

Purple Orange

- research consultation training
- policy publication evaluation

Evaluation of Service Transformation to Consumer Directed Care Project

Partnership project between Community Accommodation and Respite Agency (Cara) and ACH Group

Published by JFA Purple Orange as the shopfront of the Julia Farr Association Adelaide, Australia

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¹ We prefer the phrase 'social profit' to 'not-for-profit'. It is clearer and sets a higher bar for our accountability to the community we serve.

This evaluation was completed by JFA Purple Orange on behalf of the following stakeholders:



Community Accommodation Respite Agency (Cara)



ACH Group



Home and Community Care (HACC) Development Team Disability, Ageing and Carers Community and Home Support SA Department for Communities and Social Inclusion Government of South Australia

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The analysis presented in this report reflects the material submitted by participants in the evaluation process.

All direct quotes in this report are excerpts from material submitted by participants during the evaluation process.

"You don't need t	to have a lot of r	noney to be able	to make a difference" Agency stakeholder.

Contents

1.0	IN	NTRODUCTION	6
2.0	Е	VALUATION DESIGN	7
3.0	Ε	THICAL STATEMENT	8
4.0	Е	VALUATION METHODOLOGY, AS IT HAPPENED	9
4.1	l D	Pata collection: audit	9
4.2	2 D	Oata collection: participant experiences	9
4.3	3 D	Oata collection: agency stakeholders	. 10
4.4	1 P	Participation parameters	. 10
5.0	D	DEMOGRAPHICS OF FAMILY PARTICIPANTS	. 11
6.0	R	RESULTS #1: A SUMMARY ANATOMY OF THE PROJECT	. 13
6.1		Vorking with each other: the nature of collaboration between ACH Group and Cara	. 13
6.2		Vorking with people and their families: agency approaches to the ntroduction of the project	. 14
(6.2.1	Different approaches	. 14
(6.2.2	Development of policy and protocol documentation	. 14
(6.2.3	Setting the financial parameters	. 15
(6.2.4	Enrolment of participants	. 16
(6.2.5	3 ,	
(6.2.6		
7.0	R	RESULTS #2: HOW PARTICIPANTS USED THE FUNDING	. 19
8.0	R	RESULTS #3: PARTICIPANTS' VIEWS OF THE PROJECT	. 22
8.1	I A	Shout the supports you receive	. 22
8.2	2 A	bout agency consultation	. 24
8.3	3 A	sbout individual planning	. 25
8.4	1 A	Shout the people in your life	. 27
8.5	5 A	sbout the things you do	. 27
8.6	6 A	About hope	. 28
8.7	7 A	bout choice and control	. 29
9.0		RESULTS #4: THE EXPERIENCE OF CHANGE WITHIN THE	
9.1	0	On advancing agency commitment to individualised supports	. 33
9.2	2 0	On supporting families to have real choice and control	. 33
(9.2.1	Developing a community of practice	. 34
(9.2.2	2 Capacity of Project Officer and facilitators	. 35

9.2	2.3	On changing business support systems	36
10.0		EADING THE WORD: COLLABORATION WITH THE WIDER	
11.0	DISC	CUSSION AND IMPLICATIONS FOR FUTURE ARRANGEMENTS	39
11.1		sidering the first strategic goal: transformational change to asumer-directed funding model	
11	.1.1	On the need for information	39
11	.1.2	On a good life	39
11.2		sidering the second strategic goal: agency change management supports ongoing and sustained implementation	
11	.2.1	Differences in approach to change	41
11	.2.2	Shifting from population-based funding to individual funding	41
11	.2.3	People are more important than systems	43
11	.2.4	Changing business supports	43
11.3		sidering the third strategic goal: disseminate learning and strategies ssist transformation by other agencies	
11.4	Two	considerations for the public funder	44
11	.4.1	On the options for transferring funds	45
11	.4.2	Evolving an understanding of the relationship between need	
12 0	CON	ICLUDING REMARKS	47

1.0 INTRODUCTION

Community Accommodation Respite Agency (Cara) and ACH Group received Home and Community Care (HACC) 'Innovative Ideas' Project funding in the HACC Funding Round 26 (2010-2011) to test the transformation of HACC-funded respite packages into individualised funding/consumer directed care funding packages.

