paid relationships and quality of life (In Control, Lancaster University and Think Local Act Personal, 2014).

"It certainly has given me more choice and the freedom to manage my own affairs rather than rely on a nanny state to make decisions for you. The older you get the more you value your independence."

However, 31.3% of those who we spoke with felt that there was too much administration involved in having more choice and control. Within this figure,

users of Direct Payments were disproportionately represented with 77.8% feeling that there was too much administration, particularly in regards to the numbers of forms and needing to keep a backlog of receipts. Though paperwork is necessary, particularly in regards to detecting discrepancies, people who use Hestia's services and those across the UK have reported that the amount of administration has been burdensome (National Audit Office, 2016).

Prepayment cards were highlighted as being helpful in reducing administration, however there were repeated incidents of their implementation being fraught

with complications or errors. Our clients have reported that the setup is lengthy and they have been given incorrect passwords and security questions. When accessing accounts online, our clients fed back that the layout made it difficult for them to quickly search for past purchases.

“As a not very computer orientated person; I find the set up to be not as straightforward as it could be.”

Recommendation

Local Authorities should continue to promote the take up of prepayment cards but could review existing processes to ensure a smoother and simpler transition onto prepayment cards.

“It's been helpful having it on a card.”

Hestia will review whether any administration can be condensed.

91.67%

of people with a Direct Payment and/or Managed Account are either fully or partly aware that they have the option of being an employer when using a Personal Budget.



Susan A's Story

‘It makes a big difference employing friends who can help me. My daughter couldn't bear having strangers in the house and I wouldn't want a stranger to be able to walk in and out of my home. If someone else is chosen for you, you don't feel so much like an employer, as much as someone who is just having stuff done to you. If you're choosing your own person, you feel like you have more authority over your situation.

In September, a long-time friend who had been a carer for many years became free and she started helping me. I have another friend who I'm paying because she's one of those super organised people and she's able to focus on sorting out paperwork and miscellaneous stuff. I'd also like my ex-partner to do one or two hours a week as sometimes I need things lifted down from somewhere or things moved around. I find that different people have different skills and their support has made a big difference to me and my daughter's overall wellbeing.”



Awareness of employer opportunities is encouraging as research has found that employing a Personal Assistant increases the chance of a personal relationship emerging, thus reducing isolation, increasing self-respect and dignity and providing greater flexibility of care (OPM and ECDP, 2011).

When people were asked why they hadn't taken up the opportunity to employ staff, they responded that being an employer would be an 'extra hassle' and involve too much paperwork.

Our staff have also reported that there is a lack of information on how to undertake certain employee responsibilities. Common issues relate to clients being unsure of how they will arrange and cover the cost of

training and annual leave for their Personal Assistant.

Hestia works to ease client concerns and support them as employers by offering telephone support and signposting to appropriate information hubs. However, Skills For Care have highlighted that in many Local Authorities there is a gap in the offer of pre-employment training (2015).

People who decide not to be employers can be left with poor alternatives. Some clients felt that care agencies were ineffective as they would regularly send different carers, therefore removing any personalised elements of service provision.

“A Personal Budget is not useful if your carer is changing from one day to the next.”

Recommendation

Local Authorities are implementing e-monitoring for domiciliary care, where home care workers can scan themselves in and out using an electronic monitoring system and record their completed tasks. The system can track worker visits and could potentially replace hard copy timesheets to confirm whether visits have been undertaken on time or even at all, and the records provide accurate billing and automated payments (RBKC, 2014). Systems which reduce administration are likely to encourage an uptake in clients becoming employers.

Hestia is looking to go forward with developing a peer support group, which could be used as a space to provide support for employers.

Of the people with a Direct Payment and/or Managed Account who knew where to look,

83.7%

were able to find tailored care and support.



Andrea and Kate's Story

"We got to a stage where we desperately needed help on the weekends. We spoke to the social worker and they came up with the Crossroads Plan which offered us two types of care. We got offered an agency in North London but they would only come and look after Kate and that didn't suit me, I needed someone who would be the other adult in the house. We tried respite away from the house and that really didn't work because Kate is very much a 'home bird'. Then we had somebody who was a respite carer, but that also didn't work out. It was then that a social worker told us about Crossroads

Care and that is where we met Kate's PA who's been with us for 5 years. She's a Support Broker is her other job which actually helped us as she spoke to me about what was available and we got on really well. When Kate's PA left Crossroads, she came to work for us privately and that's when we were introduced to Hestia.

