Self-Directing within a Compensation Framework

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Kathy Rees has established and maintained a successful self-directed arrangement for her daughter through the use of her daughter's compensation funds and, more recently, government funding. Through the use of a range of strategies, Kathy's daughter obtained 24/7 support for 17 years, instead of the projected 10 years if the compensation funds had been utilized in mainstream service delivery processes. Since the expiry of her daughter's compensation funds in 2011, Kathy continues to ensure the self-directed arrangement and company structure addresses what her daughter requires. In this article, Kathy relates her experiences in establishing and maintaining the self-directed arrangement for her daughter.

As a recognised structure, self-directed support arrangements have been in place for people over many years and are now widely used across the sector and throughout the world. However, when my daughter received her compensation settlement in 1994, terminology of this nature and accompanying practices to implement self-directed supports were not commonly used. At the time, my focus was on finding service providers that had the capacity and foresight to explore alternate formats with service delivery to address my daughter's life and support requirements. The process of foreseeing a different framework at this time required considerable internal reflection and fortitude to withstand limitations in systems thinking as well as the expectations of people around both my daughter and myself. During this time, I commenced the preliminary steps that eventually led to establishing and maintaining my daughter's long-term support requirements through a company-based, self-directed arrangement. This article talks about the journey so far.

IN THE BEGINNING...

Compensation funds are widely seen to be the ultimate form of individualised funding, with compensable individuals frequently being able to assume responsibility for managing their lump sum funding and to flexibly consume money in ways that best suit their needs. As is the case for many compensable individuals, my daughter's financial affairs were placed with a nominated trust management

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1 Chenoweth, L. 2009 Self-Directed supports and personalized budgets: Key issues from research, presentation to the 'Self-Directed Supports & Personalised Budgets in Queensland' workshops conducted by the Community Resource Unit, Brisbane. [online] www.cru.org.au/seldirectedsupport/SelfDirectedSupportsLC.pps

2 Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra.

authority. This was necessary at the time, as my daughter lacked the capacity to administer her own funds or to undertake long-term planning to address her ongoing support requirements.

While having individualised funding of this nature sounds ideal, there are challenges that have to be considered with managing compensation funds. Situations where funds have been dissipated within several years after settlement, exposure to fraud, spending money unwisely, gambling, or feeling pressured to give funds to relatives can result in compensation funds expiring at an earlier timeframe than originally envisaged. Similarly, cases have been reported where family members have taken control of the compensation funds and dissipated them within failed business ventures. This can result in situations where the individual and his/her supports may become vulnerable.

While both trust fund management entities and government-funded service organisations are expected to comply with a number of legislations and regulatory processes when managing funding, individuals who self-manage their compensation funds do not fall under the same obligation. For the past ten to fifteen years, both private and public trust fund management systems have supported many compensable individuals to assume responsibility for components of their funding through the establishment of effective self-directed or self-managed arrangements. Successful outcomes have occurred where there is a sense of partnership between trust fund managers and compensable individuals and their supporters, with attention being placed on ensuring the funds last for as long as possible while at the same time being managed in innovative and individually responsive ways.

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7 Cumpston, R. 2002. Lump Sums, the Good, the Bad and the Ugly, Copyright with the Author.

8 Productivity Commission 2011, Chapter 17: Insurance arrangements for injury, Disability Care and Support, Report no. 54, Canberra.


10 These observations were noted in my PhD research which focused on addressing the long-term support needs of compensable adults with traumatic brain injuries when their compensation funds expire.
Within compensable situations, questions have frequently been asked about who the recipient or actual beneficiary of the funds really is: the family or the person with catastrophic injuries. Even before she received her settlement in 1993, I was very mindful of the fact that the funds were my daughter's and that there would be a need for a prudent approach in managing these funds. This also extended to careful consideration of practices to ensure accountability between key agencies involved in the life of my daughter, as well as a continual focus on ensuring that the supports she received were actually those she required.