The three key goals of the Service Transformation to Consumer Directed Care project are:

- 1. Engage and empower people with a disability, people who are ageing and their families, to redesign and transform their HACC-funded respite services provided by Cara and ACH Group, to a consumer directed care model;
- 2. Develop and deliver a change management strategy that supports ongoing and sustained implementation of the consumer directed care model within Cara and ACH Group;
- 3. Disseminate and share learning, resources and change management strategies across the aged and disability sectors to encourage transformation by other agencies and programs.

Cara and ACH Group approached JFA Purple Orange to assist in the independent evaluation of the *Service Transformation to Consumer Directed Care* project and we prepared this evaluation report with an understanding of the following:

- Cara and ACH Group were seeking to transform individual HACC funded respite packages into individualised funding (consumer directed care) packages which are portable and support individuals to have control and choice over how they purchase their support needs;
- Cara and ACH Group were seeking an independent evaluator to design and deliver a pre and post evaluation with 40 consumers and their families (20 from Cara and 20 from ACH Group), involved in the project, and organisational stakeholders.

2.0 EVALUATION DESIGN

The evaluation was based on the following coordinates:

Main focus: goals and impact
 The evaluation assessed the degree to which progress was made towards the three strategic goals within the project and assessed associated outcomes:

- **Data collection methods**: audit and stakeholder feedback The evaluation had two main methods for data collection:
 - Audit, where evaluators collated and reviewed all documentation relating to this project, and the relevant conditions at baseline;
 - Stakeholder Feedback, where evaluators used a survey and semi structured interviews to collect and document the experience and perspectives of participants² and stakeholders from ACH Group, Cara and HACC.
- **Sample size:** up to 20 participants from each agency plus relevant agency stakeholders;
- Data collection timeframe: baseline and six (6) months post implementation (*Pre-Post design*)
 Where possible, the evaluation gathered data from participants and stakeholders twice once prior to implementation (baseline) and again six (6) months following implementation (subject to date of commencement for each participant);
- Reporting timeline: 31 May 2012
 Collation, analysis and documentation of the outcomes of the evaluation distilled into an evaluation report by 31 May 2012 highlighting the extent of progress towards strategic goals, learnings from implementation, impact on participants and impact on agencies.

7 | Page

² Throughout this report we interchange the terms 'participant' and 'individual', and in using these terms we acknowledge the involvement in this initiative of people living with disability, people living with age-related support needs and their families.

3.0 ETHICAL STATEMENT

JFA Purple Orange operates an ethics protocol for its evaluation work.

A key consideration for whether to refer this evaluation design to an accredited Ethics Committee was based on guidance from the National Health and Medical Research Council (NHMRC) which stipulates that research which poses no more than a low research risk to participants may be deemed exempt from Human Research Ethics Committee ethical review. NHMRC describes low risk research in terms of the only foreseeable risk being discomfort to the participants and not harm.

JFA Purple Orange did not refer this evaluation to an accredited Ethics Committee based on the evaluation methodology being considered low risk.

Where an evaluation design is not referred to an accredited Ethics Committee, our ethics protocol ensures the following:

- Informed consent is obtained from participants;
- Confidentiality and privacy are maintained throughout the evaluation process;
- Interviews are set up at a time and place convenient for participants;
- Participants are advised they are not required to answer questions if they
 choose not to and can withdraw at any time without this affecting the support
 they receive;
- Consideration is given to minimising risks even though it is assessed as being low risk.

We confirm that to the best of our knowledge, the evaluation was undertaken in ways which upheld these principles.

4.0 EVALUATION METHODOLOGY, AS IT HAPPENED

4.1 Data collection: audit

The evaluators established contact with the Project Officer at the commencement of the evaluation and made regular contact every six to eight weeks to obtain data on systems and processes relating to the implementation of the project. Data was collected either in electronic or print form.

An audit chronology of the data was collated to identify:

- When approaches and systems were introduced throughout the implementation of the project;
- Discussions and decisions made by the steering and reference groups;
- Organisational operations relating to the project;
- Reported issues arising from implementing the project including participant issues.

4.2 Data collection: participant experiences

Cara invited eighty nine (89) individuals in receipt of HACC-funded respite packages to be involved in the project in August 2011. Seventeen (17) individuals commenced between September 2011 and March 2012.

ACH Group invited twenty five (25) individuals in receipt of or eligible for HACC funded respite packages to be involved in the project in January 2012. Two (2) individuals commenced in February 2012.

The questions for the participant survey were derived from the Q50[™] Framework³ and covered key areas such as participation in family and community life, access to supports, experiences with planning, hopes for the future and knowledge about personalising supports.

