

**Personal budgets: a
children's palliative
care providers'
perspective**

and

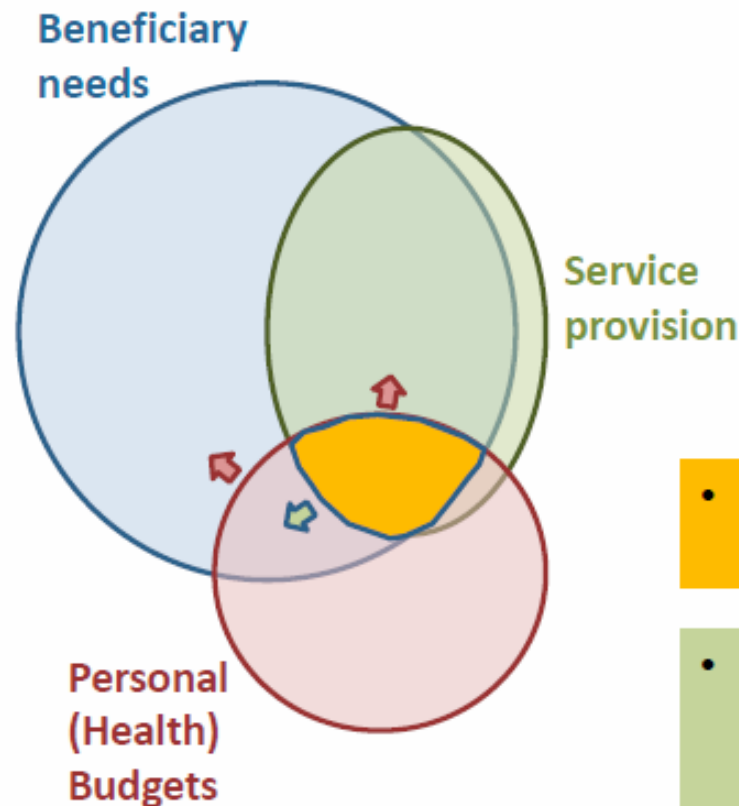
**evidence from the
SEND pathfinders**



Personal budgets in children's palliative care

- 31% of children's hospices expected to receive personal budgets funding in 2015/16.
- Personal budgets only accounted for a mean of 1% of children's hospices' care costs in 2014/15.

Considering the overlaps



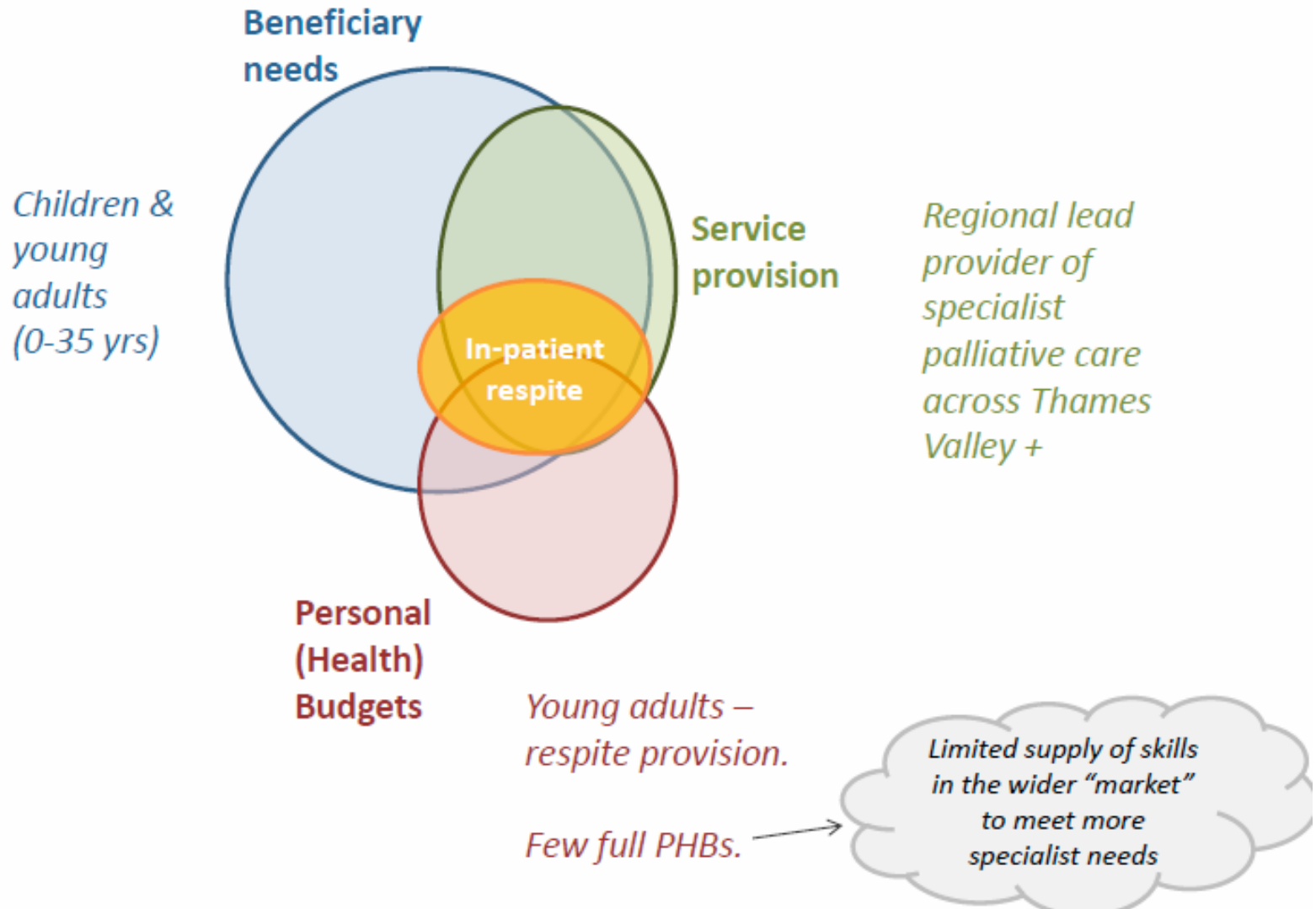
- *What is the overlap for your service?*

