



Leader Experience

Personalised Budgets Demonstration Project Review

Summary

Reviewed by participants; Permission to release to the public
July 2024

“The personal budget is a whole new way of life that can at times be very challenging but the overall feeling for both my son and us as a family is one of empowerment and liberation!”

20/6/24

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Supported by



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NOTE

The exercise has been carried out by Clan Beo. Our mission is to support people in their exploration of their own personal alternative vision for a valued life in their communities. It has been supported from the outset by the advice and fraternity of the Inclusive Living Network. Quotations used in this report have been adapted to use 'they/them' pronouns so that the identity of the person being represented would not be compromised in any way.

1.0 IN SUMMARY

In spring 2024 we decided to collate the Leader experience of the [Personal Budget Demonstration Project](#) (PBDP). We connected up with other families we knew who had been accepted onto the scheme. We circulated a survey and invested time in conversations around what we thought were important from a 'Leader' point of view. The objective, process and purpose of the review were circulated to everyone (see appendix 1). The outcome of these conversations and the survey is summarised under the following six headings;

- The Quality of Life of the Person
- The Impact on Others
- Managing Budget Challenges and Value for Money
- Connection with Other Budget People and Families
- Working with the HSE PSDP Office
- The Future for People with a Budget

A key objective for the people and families collaborating on this review is to make the process stronger and more Leader friendly. Those taking part in this exercise were clear that they see the Personal Budget Demonstration Project process as the 'only show in town' (for simplicity I will refer to it as the 'Budget' from here on in). Even at this early stage in the 'Demonstration Project' process they have seen the benefit of having a controlling role in managing funding for and self-directing their own professional supports. Their descriptions as to how the quality of life for the person has changed is striking. They are committed to listening to the voice of the person member and creating more choice for them.

That is not to say that each had a universally positive experience of the 'Demonstration Project' process. Neither is it the case that everyone is committed to sticking with this scheme as a way of continuing with a Budget. Arising from this review some have talked about how they would approach the Budget opportunity if they were to either 'go back in time' or advise other people and families who were thinking about taking it on. Participants were also generous in the suggestions for improvement they would offer to the administrators of the PSDP.

It is important for a review that starts from the perspective of the Person / Leading. We also start with an acknowledgment that most of their experience of the good things in life comes from the ordinary, everyday and natural connections they have with family, friends and communities where they live. The professional support purchased using money from a Budget is important. Its impact is best judged by how this limited resource can unlock access to the potential and abundant richness that comes from a valued belonging alongside others in our community.

PERSON / LEADING
'.....the **INDIVIDUAL**
in the context of the family and allies of their **CHOICE**
where their own **VOICE**
can be heard, understood, amplified or augmented where necessary.'

after Janet Klees

2.0 HOW WE WENT ABOUT THE REVIEW

This review was undertaken as a commitment by people using the Budget to learn from and support each other to make the best of the process. The primary purpose of this exercise is to bring together the experience of people and their families who have chosen to use the Budget to set up and manage supports for themselves to access the good things in life in their communities. It is a starting point for those participating to reflect on their experience and to support each other as they learn to manage these arrangements.

Potential collaborators were first briefed on the project. Where they were happy to proceed, we set up a time to have a conversation around some guiding questions (see appendix 2). People taking part were asked to complete a survey circulated electronically using MSForms (see appendix 3). The information from the conversations and the data from the MSForms survey were reviewed and collated for this 'report'.

The people and families participating in this review will decide themselves how widely and to what extent they intend to circulate their review. They may choose to use it to support connecting up and learning alongside others who share the experience of self-managed arrangements. They decided at the outset to make this review available to the HSE PBDP office. All those involved will have an opportunity to come together to deepen their understanding of each other's experience and decide if and how they can support each other further.

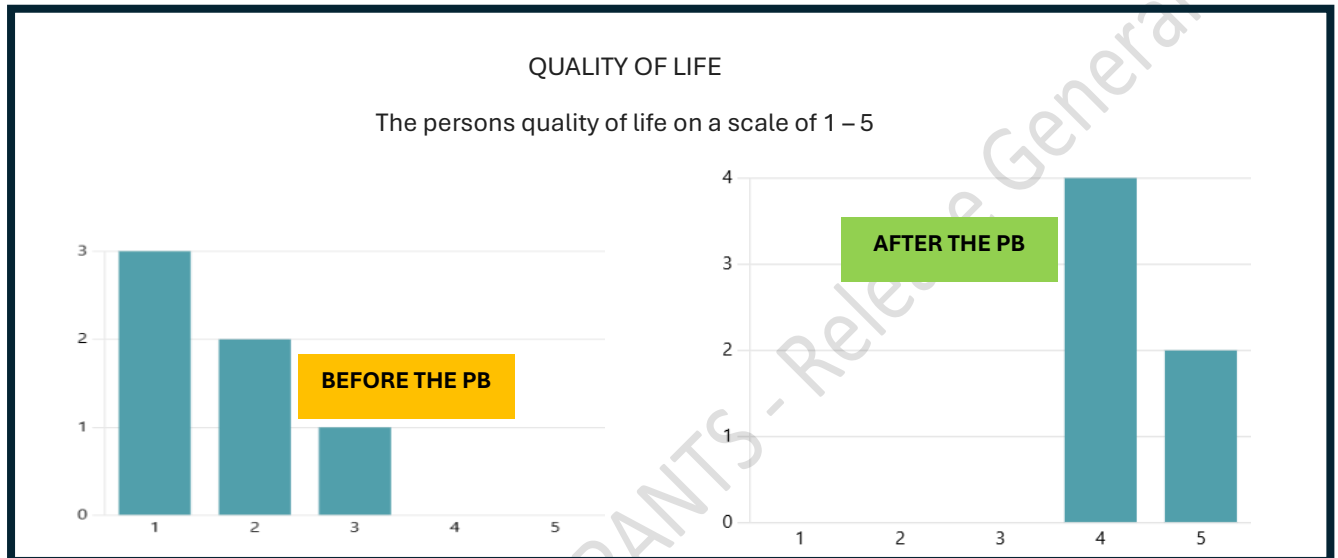
We should be clear about the limits of this review. Through our network we were able to identify and make contact with seven people and families who were part of the process. Six agreed to participate. It's a small proportion of the total. Because there is no public data available on the number and profile of people using the PBDP scheme it is not possible to say whether this exercise can be considered to offer a 'representative sample' or not.

