Navigating Care: Family Carers' Support Needs in Managing Flexible Funding

Anita Nicholls

Open Polytechnic NZ

Research aim

- What supports, knowledge and skills enable family carers to use flexible funding to provide a good life for people with intellectual disabilities?
- I explored family-carers:
  - Experiences and challenges
  - Use of flexible funds
  - Sources and access to knowledge and support.

Presentation Outline

- Background & Policy Context
- Methodology
- Findings - Bronfenbrenner's Ecological Framework (2006) was used to identify how multiple settings influence families lives
    - **Micosystem** - an individual's immediate environment such as friends and family.
    - **Mesosystem** - Interaction between microsystem components.
    - **Exosystem** - Environments which impact the individual which they are not part of.
    - **Macrosystem** - Social, cultural, economic and political influences
- Implications
- Conclusion

Policy Framework

- Flexible funding is a component of the Enabling Good Lives approach (EGL), a principles based approach which aims to give disabled people and their families choice and control of their supports to achieve a good life “like other New Zealanders”(EGL, 2025).
- EGL aimed to transform the disability sector, “shifting power and authority from government to disabled people and their families” (EGL, 2025).

A complex task

- Flexible funding use is experienced as complex and time consuming. Studies report difficulties in obtaining the knowledge and skills needed to access and use funding effectively (Fleming et al., 2019; Laragy & David, 2016; Lloyd et al., 2021).
- Constructing a good life for people with intellectual disability is challenging because of their social exclusion. People with intellectual disability are more likely to live in hardship and experience social exclusion (Hall, 2010: McLeod et al., 2025).

What constitutes a good life?

- A good life is described by quality of life measures which include:
  - “higher meaning and purpose, respect, rights, social inclusion and belonging, close relationships, contribution, voice and choice, emotional well-being, growth and development, home, materiality, and health” (Elks, 2020, p.421).

Flexible funding in Aotearoa/New Zealand

- Flexible funding is used to both purchase disability support from agencies and fund supports organised and directed by disabled people and their families.
- At the time of the study, flexible funding could be used to purchase any disability support including therapy, travel and accommodation.
- Services were put in place to:
  - Monitor disabled peoples use of flexible funding
  - Support the employment of Support Workers (payroll, employment insurance).
- Very limited support was provided to disabled people and their families to plan their use of funding, connect with communities, find employees or access resources.

Methodology

- **Design**: Multiple ethnographic case study (3 participants) - ethnographic because I was studying interactions within a social world that I was emersed in and a member of.
- Each case was analysed first, with results shared with participants for member checking before cross analysis of the three cases was completed
- **Data Collection**: Each case consisted of a semi-structured interview with one parent, and document analysis of websites and documents identified by the participant as useful in managing their flexible funding.
- **Analysis:**
  - Reflexive Thematic Analysis (Braun and Clarke, 2022)
  - Bronfenbrenner's Ecological Framework (2006) was used to identify how multiple settings influence families lives at the mico, meso, exo and macro levels.

Participants

- Three mothers managing flexible funding on behalf of their adult son with intellectual disability.
- Selection criteria
  - A family-carer who had more than three years experience of using flexible funding
  - Was identified by a parent/professional who had worked with them as using funding to enable the person supported good life.
  - Other factors considered:
    - Geographical spread over the county - (1 in South Island, 2 in North Island)
    - Service availability – (1 in an EGL area with greater support availability)
    - Rural urban/ mix - (2 lived in small rural towns one in a large city)

Findings - Microsystem

Holding a person-centred vision

Parents held a vision of what they were aiming for that was based on their son’s preferences

Elizabeth talked about her use of supported decision making.

- “I believe that he wants to be independent and make his own decisions as best as he’s able. I see that in him. I try to keep it simple, lay it out clearly for him so that he absolutely is involved in that decision. Even if it becomes difficult and inconvenient, I’ll try to honour that with him.”

Microsystem

- Each parent could ‘read’ their sons communication attempts and showed a deep understanding of their sons preferences which were used to individualise disability supports.
- Parents were guided by a set of beliefs that aligned with Enabling Good Lives principles including Person-centred, Ordinary Life Outcomes, Mainstream first.
- All had attended workshops on the Enabling Good Lives approach that included information on how principles are applied in practice.

Planning

- All accessed planning support.
- Two used their flexible funding to purchase a PATH plan (that was separate from funding allocation processes).
  - PATH plans were person centred, identified long term goals, included the disabled person and their wider support network.
- One mother had yearly planning sessions provided by a government organisation.
  - Goals set justified funding allocation. This plan did not link to the disabled persons preferences. Neither the disabled person or their support network attended the meeting. The plan was not accessible to the disabled person.

