Carers’ experiences of Individual Budgets

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Background

- Implications of IBs for carers?
- Higher burden?
- Outcomes?
- Implications for cost-effectiveness of IBs?
Method

- Data collection after main evaluation
- Initial aim to restrict to carers of OP and PWLD
- Identified through main IBSEN sample in 9 sites
- Structured interviews with carers of service users in IB and comparison groups
- Semi-structured interviews with sample of carers of IB holders
- Interviews with carers’ leads and analysis of IB lead interviews re implementation
Sample

- 56% (533) of IBSEN sample had carer
- 208 carers invited
- Structured interviews
  - 60 carers of people with IBs
  - 69 carers of people with conventional services
- Semi-structured interviews
  - 24 carers of people with IBs
Data and analysis

- Service receipt and payments
- Time spent caring and activities
- Experiences of support planning and IBs
- Outcomes:
  - Quality of life indicator (7 point scale)
  - Psychological well-being (GHQ12)
  - Adapted ASCOT social care outcomes
  - Carers of Older People in Europe (COPE)
- Differences between IB & comparison groups
- Multivariate analyses
Characteristics of people cared for

- Service user group
  - 54% learning disabilities
  - 26% older people
  - 15% physically disabled
  - 5% mental health
- 50% female
- 11% BME
- 82% same household as carer
- No significant difference in IB and comparison groups
Characteristics of carers

- 74% female
- 9% BME
- 57% aged 45-59
- Caring for:
  - Adult child - 50%
  - Partner – 18%
  - Parent – 17%
- No significant difference between IB and comparison groups in carer characteristics
Service use

- No carer IBs in own right
- About 25% carer DP or carer’s grant
- No significant difference between IB/comparison in limited use of carer specific services
  - About 9% used carer groups
  - About 5% attended carer training
- No significant difference in health service use
- No *significant* difference in costs of formal support to service user but data only available for 70 cases:
  - IB approx £270 per week
  - Comparison approx £390 per week
Carer costs and payment

- Time spent caring not significantly different
  - 81 hours per week in IB group
  - 72 hours per week in comparison group
- No significant difference in range of activities
  - Time spent managing care arrangements
    - 68% in IB group, 74% in comparison group
- Little evidence of using IBs to pay carers
- Greater use of breaks, day care and leisure activities by service users in IB group – benefit carers?
Satisfaction with support planning
Quality of life

- Significantly higher QoL reported in IB group
- Multivariate - higher QoL if:
  - IB group
  - Being satisfied with support planning process
  - Good relationship with person cared for
  - Had a break with person cared for
  - Fewer hours spent caring
Social care outcomes (ASCOT) domains

- Social participation and involvement
- Control over daily living
- Safety
- Occupation and employment
- Caring role
Social care outcomes (ASCOT)

- Comparison of groups
  - No significant difference in ASCOT measure
  - Higher levels of ‘Occupation’ in IB group

- Multivariate - better reported outcomes if:
  - IB group
  - Satisfaction with support planning process
  - Fewer hours spent caring
  - Care not causing family relationship difficulties
GHQ-12

- No significant difference between groups
- Multivariate - higher well-being if:
  - Care not causing financial difficulties
  - Care not causing family relationship difficulties
  - Regular arrangement to give carer a break
  - Living in rented accommodation
Implementation issues

- Carer lead officers – limited and late involvement
- How to assess help given by carers; carers’ own needs?
- Money for carers – through IB or carer grant?
- Carer involvement in support planning?
- Better outcomes for users -> better outcomes for carers?
Conclusions

- No evidence of higher formal support costs
- No evidence of lower carer costs
- Positive effects of IBs
  - QoL and social care outcomes
- IBs appear cost-effective for carers
- Importance of satisfaction with support planning process
- Review current separate assessment/provision – whose needs, whose resources, whose outcomes?