We did not look for inputs from people and families in individualised budget arrangements outside of the PBDP scheme. These exist under other bespoke CHO arrangements, as part of individualised service arrangements provided by HSE funded services and in other brokerage type schemes operating around the country. There is much for people and families to learn together about 'self-managed service arrangements' in all of these experiences.

The HSE PBDP office was not involved in the review of the Leaders experience of the demonstration project. That the review is independent of the PBPP serves to verify the results the PBPP office has delivered and how it has been resourced to engage with potential Budget participants. We will continue to welcome working with the HSE and PBDP office so that the voice and perspective of the person and their family can be clearly understood in the progressive development of how the Budget is made available and supported.

3.1 QUALITY OF LIFE FOR THE PERSON

In each but one conversation we had about the quality of life of the person the ‘before and after’ comparison was described as like ‘night and day’. The one dissenting voice said it was ‘too early to say’ but that while ‘life is not very exciting, the anxiety is virtually non-existent now’. Mental health challenges were described by many in the time leading up to using the Budget. Some were not using any form of professional or service type support for any number of reasons. Some were coming from second level education or service arrangements that were not serving the person well. Some described how the person had already been depending solely on their own family and community to live a life in their own place. For each person, a rating of quality of life before and after was a simple calculation.



In conversations with people and families much less was said and little emphasis was placed on life before the Budget. Where they did talk about it the tone of the conversation was dark. It was clear that prior to the Budget there was much pain in the life of several people. Some described how the person was ‘visibly depressed’, ‘having little to motivate them’, ‘staying in bed all the time’, ‘turning their anger on themselves and the people around them’. These were difficult conversations for any of us involved.

When the focus of the conversations turned to life after the Budget the tone lightened. The way they described the routine of the person, the roles they were building in their community, the joy, growth and confidence they were observing made the conversations sing of optimism and purpose. Plans for the future were practical, measured and had a clear sighted focus on what would enhance the persons opportunities to experience the ‘good things in life’.

What people say about AFTER..

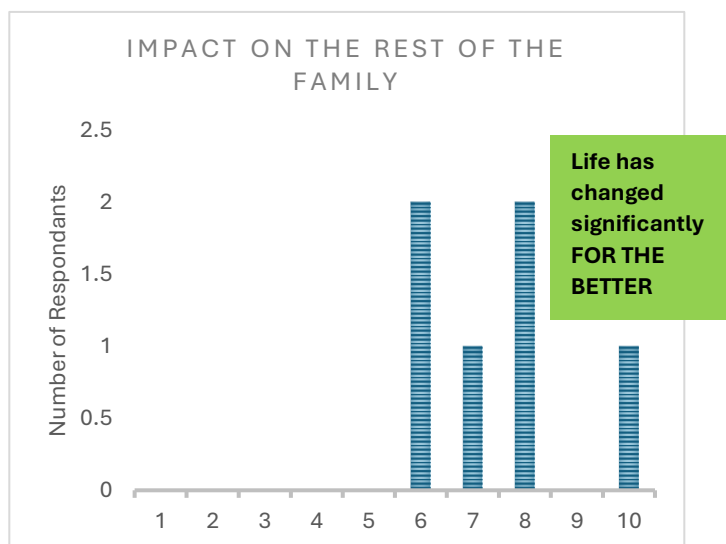
- ...with my brain the way it is at the moment it is working well for me
- ...choosing what they want to do for the day is powerful for them
- ... they are back to themselves again (as an adult this time)
- ...they just love to have a purpose
- ...loves having a voice (without needing to speak) and being listened to
- ...on the street people are talking to them, using their name
- ... so much exploration, feeling their way into what’s right for them just now

3.2 IMPACT ON OTHERS

For most people and families participating in the review it's early days for managing the Budget. Their focus is on the practical tasks of recruiting the right support, training, processing payments, etc.. It is not a surprise that despite the testaments to an improvement in the quality of life for the person at the centre of the arrangement people were less forthcoming in sketching out the impact on the family in general. However some indication on the general direction of this issue could be extrapolated from the formal survey aspect of the review.