During the early months of 1994, my daughter moved into her own home. The Coordinator of the service she was accessing at the time had known my daughter for many years and could certainly see the need for more lateral and innovative processes, apart from mainstream service delivery responses, to address my daughter's requirements. The Coordinator established a certified agreement which enabled my daughter's support staff to be engaged on a 24 hour, 7 days a week basis. This approach supported the need for an alternative way of addressing my daughter's ongoing life requirements and was subsequently expanded, with the use of contemporary business strategies, when I assumed full responsibility of my daughter's affairs in 2000. As a result of these approaches, my daughter's compensation funds lasted an additional seven years beyond the original expiry date.

NECESSARY COMPONENTS

A number of components have contributed towards the success of the self-directed approach that is in place for my daughter. These components include:

- Spending time to establish the frameworks within a company structure so that I could manage her support from a range of locations (this was because I had moved from her town to another city). This involved outsourcing the payroll system and obtaining the services of a human resources specialist to assist with managing the performance requirements of the self-managed team. My role involves fortnightly obligations associated with payroll issues as well as maintaining my daughter's team. On a quarterly basis, national data reporting, business activity statements and financial recording requirements need to be managed for the Public Trustee, the Department of Communities (Queensland), as well as to the Australian Taxation Office. To ensure that the framework continues for many years, I have also established a long-term, robust succession plan in the event that I pre-decease my daughter.

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11 These questions were posed by participants in my PhD research.
Making the decision to not employ family members, choosing instead to honour my daughter's need for a number of other people to be in her life. To achieve this, I used the self-managed team concept to employ people who are expected to operate as adults and to assume responsibility for making their own decisions, organising their own work, managing small budgets, reorganising work flows, and selecting new team members. Her support team has a committed vision to ensure that my daughter achieves her aspirations, and their role continues to enhance my daughter's independence within her community. Most of the team have remained with my daughter for many years, which means I do not have the staff turnover rate that is so widespread in the sector. This has necessitated recruiting, training, supervising, evaluating and investing in people who have subsequently committed to my daughter and her support requirements. In this way, the team is well equipped to address my daughter's specific needs, including managing a sleep disorder that results in her being awake for two days and two nights on a regular basis.

Writing a Handbook which contains a wealth of knowledge and experience related to my daughter's support. This Handbook speaks about my daughter: who she is, what she needs, her likes and dislikes, how her home is to be managed, and the expectations of team members. The Handbook includes the overarching vision for my daughter's support and how this revolves entirely around her. References in the Handbook include some of the philosophies and principles that substantially underpin and gird the framework of her support. All goals, aspirations, as well as the provision of specific forms of care and support are based on the one basic premise: that my daughter has the right to live her best life, whatever that may be.

14 Kerr, K., Smallwood, S., & Thomas, K. 2009. Paying Family Members to Provide Attendant Care: Does it adversely impact on TAC clients and/or scheme outcomes, Applied Business Project, Deakin University.
Establishing an external team who provide me with information, support and guidance as well as reality checks. These people are positive and can see the vision of what I am continuing to strive for on behalf of my daughter. These people continue to provide valuable insights and assessments of my daughter's support over time.

Continuing to ask: whose needs are being served? This involves keeping abreast of what is happening within the disability sector, as well as reflecting on the necessary obligations related to overseeing the company, namely, to exercise my powers honestly and only for the purpose to which they were granted. This involves regularly asking questions about values, particularly about the purpose, meaning, participation, belonging and relationships that enable my daughter to be included in all aspects of life.

**THE REWARDS**

The success of the self-directed approach ensured that my daughter's compensation funds lasted over seven years more than they would have by utilising mainstream disability service supports. However, none of this would have been possible if I didn't have the support of the trust fund management entity in the early stages after my daughter's settlement and again in 2000 when I assumed responsibility for my daughter's formal support arrangement. In amongst the strategies and supports that I have put in place for my daughter over the years, I continue to question my role. This is a good thing, as I know that I need to maintain a sense of freshness and curiosity to ensure that I can change things when this is needed, while at the same time continuing to manage the company that so successfully supports my daughter to live a quietly dignified and valued life in her community. The frameworks that were put in place so long ago are testament to the success of using a self-directed approach for my daughter - and I believe that she knows this too.

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