We tried all sorts and the Local Authority gave us the flexibility to try different things. With the right guidance, you can find the support that's right for you.

I think we were lucky in having the right information put our way. I don't know what happens in places where they don't get that information."



It is encouraging that those who knew where to look were mostly able to find tailored care and support. The majority of our clients use their Personal Budget to recruit a Personal Assistant and a variety of methods were used to find PA's. Examples include using personal connections, PA registers, online searches on Gumtree or advertising in newspapers written in the language of the PA they are seeking to recruit. During the consultation, no one mentioned using the e-marketplace, a platform for holders of Personal Budgets to search for and purchase products and services.

However, it is concerning that 28.3% of people were unsure of where to look for care and support. When asked about the challenge of finding appropriate care and support, Personal Budget holders responded that they felt it was like 'opening a can of worms' and they were not given enough guidance on where to look.

This reality is explained by the Association of Directors of Adult Social Services which found that in 2014, only 8% of councils reported having an information and advice strategy (2014).

Recommendation

There is evidence that Hestia's Richmond PA Register is effective as our Richmond clients were more likely to know where to look for care and support and more likely to find the help they needed. Despite an increase in the uptake of PA registers, only 56% of Local Authorities reported having a PA register available (Skills for Care, 2015).

Hestia will consult with clients and other SDS organisations, to hear about new and creative ways of searching for care and support and will share this information with our staff and the people who use our services.

People with a Direct Payment and/or Managed Account are unclear on what a Personal Budget can be spent on.



Mr and Mrs Ahmed and Saeed's Story

"We started receiving a Direct Payment for our son Saeed nearly three years ago.

The people who gave us the Direct Payment said "this money is for your son, use it." They didn't say it had to be spent specifically on activities and truthfully, I put my hands up, I spent it on him. I spent it on shopping, clothes, going to the cinema.

We went to a meeting and they said that the payment is being spent the wrong way and we switched to a managed account. As parents, we didn't have the knowledge and we didn't get the advice. If I had the right information and advice at the beginning, of course I would still be using the Direct Payment. If we knew exactly what the money was for then I wouldn't have bought him clothes."



A Personal Budget can be spent on anything that meets the agreed outcomes of the support plan, yet 43.3% of people are unaware or only partly aware of this. If a Personal Budget is put in place without adequate support and information, the user is less likely to benefit (National Audit Office, 2016).

Our clients have reported that with limited or conflicting information from the Local Authority, they are unclear on what the budget can be used for.

“The social worker said we could use it for activities and when that social worker left, we had a new worker who said: No, you cannot do that.”

The outcome is that people are wary of using a Personal Budget incorrectly or using it in innovative or creative ways.

“We’re very scared of what we’re doing.”

“I sometimes break free, and go...This is the budget he has been given, I believe that this meets the general criteria of his care plan.”

What can also be unclear is that Local Authorities advertise similar broad visionary intent that a Personal Budget can be spent on anything that meets the agreed outcomes of the support plan. However, our staff have reported that this is not always the case. Local Authorities draw different interpretations from these guiding principles, with some purchases only accepted in selected boroughs.

Recommendation

People who use our services have requested a bullet point list of what they can do and what they cannot do. As long as the guidance still offers flexibility, Personal Budget holders would be better informed on what they could potentially use their budget for.

“I need support in this. Being left to do whatever is OK for a parent who understands the system, but not OK for those who don’t know.”

The use of case studies in promotional materials could also inspire people to use their budget in innovative and creative ways.

Hestia will consult with clients and other SDS organisations to find out about innovative and creative ways of using a Personal Budget and we will share this information with our staff and the people who use our services.

Direct Payment users were less likely to fully utilise their whole budget as

26.5%

had money left over at the end of the financial year.



Susan B's Story

"I started receiving a Personal Budget in June or July 2015 and it pays for my carers. However, I have found the money too restrictive to do what it is meant to, which is to help me live more independently.