In our conversations when people responded to the 'before' question they talked about feeling 'on their own', 'burned out', 'stressed out', 'leaning too much on a sibling, more than was healthy'. Others talked about feeling 'tied down', 'living in a very small world'.

In talking about 'after' the Budget a few people said; 'the family is more relaxed', 'having more time' and 'feeling more in control'. One talked about the freedom to plan for themselves for a weekend. For some, despite having no experience of running a business, the move to having more control over this aspect of their life was less of a burden than expected. One person highlighted how having the Budget made things simpler by 'not having to go through the middle-man in services' anymore. Another highlighted how support arrangements were being tailored to suit how the person and family worked for holidays, shared parenting, work / life pattern, etc.; the ordinary but inevitably unique ways each family conducts itself.



Working on managing a Budget means that the person's family members and (sometimes) chosen allies from the community have to figure out how to really collaborate together, acknowledge where one person is strong and where another can grow into a role, who leads in different circumstances. Stepping in and out of roles with each other is challenging in any long-established relationship. For some it leads to new and unexpected benefits. In one conversation a family member described bringing the person who owns the budget along to meet the accountant. They and their accountant were able to see how proud that person was in that engagement and were able to see how that simple act can have a fundamental change in mindset.

One person in the review commented that the Budget had allowed her to have a life of her own and be a 'mother to her son rather than a carer to a person with a disability – two equal people with their own individual interests and roles'. Some reported being surprised at who was 'turning up' in the person's life. Another gave examples of how the Budget had 'created space for other members of the extended family to take on practical jobs' that they hadn't seen space for before – bookkeeper, solicitor, driver etc.. In more than one conversation there were significant 'mindset' type changes noticed in how brothers, sisters and close family relations were seeing how people with disabilities should be treated.

".....is definatly helping everyone to understand and see them as an individual"

At the same time the person themselves at the centre of the arrangement is taking on roles they would not have had before – e.g. employer, interviewer, company board member, employee – either by themselves or alongside either a family or community ally or a professional supporter. How comfortable a broader range of people close to the person feel in the natural environment of the family and extended family has an important bearing on the 'legacy concerns' that every family has when thinking of the future. One person highlighted how 'seeing the person as leading out on what they wanted in their life' helped other people understand how they could be 'the helpful one rather than responsible one'.

3.3 CHALLENGES MANAGING THE BUDGET

In case there be any ambiguity, all participants said that managing a Budget means they have to invest time and effort, learn new skills and think differently in order for it to work. The decision to take on a Budget was not taken lightly by anyone who took part in the review. Even for people and families already using 'unofficial' or 'professional' supports paid for from their own resources highlighted how steep the learning curve has been to move to a more formal or 'official' mechanism.

Challenges like insurance, recruitment, training and supervision were met by some people with the benefit of support and advice from other people and families who were on a similar journey. It was clear in the conversations that the common challenges for each 'enterprise' were being met in their own individual fashion. The flexibility granted by the allocation of the Budget has been utilised to the optimum in each individual circumstance.

CHALLENGES... What people say

...there was an element of panic initially
...it definitely was not made easy for us
... it's hard being a parent and an employer
... a lot of people passing through our kitchen means we have to set boundaries
... finding staff has been hard even though we always had people working for him before
... setting a standard for what a professional does is even harder
...trying to keep the energy up and the focus right for the professional supporter, helping them with challenge, keeping expectations high for the person and their supporter, its so easy for them to default to just 'caring mode'

It should be remembered that each person we had a conversation with was successful in coming through the process of learning about the Budget, making the initial contact with the PBDP office and setting up the arrangement. Each person emphasised how important it had been to reach out to access experience or skills outside of their own resources. Each were clear about the resilience necessary to successfully complete the process. Each person highlighted a fellow feeling for the people that didn't get beyond the 'expression of interest' stage and had some suggestions for how the process might be improved (see below).

For most of the people in our conversations the idea of what the right type of professional support is like, where to find it and how to hold on to it is something that they are learning about as they go along. This is most especially the case for those who have not been connected up to others who are travelling the same path as themselves. Even for people and families who had already been sourcing professional support on an independent (often sessional) basis, the challenge of articulating, communicating and sustaining 'good' professional support has been difficult. At this stage, in most cases people have secured at least one good person to start with. However, for most the experience involved having to 'deal with a lot of frogs before finding a prince'.

Once employed, the management of a professional supporter, what their duties were, to contract or not to contract, what boundaries are set in the relationship, how to train people, what type of training resources are available, necessary, etc. are the type of people management challenges that each person and their family have had to grapple with more or less on their own and without any clear direction or consistent guidance. Some were lucky to have some peer support to work through some of these challenges. Most however have just had to 'muddle through'. For some, securing an insurance quotation for an arrangement has been a particular costly challenge.