Mesosystem

Support networks were valued, relied on and purposefully constructed

1. Robyn talking about building a support network and its value.
    - “I've helped friends make (the community) more inclusive. I don't think that you can move into a community, and it automatically is”.
    - “Because if something happened to William now as a 25 year old anywhere in (the area), somebody would find (me) within 5 minutes. I can’t go anywhere with William, without 10 people saying hello. So we’ve just been very welcomed and we’ve just got a massive circle of support.”

2. Bobbi talking about securing her son’s work at the chicken farm
    - “Because we’re a smaller town, smaller community, people know someone that knows someone.

Mesosystem

Support networks

- Using flexible funding was a time-consuming and complex task that no participant could manage without significant support from others.
- Support networks were formed over many years and purposefully built. They provided skilled trusted support workers, enabled social inclusion, belonging and community participation.
- Goal implementation was often achieved via an existing relationship within a families support network rather than through use of a disability support service.

Mesosystem

Information that is timely, trusted and accessible

- Each parent found accessing the information they needed challenging. All commented on the need for constant vigilance to access essential information.
- Information was actively searched for to support change or major transitions
- Other family-care givers and organisations or workshops facilitated or managed by parents with a disabled child were trusted.
- One parent valued the accessibility of recorded video presentations. Elizabeth said:
  - “But (watching a recording) means I can do it lying in bed at odd hours of the night or at the weekend. That makes a lot of sense to me. But now that Covid's finished, a lot of these things are going back to in person, which changes things again. So everything was online because of COVID, of course. And now I can't get there.

Exosystem

Social isolation

- Each mother reported that stigma associated with disability acted as a barrier to their sons' community participation
- Rural areas had fewer services but provided accessible social networks which supported inclusion
- Each parent's determined advocacy was required to reduce their son's social isolation
  - "He had a 21st birthday party. We had 150 people there. I told everybody to not bring presents and then caught them out on the night and said to them all, there's no such thing as a free party and free booze. What I want each of you to do here tonight is commit to inviting William on one social outing in the next 12 months…It was just interesting because people don't, they didn't really realise that (it) was an issue for us." (Robyn)

Macrosystem

An invisible workforce with unmet needs

- Family carers had limited access to resources and professional development. They are not always recognised by training providers as part of the ‘disability workforce’.
- Each parent was challenged by the need to navigate complex bureaucratic processes that changed over time and were inconsistently implemented between organisations.
- Each parent navigated these challenges through determined advocacy.

Implications - Microsystem

To hold and implement a person-centred vision parents are likely to be supported by:

- A clear set of principles to guide their practice (Lord & Hutchinson, 2003).
- Be able to recognise and value the disabled persons feelings, preferences and communication attempts.
- Advocacy skills

“***Even something that you’ve heard years ago. You know you’ve still got it there in your pocket if you need to, to bring it out.”*** **(Bobbi).**

Person-centred planning sessions

The research suggests that person centred planning should be:

- unconnected to funding decisions and support goals linked to the disabled person’s preferences.
- include the disabled person and their family’s support networks.
- be written up in a form that is understandable to the disabled person.
- reviewed regularly.
  - National Quality Forum (NQF), (July 31, 2020). Person-Centred Planning and Practice FINAL REPORT. Department of Health and Human Services. USA.

Mesosystem

Information sharing

How should we design information and professional development for care-givers?

- Provide opportunities to learn from peers and relate information to their own circumstance through conversation/chat
- Consider the length and complexity of information offered – bite sized video may align with family-carers time commitments.
- Locate on websites/spaces frequented by your target audience
- Provide information in diverse formats, Facebook live, face to face workshop, website, email newsletter, webinar, through peer support, online group chats.

Communities of Practice

- Could we improve our methods of information sharing through parent group Communities of Practice (CoP)?
  - Learning within parent groups fit with Communities of Practice (CoP) theory - (Nind et al., 2021; Skelton et al., 2020; Sweet et al., 2020).
  - Learning is informal, emergent and occurs through interaction and observation of others (Nind et al., 2021).
  - Imagine More – Peer Support Groups

  (CoP, Lave and Wenger, 1991)

Exosystem and Macrosystem

- Design systems to meet the needs of disabled people and their families rather than to only meet the needs of government and services.
  - Focus on providing support rather than compliance
  - Provide clear guidelines that are consistently implemented across multiple agencies
- Recognise disabled people and their families managing flexible funding as a ‘workforce’.
  - Provide access to knowledge, training and resources that are specifically designed for this unique workforce.
  - More research is required on learning designs that would best meet the needs of this workforce.

Conclusion

- Family carers are central to enabling a good life for people with intellectual disabilities through flexible funding.
- Navigating funding is complex, requiring time, advocacy, and deep personal commitment.
- Support networks and person-centred planning are essential, yet often under-supported by formal systems.
- Information access and learning must be tailored to carers' realities: peer-led, flexible, and accessible.
- System transformation is needed: recognising carers as a vital workforce and designing supports that reflect their lived experience.

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