The survey was created online using Survey Monkey.

When individuals commenced with the project they received a participant information sheet explaining the purpose of the evaluation and inviting them to participate. Individuals interested in participating signed a general consent form. Evaluators then made contact with individuals and offered the following options:

- Completing the survey online;
- Participating in an interview, based on the survey questions, with one of the evaluators, either by phone or in person, with responses either recorded by hand or digitally.

Fourteen (14) individuals⁴ chose to participate in the baseline survey. A total of thirteen (13) surveys were completed:

³ The Q50™ Framework is a proprietary tool that provides a mechanism for mapping, analyzing and measuring people's lifestyles.

- Eleven (11) individuals⁴ supported by Cara participated in the survey between late September and late November 2011;
- One (1) individual supported by Cara participated in the survey in February 2012;
- Two (2) individuals supported by ACH Group participated in the survey in February 2012.

For evaluation consistency the same individuals who completed the baseline survey were invited to be involved in the post survey six months after completing the baseline survey. They were contacted in writing with a follow up call to seek their involvement. Seven (7) individuals⁴ chose to participate in the post survey. A total of six (6) surveys were completed:

- Seven (7) individuals⁴ supported by Cara participated in the post survey in March and April 2012.
- No individuals supported by ACH Group chose to participate in the post survey.

Factors that account for the reduced participation rate in the post survey include:

- Three (3) individuals supported by Cara who participated in the baseline survey were no longer actively involved as they perceived that the project could not meet their current needs;
- One (1) individual supported by ACH Group stated his arrangements had not changed and he was not in a position to complete the post survey.

4.3 Data collection: agency stakeholders

Evaluators invited key stakeholders from Cara, ACH Group and HACC to participate in baseline and post semi-structured interviews. The focus of the baseline interview was on stakeholder expectations for the project and background information on the reasons for this project. The focus of the post interview was on the highlights and challenges experienced as a result of the project. In total seven (7) people were interviewed:

- Two (2) stakeholders from HACC;
- Two (2) stakeholders from Cara (including the Project Officer);
- Three (3) stakeholders from ACH Group.

4.4 Participation parameters

A total of twenty one (21) individuals participated in the evaluation. Not all people participated fully in all elements of the baseline and post evaluation as people self-selected. As with all self-selecting evaluations, the findings might only be regarded as indicative of issues and/or experiences voiced by those participating in the evaluation.

5.0 DEMOGRAPHICS OF FAMILY PARTICIPANTS

<u>Cara</u>

Baseline (11 surveys)	Post (6 surveys)	
100% of survey respondents were parents of a person living with disability.	100% of survey respondents were parents of a person living with disability.	
Age group of survey respondents:	Age group of survey respondents: o 50% aged 46-55 o 33.3% aged 56-65.	
Age group of family member living with disability: 54.5% aged 26-35 36.4% aged 25 years or under 9.1% aged 46-55.	Age group of family member living with disability:	
The responses provided identified that people have a lived experienced with a range of disabilities including: o Cerebral Palsy o Intellectual disability o Physical disability o Severe and multiple disabilities.	The responses provided identified that people have a lived experienced with a range of disabilities including: o Cerebral Palsy o Physical disability o Severe and multiple disabilities.	
63.6% of respondents stated their family member had lived with disability all their life.	83.3% of respondents stated their family member had lived with disability all their life.	
70% of respondents stated that they provide over 125 hours of unpaid personal support a week.	83.3% of respondents stated that they provide over 125 hours of unpaid personal support a week.	

ACH Group

Baseline (2 surveys)	Post (0 surveys)
One survey respondent was the life partner of a person living with age-related support needs and the other survey respondent was the son of a person living with age-related support needs.	ACH Group's timeframe for resolving methodology for the project and commencement of recruiting participants in January 2012 resulted in participants not being involved long enough to provide meaningful post data.
Both survey respondents were aged between 66 to 75 years of age.	meaningrui post data.
Age group of the two family member living with age-related support needs were 76 to 85 years and over 85 years of age.	
The responses provided identified that people have a lived experienced with a range of health, disability and age-related support needs.	
One family member had been living with their age-related support needs for up to four (4) years and the other family member for up to twelve (12) years.	
One family member stated they provide 24/7 support to their loved one living with agerelated support needs and the other family member provides up to 20 hours of support.	