'Value for Money' means different things to different stakeholders. It is a challenge to people and families to fit their idea of 'value for money' with the more formal but still often loosely defined or received administrative idea of 'VFM'. In many of the conversations the starting point for the 'value for money' issue has been to emphasise how it has been possible to ensure that professional support was 'focused', 'effective in leveraging the right help', 'tailoring a good life', 'allowing for trial and error' or being able to access 'people who have a wide range of skills that fit' with the interests and specific requirements of the person being supported by the Budget.

"Throwing out the net for a professional supporter was a highlight; despite not getting a great haul, just finding one really good person that can see them for who they really are and not constrained by limiting thoughts or organisations or structures"

All people and families involved in the review have asserted that they are getting '100%' value for money and most arrangements have little left over from the allocated Budget at the end of each month. Some are clear that they are not getting near enough Budget to pay for the type of professional support that is needed to leverage access to the good things in life for a person. For some this perspective comes from an awareness that they were not able to 'unbundle' the full resource amount that had been allocated to a service to 'take on' a person originally. Some compare what they see as the totality of resources associated with a traditional day service (e.g. administration/management, infrastructure, equipment, transport etc.) and estimate that this is significantly more than the resource they have available in the Budget.

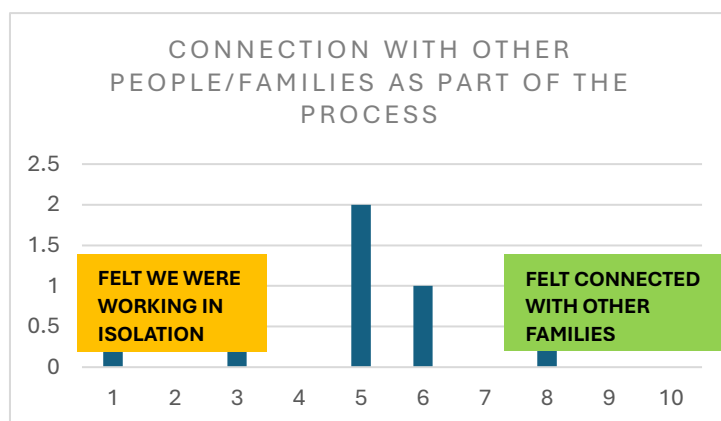
All of the conversations found that the initial approach to the boundaries that were set around allowable expenditure was challenging to plan around and, on the face of it, overly restrictive. For each arrangement it was easy to understand that there could be no overspend on an allocated Budget. What was challenging was the idea that what some considered as a justifiable expense had to be 'shoehorned' into the Budget under what some thought as a tenuous relationship with an expense heading.

Another conversation in the review wanted to highlight a resistance to acknowledging a quantification of freely given contributions by family, friends and community allies. In some other conversations the idea of putting a monetary value on these freely given resources was thought not to be either important or 'right'. Payments from a Budget for family have always been a difficult territory to navigate. Some understood that there was some ambiguity around the 'rules' for compensating family for additional expenses they incur arising from taking on the Budget or payment for professional input into the management of the Budget (especially when it involved relatively small portions of the total expenditure). One [source of information](#) quoted in one of our conversation detailed that only payment "for informal care from a spouse, partner or close relative" was being ruled out. Some were unclear on what the definition of 'family member' was when it came to compensation or payment for professional support. One person summed up that the only way to get through these difficulties was for the scheme to have 'more flexibility for individual needs, less rules, more trust'. They asserted that "we are not doing this for fun. There isn't ever enough for what anyone might call fun".

3.4 CONNECTING WITH OTHER BUDGET FAMILIES

In the process of getting set up for a Budget most but not each person taking part in this review had developed some personal connection with the Inclusive Living Network or one of it's key people. Most reported that while the ILN contact was useful, it was at the same time minimal; 'the work was still ours to do'. All reported that up until that connection they felt that they were on their own, "fumbling about in some administrative swamp", as one person said. When eventually they did connect up with others on the same pathway all reported feeling good that they 'were not the only ones' on the journey.

Few had undertaken the formality of a Person-Centred Planning exercise (other than engaging with the HSE resource planning process). They were content to start with a simple, gut feeling; 'an individualised arrangement is the right thing'. Once established, people reported that they are looking beyond the immediate challenges to the sustainability of this type of arrangement. Each person talked intuitively about the voice of the person at the centre of the arrangement but had little awareness of this as a 'rights based' issue or of a regulative context (e.g. 'Capacity Legislation').



Awareness of much of the training or other supports available for managing a Budget arrangement came to people's attention primarily as part of the conversations in this review process. The PBDP office had highlighted open access to the HSE Land training platform to one family. Awareness of the peer-led InConversationSeries.com program and the on-line OpenFuturesLearning.Org training platform for staff working in this type of arrangement was by word of mouth. Different tools for the management of payroll, use of accounts / legal professionals or access to an insurance quote again came from contacts between families only after they came across each other.

"Connecting with someone helps figure out what works or doesn't for a family-based program and how its ok not to duplicate what a traditional service does"

Few people in our conversations had any stories or example to call upon to imagine the work involved in the intentional growth of community natural support networks. However they have all been surprised by how neighbours, businesspeople and other people in the community have connected up with the person using the Budget. Some families have opened up to mark the persons use of the Budget with a celebration or an invited circle of friends. In more than one example some of those turning up were not previously known to the family. One parent assigned the role of 'community educator' to the person using the Budget because of the visible impact they were having in their community.