I have all this money going spare which I could be using but I'm only allowed to spend it on things like gardening and going on holiday. I can't find any hotels that use electric beds. There are some self-catering places but then I have to find someone to come with me and my carers are married, they can't go away for a week.

The money for the gardener is very nice and I appreciate it, it's nice to see a nice garden, but I could be using it on acupuncture and at the end of the day, it is the acupuncture which is helping me. I also need my carers to cover weekends but I'm not allowed those hours. I couldn't use the money to buy a trolley with a tray for food, as that has to come from Occupational Therapy. I could be using this money, which is frustrating as its tax payer's money and we've all paid for it."



Direct Payment users had money left over, not because they had surplus funds, but because they were not able to effectively use the amount for their care and support needs.

Three reasons were identified:

1. People reported that they were given conflicting information from social workers on whether they can save their Direct Payment. Receiving conflicting information from different professionals is a theme which ran throughout the research.

"Some social workers have told me that you can save it for extra things but then they take it back from me."

2. The budget was not flexible enough as any money saved from one activity could not be used for another and could only be spent on care and support which fell within restrictive categories. The rigidity of Personal Budgets is preventing them from being used holistically. Instead of using it on social care that is actually needed, users are being advised to spend it on unnecessary care and support, simply because it aligns with traditional delivery. In Control have cautioned that the consequence of splitting service provision into clusters of need is 'financial inefficiency, poor co-ordination, high levels of bureaucracy, clashes of service ethos and confusion for all concerned' (p.7, 2015).

“Any money saved from an activity cannot be used for another activity.”

3. People who were looking to spend their Personal Budget on day opportunities struggled to purchase relevant support due to the closing down of community centres, reduced transport and a limited supply of local activities. With a reduced market, brokers will struggle to meet the needs highlighted in support plans.

“They give you this spiel that there’s lots out there for them to do but it’s just not true.”

Recommendation

Social workers could better utilise independent Self Directed Support (SDS) organisations as sources of information and advice. When holding interviews and focus groups, we consistently heard that Personal Budget holders were highly satisfied with the support and information they received from independent SDS organisations.

The Integrated Personal Commissioning Programme is aimed at individuals with high levels of both health and social care needs (NHS, 2016), yet we would suggest that individuals with low complex needs would also benefit from greater integration.

Further investigation could be made into why Direct Payment users are not using the funds, rather than Local Authorities simply retracting the amount at the end of the financial year. The Local Authority has confirmed that the person has support needs and has provided a costed budget for those needs. It should be of concern if the person is not using it.

“It would be nice if somebody rang to check up on me.”

Hestia will support Managed Account users with funds remaining to relay their concerns to the Local Authority.

If people experience a delay in payments due to reviews or administrative errors, they can receive the reimbursement back in one lump sum. This amount can then be taken away again if it is not spent by the end of the financial year.



Isabelle’s Story

“They stopped my daughter’s payments when she started at a Residential college in September 2014. We did not need so much money now that she was going to residential college, which is fair enough as she wasn’t here. They took away some money which they had given us in September by calculating how much we could receive and deducting the overpayment. However, it ended up that over a 6 month period we only received £100 for her care and we needed the money for half term and holidays when she came home. When I stopped receiving the money I phoned up the Local Authority straight away, but when they explained it to me it was very

difficult to understand how they had calculated everything.

Nobody told me what to do, but I ended up sending them everything I had calculated, which showed ‘at this day she was here’ and ‘at that day she was there’ and I showed them that they had taken away money for when she was at home. When they saw this evidence, they actually realised that I was entitled to more than I had expected and paid it all back to me.

They gave me the reimbursement but I have not been able to use all of it. I am still waiting to find out if the unspent money will be taken away from me, but I suppose it’s going to be.”



There is a lack of awareness that the retraction of these funds can be disputed.

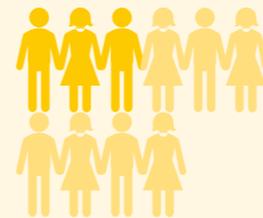
Recommendation

Any clients who underwent reviews or experienced administrative errors should be offered an automatic extension from retraction.