6.0 RESULTS #1: A SUMMARY ANATOMY OF THE PROJECT

"They've exceeded our expectations"

HACC Funder.

6.1 Working with each other: the nature of collaboration between ACH Group and Cara

Both ACH Group and Cara had an interest and record of activity in exploring the potential of individualised funding prior to knowing about the HACC 'Innovative Idea' initiative in the HACC Funding Round 26 (2010-11). Cara had identified ACH Group as an early practitioner of individualised funding and wanted to explore how they could learn from ACH Group's experiences. ACH Group saw this as a mutual learning opportunity. The shared interest led to discussions between the agencies about how they could work together, and learn about the different cultures and experiences associated with ageing and disability.

The HACC 'Innovative Ideas' Project funding round provided a collaborative learning opportunity for the agencies who applied for funding to advance an understanding of the model and to grow agency and sector capacity.

The bid was successful, giving ACH Group and Cara the opportunity to implement the project from 1 February 2011 to 30 June 2012.

To support the implementation of the project the agencies established the following arrangements:

- Appointment in June 2011 of a Project Officer to implement the project. The resources of the Project Officer were shared equally between both agencies;
- Establishment of a Project Steering Committee in June 2011 comprising of representatives from Cara and ACH Group management and consumers to:
 - Take responsibility for project feasibility, project plan and achievement of key objectives, goals and outcomes
 - Provide leadership and guidance to the Project Officer
 - Ensure the scope of the project aligns with the requirements of stakeholders
 - Address any issues that have an impact on the project;

 (Information taken from the Project Steering Committee Terms of Reference)
 - Establishment of a Reference Group in July 2011 comprising consumer and staff representatives from ACH Group and Cara and other agencies working in the disability and ageing sector with a strong interest in promoting individualised funding/consumer directed care to:
 - Share information and ideas

- Contribute to the development of individualised funding/consumer directed care at Cara and ACH Group and in South Australia
- Promote and support other organisations considering the introduction of individualised funding/consumer directed care.

(Information taken from the Reference Group Terms of Reference)

6.2 Working with people and their families: agency approaches to the introduction of the project

6.2.1 Different approaches

Using the evaluation audit trail to review the chronology of the project, it is clear the agencies undertook different methodologies to introduce the pilot (herein after referred to as project) in their agency.

ACH Group spent time preparing methodology tools, documents, and training resources for staff, and they examined a range of considerations in terms of finance, quality assurance, and marketing. ACH Group undertook this work to develop a complete methodology prior to commencing the recruitment of participants. We have termed this a *Reflective Practice* approach.

"I really wanted to work at what it was that we wanted to offer"

ACH Group Stakeholder.

By contrast, Cara limited their enquiry into the precise details of the methodology, instead opting to establish broad brush strokes and then enrol participants, on the basis that their early experiences would help inform the detail of the methodology. We have termed this an *Action Research* approach.

ACH Group prior to the commencement of this project had already worked with individualised funding methodology and were using this project to learn and extend what they knew to increase choice and control for people living with age-related support needs.

6.2.2 Development of policy and protocol documentation

Various elements of the project methodology included:

- Information booklet and guidelines for expression of interest (Cara);
- Consumer information kit (ACH Group);
- A short practice guide to assist facilitators work with people to inform the design of their plans, budgets and decisions. The guide included requirements for 'back-of-house' business support processes at the agency (both agencies);
- ACH Group developed an assessment approach with twelve (12) domains, to assist participants to identify individual needs and goals. The approach included two tools, one for the family carer and one for the person receiving the care. By contrast, Cara did not use a specific

assessment tool, instead focusing on a broader conversation about what the participants would find helpful;

- Approach to risk assessment (ACH Group);
- Individual funding agreements (both agencies);
- Development of an expense log and twelve (12) month individual service usage balance sheet for participants who wanted to use these tools (both agencies);
- Arrangements for participants to recruit staff as more direct contractors (i.e. contracted to the individual participant through the agency which is organised through the agency or other appropriately accredited entity);
- Methodology to give the participant sign-off authority over staff timesheets prior to lodgement with agency (Cara). This also applied to other invoices;
- Data reports were created from the existing database to identify individual usage and the funding individuals had available (Cara);
- Informal feedback was sought by the Project Officer through asking questions as part of the initial home visit. No formal feedback arrangements were in place (both agencies).