None of this is to say that the process of opening up to connection with other families or believing in the idea of an 'abundant, open or generous' community has been either simple or easy. In more than one conversation people talked of experiences of unsupportive comments from people in the community previous to the Budget arrangement. As such for many, these past experiences meant that 'opening up to community' has been a brave but ultimately valuable step. In many conversations people described how the person had influenced people in their communities to have a different view of people's rights in relation to presence, participation and valued social integration.

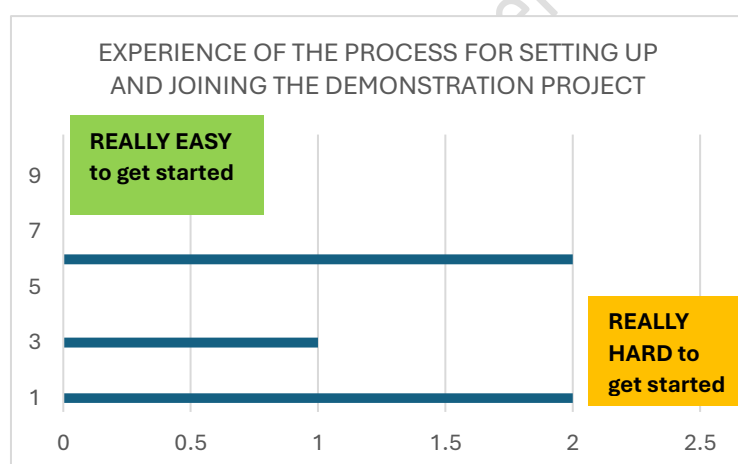
Finally, there is no doubting the value that people placed on being connected with other people and families who have chosen the Budget option. All emphasised that while they didn't want to pretend that they had all the answers or that everyone should take this option they were all open to connecting with others and were happy to offer advice to anyone considering starting out (see appendix 4).

3.5 WORKING WITH THE PERSONAL BUDGET DEMONSTRATION PROJECT IN THE HSE

While it was not the primary purpose of this review, we could not look at the Leader experience of the Budget without considering relationships with HSE PBDP. In our conversations several people highlighted that when they had contact with the 'Pilot' office the response was flexible, approachable and caring. There was also an appreciation of their focus on quality-of-life outcomes. In these conversations the efforts of the 'Pilot' office staff to offer follow up and support was appreciated.

In our conversations people for the most part understood that the resources made available to the PBDP office and the support from the HSE internally fell short of what was necessary. There was also some understanding of the pressures that the pandemic brought to bear on the process.

Most of the people in our conversations found the process for setting up to be difficult and 'put a lot on the family'. Some had different understandings on the extent of the authority of the PBDP when it came to securing a 'full' budget for a person. Most found the process overly long. Sometimes (from their point of view) the process was unclear and unnecessarily rigorous. Some found that their persistence rather than eligibility was at the heart of their success. Some experienced delays in response times. However at least one person and their family valued the opportunity to link up with others that this delay prompted.



Some found the perceived 'slow waltz' policy of engagement and lack of support from CHO areas and services to be frustrating. Once the participation in the Budget was approved many found that the time between then and receiving the first cheque was unaccountably delayed. They reported that there was little consideration of the significant initial setup costs and cash flow implications for the arrangement. Most, at some stage in the process, had to supplement or delay payments including those to professional supporters.

Many people and families who engaged with the PBDP did not make it further than the 'expression of interest' or other early stages of the process (the experiences of these people and their supporters was not part of this review). In all our conversations there was a fellow feeling for those who applied and who didn't have the personal resources, guidance or resilience to meet what were presented as significant administrative challenges.

It was understood by most that provision of logistical and capacity building supports may not have been within the purview of the PBDP office. However, it was suggested by some that it was within the remit of the PBDP to provide information around resources and partnership opportunities in other supportive corners of the HSE, CHO areas or parallel projects (e.g. Community Participation Networking). It was also noted that there was a reluctance to connect people at the 'expression of interest' stage with other people and families on the journey and with potential community sector and service provider allies. Again, the PBDP office may have had their own reasons for not providing specific contact information.

The PBDP have got a number (?) of people over the line to avail of a Budget. This was achieved despite resource, institutional and social challenges that were not of their own making. There is potential for the PBDP to develop a person and family friendly remit and approach through a more focused engagement with a wider stakeholder group. This will not be possible if the function is devolved into separate CHO/area functions. This will create a potential for an unhelpful divergence of approaches and levels of priority for the Budget scheme.

3.6 THE FUTURE FOR PEOPLE WITH A BUDGET

It was clear from our conversations that the people and families are committed to the Budget or some other form of Individualised Service Arrangement – ‘there is no going back’, ‘can’t imagine any other way’. When asked ‘would they do it again’, even those who found (and continue to find) the process to be difficult to manage were resolute in their affirmation of a ‘one person at a time’ ‘self-directed’ ‘personal budget’ supported arrangement.

