PEARLS OF WISDOM

New Horizons – the result of good planning

Listening to a guest speaker at a local event held in 2013 proved to be a major turning point in the life of Laura and her family. The guest speaker spoke about her own experience of self-direction, explaining how she took responsibility for directing her daughter's arrangements and how she lived through the trial and error of managing this arrangement on a daily basis over a number of years. She also explained how the greater independence and flexibility offered through self-direction opened up new possibilities for her daughter's life. From these discussions, Laura walked away thinking for the first time in her life, maybe, just maybe, her own daughter could also enjoy independent living, instead of continuing to live in the family home.
Laura said, 'You know, I hadn't thought about this before and then suddenly this woman comes along and shows me that a different pathway was possible'. She went on to explain that she talked to her husband, and then her other family members, about what this new possibility could look like. 'From that point onwards, our whole life has changed!' Laura exclaimed. 'We have gone from being with a service provider in receipt of standard services to now being in a situation where my daughter has a life – and the beginnings of a really good one at that'.

Laura explained that the service provider often asked her what she wanted for her daughter but would then simply do what they wanted to without Laura understanding what was involved. The service took between 33% to 38% out of her daughter's funding without explaining what this funding was being used for and support staff were forbidden to speak about the funding with Laura at any time. After many years of questioning such behaviour and feeling that she was being seen as a problem by the service Laura finally made the decision to have her daughter's funding transferred from the original service to a Host Provider and to direct the funds herself on her daughter's behalf.

However, Laura explained that commencing self-direction was not without its hiccups and stumbling blocks. Like most people who receive support through a service provider, Laura had very little knowledge or experience of what it takes to manage funding or staff. She feels strongly that more open communication with service providers would help people understand more of what is involved in these matters rather than simply accepting that such arrangements can only be managed by a service.

As well as the general problem of lack of experience Laura had particular problems with moving the funding from the original service provider to the Host Provider. These included problems with funding that had been approved but could not subsequently be allocated because nothing was in writing, and being told by Departmental staff that other families needed the money more than she did. Laura said that because she appeared to be managing, even though there were no support staff and no respite supports provided for her daughter during this time, the Department would not provide her daughter's funding to the new Host Provider. Some behind-the-scenes championing of her daughter's case finally resulted in the funding being made available.

Once the funding had been transferred Laura started a process of dedicated planning to look at how her daughter's requirements could best be met through these new self-directed arrangements. She said that her previous experiences with a service provider's approach to planning didn't actually focus on her daughter's strengths or the possibilities for her to learn new things so that she could be involved in life beyond her family home. Now, as a result of very focused planning which did explore her daughter's strengths and capabilities, and which also looked more fully at what would be available in the community that could match her daughter's interests, she has developed a very different plan and a new vision for her

daughter. Laura said that this took some time as she, herself, had to see different possibilities which meant her own beliefs were challenged and stretched. As a result of this early planning work, Laura said her daughter is just starting to experience a new life with new opportunities and the possibility of meeting new people in her community.

Laura said that she could not have done this planning work without the assistance of a planner who knows a lot about supporting people with disabilities through self-directed arrangements. 'The planning process is unfolding now into something that has been beyond my wildest dreams, something I thought could never happen in a million years'. The goal of independent living is something that seems possible now. Regular things like joining a swimming club and being a member who meets other people who enjoy swimming are becoming a reality for her daughter.. Last weekend, a trip to Dreamworld was the culmination of a previously impossible dream. Laura also said that her daughter now enjoys cooking with her support workers and is looking forward to sharing the results with her family first, and then sharing with her neighbours. She went on to say, 'Initially, I thought that this was ridiculous, my daughter cooking, but now I can see a whole lot more happening for her. It is all a bit mind blowing, really!'

Laura talked about the greater level of flexibility she has in using support hours for her daughter. Instead of having 17.5 hours a week of support, which her daughter had through the previous service provider, now her daughter has more hours of support and the flexibility of when this support occurs. Laura explained that the amount of funding was exactly the same, but because the fees paid to the Host Provider were substantially less than those paid to the previous service, she found that she had more funds to provide the supports her daughter needs. In addition, by having more funds available she was able to look at what her daughter wanted to do during the week as well as on the weekend, and put supports in place at times when her daughter required this. She said she has found self-directing her daughter's support has provided far more flexibility than she had ever experienced, and she knows that the arrangement can be changed again when her daughter's interests and support requirements change. Again, this flexibility can occur within the existing funding allocation.

Laura is deeply appreciative of having the support of the planner who helped her to change her whole outlook on life. Now, instead of feeling like 'being in a box with the lid jammed down', as she did in the past, the possibilities offered through self-direction mean that, as well as her daughter having a new life opening to her, the whole family can experience new beginnings as well. For her, one of the best things is having time with her grandchildren. 'I am excited that I can have more time with my grandchildren, something that was not possible before. The change in how we are managing things has been good for everyone.'