Hestia will create a fact sheet, advising Personal Budget holders what they are entitled to, including their right to dispute the retraction of funds and will circulate accordingly.

30.5%

of people felt that the financial value of their Personal Budget did not meet their care and support needs.



Christopher's Story

"I'm very grateful and I know they fought very hard to get me as much money as I get, but with the greatest respect I just think it should be more.

I would say the amount I get given isn't enough for the hours I need, it's only by the good graces of my PA that she does extra things. It is purely a business arrangement but if she was a hard headed business person, and said 'I've done my hours, sorry', I'd be in trouble. She does far in excess of anything she gets paid for... far, far in excess.

The payments have stopped covering the hours I need because I have become less mobile since my last review and I need more help. My PA spoke to someone at the council who said it might turn into a six month review to follow up on any changes, but I haven't heard anything yet.

There's going to come a time quite obviously when someone's going to turn around and say, 'I'm sorry but it's not worth it. I love you dearly and I don't want to see you in distress, but I can no longer afford to come and look after you.' And it worries me."



The people who use our services reported that their needs can quickly increase between each annual review and their allocated budget would stop covering the cost of their care and support. Our clients are not being told that they can request a review if their needs increase.

They also reported that the Resource Allocation System did not accurately reflect what they needed to pay for their care and support needs. Unless their PA is willing to work additional hours, users felt that their options were to advertise for a PA at a lower pay and struggle to recruit, or advertise at a higher pay rate and receive insufficient hours.

The National Audit Office has reported that in most Local Authorities, staff ignored the indicative budget when support planning (2016).

“The money that I get doesn’t cover the amount of hours I need.”

Recommendation

Twelve London Local Authorities have implemented a new Resource Allocation System which is directly related to need and with the budget calculation embedded into the assessment. The new system includes current market rates which have been used to pay local existing services, and is therefore sufficient to purchase care and support. It is also much easier to update the rates so any rate fluctuations can be taken into account (Westminster City Council, 2016).

Hestia will create a fact sheet which will tell Personal Budget holders what they are entitled to, including their right to additional reviews of their need and will circulate accordingly.

Young people and their families are facing challenges when they transition onto a Personal Budget within Adult Social Care.



Jane and Tom's Story

"There are wonderful people out there who go the extra mile for nothing, but when my son transitioned into adult social care; I felt such a panic as everything was falling away. I spent hours on the phone trying to find him things to do, and eventually some things did come along, but no infrastructure was provided.

The Local Authority put me in touch with an organisation that would help me find a PA but they did not help me look for any activities in the community. I enquired about volunteering at a garden centre and the Local Authority was supposed to send someone to the interview with my son, but it never materialised. It wasn't appropriate for me to go with him.

It takes such a toll on the carer and you stop listening to the opportunities as people disappear, funding stops, organisations merge and people leave. But if I don't take control, what do I do? If I wait for someone else, it won't happen."



When moving into Adult Social Care, young disabled people face a significant decline in activities and resources available to them, particularly in regards to employment support. One mother reported that, 'once you get to 25 years old you have little to do apart from walk around the streets or shops with your Personal Assistant'. In response to this low market supply, young people are not seeing a seamless connection between support planning and brokerage.

Our evidence also found that it is common for people to experience a gap in payments when transitioning from child to adult social care, due to an absence of communication between the different departments. The CQC research into the transition to Adult Social Care found that if the move was coordinated, it was due to proactive parents rather than professionals. Only 50% of young people and their parents said they had received support from a lead professional during the transition (2014).

Recommendations

Greater investment is needed in employment focused or generic activities aimed at young people transitioning into Adult Social Care.

“Why are young people left with no proper future past 25 years?”

Encourage greater practice of an assigned lead professional who will oversee the young person’s transition to Adult Social Care.

Through our quarterly communications, Hestia will circulate relevant information to clients transitioning into Adult Social Care and will encourage them to contact our team if they have any questions.

Acknowledgements

We would like to thank all of the clients who took part in interviews, participated in our focus groups and responded to our survey. We are immensely grateful for your enthusiasm, passion and insight. This piece of research would not have been possible without your help and support.