“It’s a healthier long term arrangement for them. They have an input, more choice. Agency is the word that comes to mind – trying to support them to have agency in this arrangement”

In the conversations most people felt comfortable articulating a vision for the person in the future. Each talked about where their next focus was going to be – ‘really focus on how they learn’, ‘get their financial security established next’, ‘start working on a forever home’, ‘explore music and other ways of being creative’, ‘finally get a job’, ‘an independent life in 10 years’.

Most people and families talked to had in mind some ideas for the long-term safety and security of the person. There was a focus in some of the conversations on building a persons’ capacity to self-manage. Some were confident enough about the connections the person themselves were building with a wider circle of family and community allies to talk about ‘capacity’ and ‘self’ with a wider view of what we might see as a ‘person who is living and leading in their own life’. It was clear in most conversations that the experience of the Budget has reinforced a mindset for the individual as a **person ‘leading’** support’ rather than a **person ‘needing’** support’ in exploring choices and opportunities to experience good things in life.

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In each conversation there was a perception that there was a resistance to engagement by funders on longer term arrangements for ordinary progression in an ordinary life. It was anticipated that acknowledging the need to have some mechanism in place to take account of the evolution of funding for professional supports to accommodate normal developments in a persons’ life was not going to be readily forthcoming from the HSE. In one conversation, establishing family/chosen ally involvement to support the capacity of the person to take the lead in negotiating the level of professional supports was the most important issue for the future. It was clear in these conversations that for there to be progress on this matter there would need to be an experience of trust in relationships, systems and equity that is not, as of yet, universal.

The future for any person and their family will always be about much more than a Budget scheme. In our conversations there was a universal understanding that securing the current arrangement was an important step for people, their families and chosen allies. The person, their choices, their voice and their quality of life is served well by the potential that a PBDP type scheme offers. Like any ‘pilot’ the scheme itself will work better where it adapts to the real-life Leader experiences and lessons offered by stakeholders at this initial stage. For this to happen there needs to be more trust at many different levels.

“So as their world expands, and in the natural cycle of things, I am gone, I don’t have such a massive part in their life that they are destroyed by my absence”

4.0 CONCLUSION

People and their families 'are not for turning'. They are learning how the Budget can work for the person and the family. They are clear that this is just one format of PLfaMILSA (Person Leading Family/Ally-Managed Individualized Lifestyle Support Arrangement).

The experience of the Budget in its impact on the quality of life of the person at the centre of the arrangement is universally positive. The conversations about this Quality-of-Life outcome was unequivocal and enthusiastic. The focus and flexibility of the Budget is working for the person.

The impact of the budget on the lives of others close to the person has significantly changed for the better. Some of those impacts were unexpected. Some anticipated that this will have a positive influence on 'Legacy' concerns of mothers and fathers around what happens when they are no longer capable of continuing to provide the type of support they now provide.

People in our conversations were clear about the challenges associated with managing a Budget. Even for those with experience of running a business it has not been easy. Most challenges come from being an employer. Some come from the way the Budget scheme is set up and administered.

People had different opportunities to connect-up with others who were using this scheme both at the set-up stage and once they were up and running. In all but one conversation people highlighted how connecting up with peers has been supportive.

In most conversations the Leader experience of support from the PBDP office staff was positive. However most highlighted how difficult they found the process of setting up and how restrictive the structure and operation of the Budget scheme is.

In each conversation people were clear that the preference for the future of any funded support in their own life would be in an Individualised format. The conversations highlighted the need to improve the operation of the PBDP scheme. In addition all people taking part were clear about the importance of finding their own way to ensure the voice of the person continues to be strong in leading out with the type of support they will use in the future if their quality of life is to be assured. For this to happen more space must be made to have trust in the person as an individual making their own choices in the context of their relationships with family and chosen allies.

INTRODUCING - PERSONALISED BUDGETS DEMONSTRATION PROJECT REVIEW

Clan Beo, with the support of the ILN and people and their families who are taking part in the Personalised Budgets Demonstration Project are carrying out a review from the point of view of the people and families participating.

The purpose of the exercise is to ensure that the voice of the person and their family who have been part of the process is at the centre of its continuing development. This review is not supported by the HSE, the PB Project or any government department associated with funding or administering it. It is an independent, Leader centred review of a project that has been in place since October 2019. The review is anchored by five questions;

- How is the life of the person at the centre of the arrangement different now from their life before they engaged with the Personalised Budgets Demonstration Project (or PB Project)?
- What is it about the PB Project that works well to support making the arrangement easy to operate and effective for the person?
- How has the HSE supported the person and their family in getting to this stage?
- What does the future look like for the person at the centre of the arrangement you are involved with?
- What would an optimally effective PB Project look like?

This review process is only possible to be carried out where participating people and families are known to Clan Beo, are comfortable to be part of the review and are committed to continuing their involvement and/or contributing to making the scheme work better. The review did not seek to engage;

- with people who are part of one of the many other self directing schemes in place around the country
- with people and their families who applied to the PB Project and who for any number of reasons did not pursue their engagement

Over four weeks, there will be an open conversation between ourselves and the people who choose to be part of the review on the understanding that they are confidential. A record of each conversation is written up and shared with the person involved to check that it is a true representation and that they are comfortable for this information to inform the review output.