- *How might it grow... through service development?*

- *How might it grow... through extension of Personal Budgets?*

Helen & Douglas House overlaps

Context



Personal budgets work well when

- ✓ Commissioners assess the child or young person as needing a service which can be provided by a VCS children's palliative care provider.
- ✓ All are clear about the outcomes that can be achieved by individual from accessing the service – and the cost-benefit.
- ✓ Commissioners acknowledge that a statutory funding contribution is needed to enable this.

Personal budgets work well when

- ✓ Sufficient money is allocated to the budget.
- ✓ The funder (CCG and/or local authority) and the individual are both able and willing to pay.
- ✓ Agreements are established “up front”, and funding decisions are honoured (open conversations).



Personal budgets work well when

- ✓ Greater choice and flexibility is afforded to the individual to get the type of care they need, when and where they want it.
- ✓ CCGs and local authorities are not constrained by local/block agreements).



Personal budgets are challenging when

- Care offered by a VCS provider is perceived as “free” and not accounted for in assessment.
- The hospice cannot influence the budget assessment process and does not know an individual’s allocation.
- The budget is already committed (e.g. in paying for personal assistants) and there is apparently nothing left in the pot.

Personal budgets are challenging when

- Decision to award funding (e.g. by a social worker) is overturned by senior colleagues.
- The individual is unwilling to part with “their” budget; funding negotiations have potential to affect the care relationship.
- The individual (“customer”) wants something outside of your care model.

Personal budgets are challenging when

- A large volume of individual negotiations, with differing ability or willingness to pay agreements.



Mitigating the challenges

- Raise awareness of personal budgets with users/potential users - and the need to include hospice care as part of the assessment process.
- Influence the funding authority where possible and emphasise the cost-benefit of your service.
- Have early conversations with the individual about outcomes and associated contributions from a personal budget.

Mitigating the challenges

- Establish funding agreements and “terms” in writing.
- Separate the care relationship from the funding negotiation/chasing payment.
- Offer flexible payment plans (where appropriate).
- Establish an organisational policy for personal budgets and guidelines.

Other things to consider

- How does your organisation's approach to assessing needs and allocating care compare with personal budget assessments?
- How do personal budgets fit within your organisation's overall approach to seeking public sector funding - and existing funding agreements?
- Recognise and respond to varying geographical and individual assessments and allocations.

Other things to consider

- Equity - are you privileging or denying care to someone on account of a personal budget?
- “Choice” exists on the provider’s side as well as the budget holder’s; retain autonomy in overall decision-making.
- What should you do if someone using your service unreasonably withholds funding or abuses their personal budget?

Evidence so far from SEND reforms

[www.sendpathfinder.co.uk/
personal-budget-
information](http://www.sendpathfinder.co.uk/personal-budget-information)



SEND pathfinder findings

- www.gov.uk/government/uploads/system/uploads/attachment_data/file/448156/RR471_SEND_pathfinder_programme_final_report.pdf
- Having access to a personal budget did not appear to have had a significant influence on pathfinder families' experience, even though direct payments did.

SEND pathfinder findings

- Personal budgets and direct payments were important to those who had them - particularly in terms of organising services such as personal care, respite and leisure.
- Led to greater confidence among a few families that their child was receiving the best care available.
- Evidence of lack of information about personal budgets, particularly direct payments.