



# Implications for family carers when people with psychosocial disability have individualised funding packages – literature review

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# Aims



- To review national & international evidence showing impact of individualised funding programs on family carers of people with a psychosocial disability
- To inform debate and policy development in the context of the roll out of the NDIS.

See full report:

[https://www.mindaustralia.org.au/assets/docs/News%20&%20Media/Mind\\_Literature\\_Review.pdf](https://www.mindaustralia.org.au/assets/docs/News%20&%20Media/Mind_Literature_Review.pdf)

# Method

- Report reviews 91 references
- Found few studies of family carers of people with psychosocial disability
- Review widened & reviewed:
  - individual funding allocated to carers
  - individual funding allocated to family member with psychosocial disability
  - outcomes for people with psychosocial disability and other types of disability when a ‘flow-on’ effect for family carers was indicted
  - impact on carers of people with all types of disability

# Background – individualised funding models



- In Canada & USA 40 years; Europe 30 years
- Nationally & internationally different names & designs
- Differences in design:
  - who hold funds
  - if can purchase from open market
  - if recruit, employ & manage staff
  - level of administrative responsibility expected
  - extent of information & support provided
  - adequacy of funds

# Individual funding brings change of perspective



- Funding allocated to meet needs of person with disability
- When person's needs are met, demands on family carers reduced
- Planning considers family context, including carers

# Findings

- **No simple answer**  
What suited some people didn't suit others
  - “It all depends”
  - “Devil is in the detail”
- **Better outcomes overall and no adverse effects**
  - when conditions were conducive
- **UK Act gave individual budget to carers** – rarely used
- **Is a BIG change** in philosophy, policy and practice
  - systems are evolving – dynamic ongoing learning

# Carers' concerns

- Having to 'fill the gaps' and provide support when funding is inadequate & services unavailable
- Shouldering the burden of managing administrative responsibilities without adequate support, i.e.
  - recruit, employ and direct paid support workers
  - manage finances, taxation and insurance requirements & acquit financial accounts
  - find services & activities in competitive market

# Conditions leading to positive outcomes



## Program design

- Adequate funding
- Assistance to: access information, plan, find services & manage administrative responsibilities required
- Education sessions & facilitation of peer support to provide information, increase confidence and plan creatively
- Oversight to manage risks
- Staff working from empowerment principles
- Appropriate services to purchase

## Family carers

- Being proactive, finding out the rules, considering own and family member's needs and wants, creative planning, negotiating with bureaucracy.



# Choice, control & flexibility



- Family carers welcome having more choice, control & flexibility
- They organised supports to suit their needs & preferences e.g. specify times when support worker came; took support worker on holiday
- “I’m the piper, I pay the money” Leece, J. (2010:196).

# Carers NSW NDIS experiences

## - typical of many other findings

- Some carers struggled to understand & embrace NDIS
- Not all carers had access to capacity building opportunities
- Some carers found NDIS gave them more administrative work
- NDIS planners varied in their treatment of carers & consideration of carers perspectives
- Despite difficulties, overall positive reports & learnt from experiences

Carers Australia - NSW (2014)

# Carers NSW NDIS example



David cared for adult son Gary who had psychosocial disability. Gary's existing service provider gave preplanning support. Helpful NDIS planner. Gary allocated sufficient therapy, personal care, domestic help for the first time. Gary's supports resulted in David having four times more respite than previously. Gary opted for 'direct payments' – i.e. they managed the funds and employed support workers.

“This is FANTASTIC. A little bit of work to set up but assisted by a bookkeeper who also does payroll of support workers”.

“We have more choice and control, support is totally tailored to my son, support workers undertake the training we want and we get more bang for our buck.”

Carers Australia - NSW (2014:11).

# Positive outcomes for family carers



- Less emotional, physical & financial strain; more satisfied with their life; more satisfied with the care they provided to their family member; less worried about their family member. Brown, R., B. Carlson, S. Dale, L. Foster, B. Phillips and J. Schore (2007).
- Many carers said their increased happiness due to the person they cared for being happier.  
“If he’s happy, I’m happy. It rubs off, doesn’t it?” Larkin, M. (2015:37).

# Positive outcomes for family carers

## Direct benefits when family member:

- Had activities and holidays which gave the person a break and their carers respite
- Allocated domestic assistance while sharing residence with family carers

## 'Flow on' effects when family member:

- Spent less time in hospital
- Had fewer criminal justice contacts
- Gained confidence and found a job
- Was less stressed due to improved care

# Marginalised, disadvantaged & minority groups



- Little attention given in literature
- Little known about their needs
- Some studies tried, but difficulties recruiting
- Likely to miss out on information
- Likely to miss out on benefits
- Footnote: NDIS has task groups focusing on Indigenous participants and engagement

# Conclusions



- Carers from marginalised, disadvantaged & minority group need extra support to gain potential benefits
- Family carers benefit when individualised funding packages result in better outcomes for family member
- Family carers who are proactive in seeking information and support benefit the most

# References



Brown, R., B. Carlson, S. Dale, L. Foster, B. Phillips and J. Schore (2007). Cash and Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home- and Community-Based Services. Final Report. Princeton, New Jersey, USA, Mathematica Policy Research, Inc.

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Larkin, M. (2015:37). "Developing the knowledge base about carers and personalisation: Contributions made by an exploration of carers' perspectives on personal budgets and the carer-service user relationship." Health and Social Care in the Community 23(1): 33-41.

Leece, J. (2010:196). "Paying the Piper and Calling the Tune: Power and the Direct Payment Relationship." British Journal of Social Work 40(1): 188-206.



# Mind Carer Development Fund

- \$1.5 million fund to progress carer mission
- Commissioning agents; panel comprised of carers
- Three works 2015 /16 – literature review and NDIS, National Practice guide for working with carers and economic replacement study



# A carer perspective on the research

- Commissioned as major concerns that carers were left out of schemes, lots of fear
- Expected outcomes to be dire

## Learnings

- We were looking for like for like language, funding in NDIS – did not mean other carer supports were available in the countries reviewed,
- Learnings about – what leads to a good life being a useful discussion to have with (and for) carers and;
- Over time carers get better at it

**Can achieve the good life that started the community sector**