APPENDIX 2

CONVERSATION FOCUS - PERSONALISED BUDGETS DEMONSTRATION PROJECT REVIEW

1. Protected disclosures
 - Who
 - Where
 - Company name, How long, What budget
 - What stage at (school leaver, in service <5, <10, <20)

1. The Person
 - What was the persons life like before the Individualised Funding Arrangement (or Budget? what is it like now?
 - What type of professional and natural community/family support did the person avail of before / now?
 - What have been the highlights and challenges for the person over the course of their time involved in the IFA?
 - What value for money is the person getting for the funding being provided to support them living their life
 - What does the future look like for the person at the centre of this IF Arrangement?

2. Supporting the Arrangement
 - How connected have you been with other people and families who are successfully engaged with the process?
 - How has connections with other people and their families impacted on how the process has gone for you?
 - What professional support have you used in setting up / running & sustaining the arrangement (e.g. mainstream/ disability specialised support)

3. The HSE
 - How has the HSE supported the person and their family to join and continue with this IFA

4. The Future
 - Will you continue with the IFA in its present guise?
 - What would be helpful to any person or family at the outset to get going?
 - What would be helpful to any person or family at this stage to keep the process working well for the person?
 - If you knew then what you know now would you still have taken on the pilot?

5. Review Output
 - Who should see the review output (who shouldn't)?
 - Can you provide examples, illustrations, quotations, other resources to support the details you want to see highlighted in this exercise?

APPENDIX 3

MicroSoft FORMS SURVEY CONTENT



REVIEWING THE PERSONAL BUDGET 'DEMONSTRATION PROJECT' (Self/Family Managed)

THIS SURVEY IS FOR THE PEOPLE USING THE PERSONAL BUDGET 'DEMONSTRATION PROJECT' so that they can have a voice in how it is evaluated.

The information in this survey exercise is gathered by people and their families themselves.

It will be made available to people and families to support them tell their own stories.

1. YOUR NAME

2. I CONFIRM THAT WE ARE PART OF THE PERSONAL BUDGETS PROJECT (the 'Demonstration Project')

YES

NO

3. HOW LONG have you used a Personal Budget project for?

Less than 1 year

More than 1 year, less than 2

More than 2 years

4. What was the persons QUALITY OF LIFE like BEFORE you started using a Personal Budget project?

♡ ♡ ♡ ♡ ♡

5. Describe the type of SERVICES the person USED BEFORE before you started using a Personal Budget project

6. What was the persons QUALITY OF LIFE like AFTER you started using a Personal Budget project?

♡ ♡ ♡ ♡ ♡

7. How has the change to using a Personal Budget scheme impacted on THE REST OF THE FAMILY?

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

We are much WORSE OFF than before

Life has changed FOR THE BETTER significantly

8. How has the person's connection with ORDINARY COMMUNITY PEOPLE, PLACES AND SERVICES been impacted since they joined a Personal Budget project?

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

They are much LESS CONNECTED than before

They are much MORE CONNECTED than before

9. How CONNECTED TO OTHER PEOPLE AND FAMILIES have you been as part of the process of joining a Personal Budget project?

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

We had NO CONNECTION with other people/families

We were TOTALLY CONNECTION with other people/families

10. How did you find THE PROCESS FOR SETTING UP AND JOINING THE 'DEMONSTRATION PROJECT' ?

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

We found it REALLY DIFFICULT to get started on the personal budget

We found it REALLY EASY to get started on the personal budget

11. ADVICE FOR OTHER PEOPLE - What words of advice would you offer to others who are thinking about engaging with a Personal Budgets type process?

12. FUNDER SUPPORT - What was the most useful type of support you availed of from the HSE Personal Budgets 'demonstration project' team?

13. FUNDER CONTINUAL IMPROVEMENT - What improvement would you suggest in the way a Personal Budgets project is administered by the HSE?

14. INSURANCE - What PERCENT (%) of the overall personal budget is taken up by employers/public liability insurance?

General

15. IF YOU ARE COMFORTABLE sharing YOUR CONTACT DETAILS please include your email address below

16. ANY FORTHER COMMENTS

If you have any further comments please include them in the space below (to contact me directly use this email address - connect@clanbeo.org)

This content is neither created nor endorsed by Microsoft. The data you submit will be sent to the form owner.

 Microsoft Forms

REVIEWED BY PARTICIPANT

APPENDIX 4

ADVICE OFFERED FOR YOU, YOUR FAMILY, CLOSE FRIENDS AND ALLIES WHEN EXPLORING THE BUDGET (or starting any PLfaMILSA (Person Leading Family/Ally-Managed Individualized Lifestyle Support Arrangement))

By 'You' we mean the person at the centre of the arrangement, whose lead family and chosen allies follow, whose capacity is appropriately supported, whose choices are discerned and respected, and whose voice can be heard, understood, amplified or augmented where necessary.

These unfiltered bits of advice came from the conversations we had with as part of the review. They are offered to you to consider and may or may not suit you in your specific circumstances.

Before You Start – Basic Ingredients!