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Finally, our sincere thanks go to David Siddall who volunteered his evenings and weekends to complete case study photography for this report.

To read more about how we can help or how you can support our work,

please visit our website at:

www.hestia.org/support-us

Tel: 020 7378 3100

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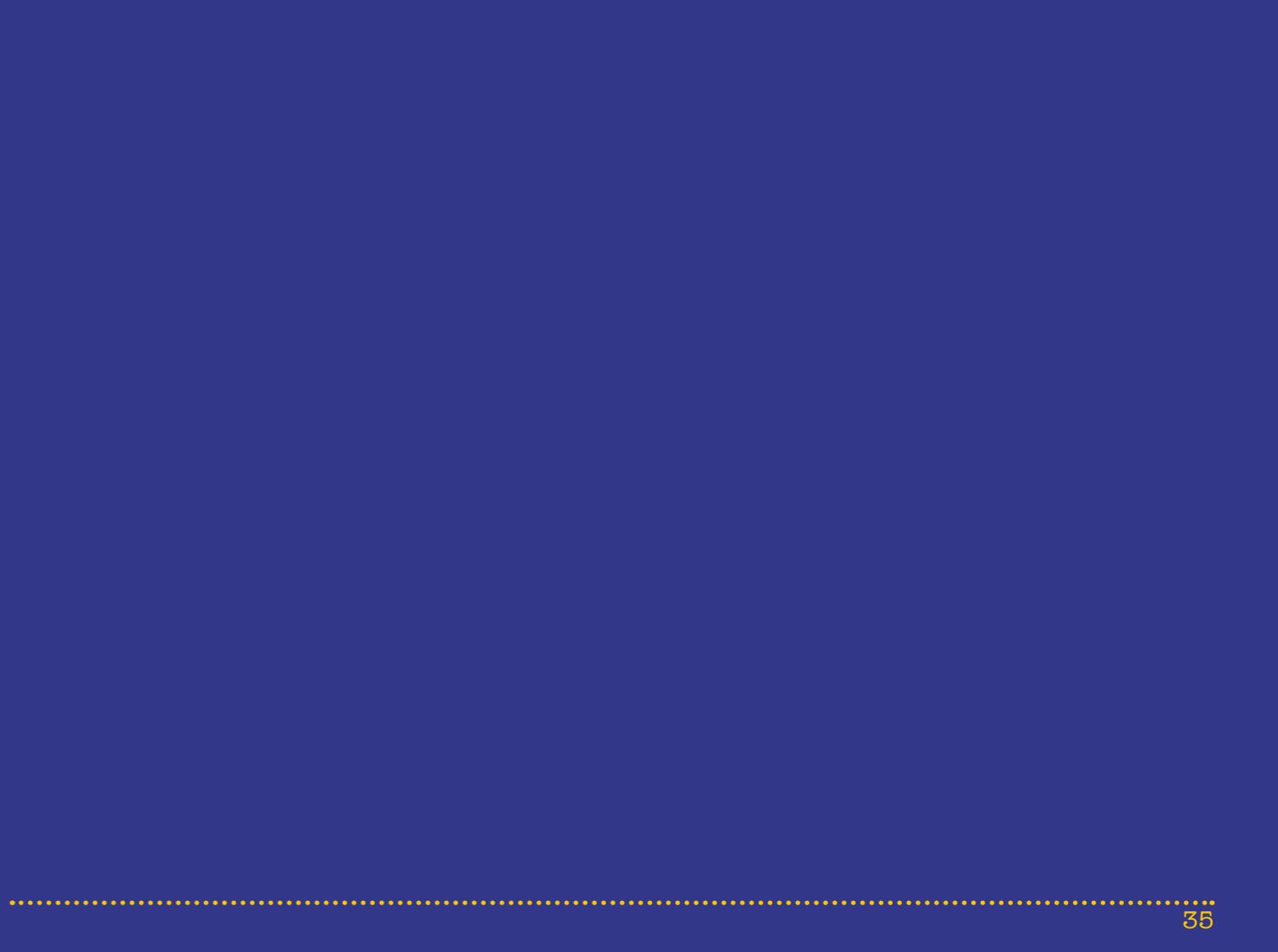
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