- Us the help of people who really care for you and who will be there through thick and thin
- Put some shape on how you would describe what a 'Good Life' should look like for you right now (use the pictures, words and phrases that you are comfortable with)
- Make a picture of what a really great life would look like for you in the future – A vision
- Practice sharing your idea on what a 'good life' should be like now and this 'vision' for a future with people who have your back
- Make a list of the things you know are interesting
- Describe what you know makes things work really well for you (& what makes things go badly!)
- Start making a list of all the things you have going for you – the people who know you, your life experiences, the things you own, the type of resources you can have access to

Reach Out – Fly United!

- Tell people close to you that you and your family are considering all options to ensure you get the best support possible
- Find other people who are on the same pathway as you, listen to what their experience has been (but do your own thing)
- Find someone who is good with figures, someone who is good with filling out forms, someone who is not afraid to do the official / formal stuff like opening a bank account on your behalf
- At the very least ask other people who are using the Budget about completing the forms (they may have other things they can help you with as well)

Some Resources

- Training / Employment
 - The In Conversation Series – Irish peer led training - run by families for families when funding is available
 - HSELand – Irish Health Service Portal for OnLine Training – Free, Open to anyone
 - Open Futures Learning – OnLine Learning Provider – Inexpensive, Progressive
 - Simple, inexpensive, payroll management – e.g. Bright Pay (from thesaurus.ie)
 - Future Solutions – Individualised service arrangement advisors
 - The AT Network - Facilitate Direct Payments to people, provide leadership and support to empower people with disabilities
- Peer Support
 - Clan Beo
 - Connect Family Network
 - Inclusive Living Network
 - LEAP
- Recruitment
 - Use the mainstream to find people who will help you in the mainstream - Indeed.ie,
 - Local Community Resources – Family Resource Centres, Local Partnerships, Noticeboards

Do' Don'ts

- Adverts
 - Keep the 'ask' simple and direct when describing to people what professional support you need
 - If advertising for a professional supporter put your best foot forward, be plain speaking, describe what the person will be doing, be inspirational, focus on your life and not your condition
- Employment
 - You are involved in choosing who comes into your life – trust your gut feeling
 - Keep close to the people you trust while the professional supporter is learning about you so that you can feel safe
 - Have everyone complete the HSE Land 'Safeguarding' training before the start working with you – ask for a copy of their Certificate
 - Pay people well, they are doing an important job - be up front and formal in all professional payments, take the necessary steps to ensure revenue compliance
 - If you have never had someone work for you before, just get started – remember you and your family are the employers, you will make mistakes, you will learn
 - Decide soon after you start working together if this seems like the right person but leave the conclusion of the formality of any full-time commitment / contract until you have seen the results you are looking for
 - Use a long trial period to get to know each other and learn about each other
 - Never underestimate how little people know about the person, what works/ doesn't, how the person communicates, what's important for them, etc.
 - Never take for granted your own expertise, knowledge and experience
 - Decide what 'professional' means for you and your family in your home and in the community
 - Keep records and be clear in all your contact with your professional supporters
- Managing Professional People
 - People will often be working from your home – talk to everyone in your home about what that will be like and get some boundaries agreed before you invite a professional supporter in
 - Review boundaries after you have been up and running for a while and adjust to take account of holidays, visitors, any variety of domestic arrangements as they arise
 - Agree with professional supporters how you (and they) are to be introduced in the community
 - Make space for ongoing learning, some formal training
- Managing the Budget
 - Doesn't expect all budget to be spent on professional supporters, there are many other costs to consider – insurance, bookkeeping, accountant, travel, expense, training
 - Use an accountant to sign off every year and keep all professional and above board
- Life
 - It's your life, it doesn't belong to a budget
 - The Budget only pays for professional supports and most of your quality of life comes from doing ordinary things, with the ordinary people, in the ordinary places in your life – their job is to be the bridge to make the ordinary easier
 - Ordinary still needs to be managed
 - Decide how you want to tell your story; privately, publicly, in social media. Decide who you want to hear that story and how you want them to treat it. You will be asked, so be comfortable with what you are willing to share

When Dealing With the HSE

- Consider letting your local HSE CHO Disability Manager know what you are thinking about early in the process and keep a record of all your communications with the HSE
- When you contact the Personal Budget Demonstration Project office ask for
 - all the application forms,
 - details of the steps that you go through and approximate timelines,
 - eligibility criteria,
 - contacts for others who have been through the process
- Keep calling back if you don't get a response

When Dealing With an existing service provider

- Remind them that you are looking at all choices that are open to the person & your family
- Ask them for details of how they as a service are funded by the HSE to support the person
- Don't be disappointed if you don't get a straight answer
- Keep a record of all your communications with the service provider

Being Real!

- This is new so be prepared. If you don't have a clear idea of what you want you will get pulled every which way
- Train your mind to think that this is your right and equal participation should be normal
- It all comes back to choice – we make choices alongside others who are important in our lives. There is a compromise with every choice.
- The family needs to know and be honest about what they want for themselves and not lose sight of that (it's not 'selfish' to want this and is an ableism trope)
- Keep records of everything every email, every phone call – a dedicated diary or notebook works for some people
- There is no perfect model no matter what one you choose, pick what's right for you and focus
- There is work to do and nobody will do it for you and your family/allies
- Be prepared to make mistakes
- The Budget cures nothing