6.2.3 Setting the financial parameters

HACC funding typically covers lower levels of support, translating to just a few thousand dollars per individual per year. In a typical HACC-funded arrangement, an agency will receive a quantum of funding on behalf of individuals, to be transacted as support hours. Agencies have traditionally rationed services and managed HACC funding as a 'pool' or 'bucket' of money, with individuals receiving different levels of services determined through an agency needs assessment. The move to an individual allocation methodology will impact agency financial and service infrastructure. In this project, the unit of currency changed in effect from support hours to Australian dollars.

Cara resolved this by examining how much it cost them to deliver a support hour to an individual. This dollar rate was then multiplied by the number of support hours typically allocated to the individual per year, and this gave an indicative individual budget. Participants were only charged for the direct support service they received from Cara at the rates of \$38.00 an hour on weekdays and \$42.00 an hour on weekends.

ACH Group undertook comparable approaches, by dividing the total HACC dollars available by the contracted number of people to determine the annual individual budget allocation.

We note that individual funding packages for older persons tended to be at a significantly lower rate (around 25%) than those for persons living with disability, and that the packages for older persons included a co-contribution component from the participant. These agency differences appear due to historical arrangements relating to the distribution of support funds in the separate disability and aged care sectors. Additionally, each organisation has

individual agreements with HACC for each project which would all differ in regards to the number of people supported by the project.

ACH Group determined the costs of agency accountability requirements and infrastructure costs. The fee structure comprised two (2) components:

- 15% Coordination Fee comprising costs of assessment and review;
- 15% Administration Fee comprising agency costs such as insurance, quality accountability etc.

Cara did not include a specific fee structure for this project as this was incorporated into the calculated hourly rate of \$38.00 an hour on weekdays and \$42.00 an hour on weekends.

In terms of general purchases, both agencies gave participants the choice of either paying for purchases up-front and seeking reimbursement, or asking the agency to transact the purchase on their behalf. Agencies reported they approved payments by first checking off the purchase against the relevant individual plan.

6.2.4 Enrolment of participants

Because of their *action research* approach, Cara began recruitment in August 2011, extending an invitation to eighty nine (89) individuals in receipt of HACC funded respite packages. The invitation comprised a letter and information kit, followed by phone calls. As a result of this approach, seventeen (17) individuals commenced between September 2011 and March 2012.

Cara noted that the letter and follow-up call may not have been sufficient to engage some invitees with the benefits of the scheme, and that a face-to-face presentation may have been more helpful.

Because of their *reflective practice* approach, ACH Group began recruitment in January 2012, extending an invitation to twenty five (25) individuals in receipt of or eligible for HACC funded respite. The invitation comprised attendance at a high tea in January 2012 where invitees were given a presentation on the opportunity to be involved in the project. Two (2) individuals commenced in February 2012.

ACH Group reported a significant number of invitees were interested in exploring the opportunity but most subsequently concluded they wished to remain with their current service arrangements. ACH Group reported those who did take up the opportunity did so because they were seeking greater flexibility in their support arrangements.

Cara reported some individuals interested in the project did not join because it would result in less service. This is because Cara had been serving these individuals at a level higher than that paid for by government. Though this appears to have been a reasonable response to the issues experienced by each individual, it had not been addressed with government to secure a higher level of funding.

In these instances, the Project Officer referred the individuals to Disability Services for an updated funding assessment.

On a separate point, four (4) individuals who had initially enrolled decided to withdraw from participation because apparently it wasn't possible for them to amalgamate the funding allocation with other funding they were receiving from the South Australian Government for disability supports.

The Project Officer reported several other reasons for people declining the opportunity to participate. Some individuals were sufficiently content with their current stable arrangements which they did not want to disrupt. Paradoxically, other individuals did not engage with the project because they were experiencing crisis and could not attend to the project's possibilities.

In some cases, individuals became enthusiastic and enrolled once they received useful information about the possibilities. Indeed, the Project Officer noted some individuals were not particularly well-informed about a range of entitlements and possibilities within the disability funding system. As such, the enrolment process helped provide individuals with better information about the disability support system overall (whether they chose to enrol in the project or not). The Project Officer reported that, in some cases, individuals had such low levels of information that they were not aware of how to contact the main government agency for assistance.

6.2.5 Internal communications in each agency

ACH Group and Cara used agency newsletters to inform internal stakeholders about the project. Other relevant project communications and presentations were undertaken via staff training sessions and board, team and consumer reference group meetings.

In addition the Project Officer's role at ACH Group included liaison with a range of internal stakeholders. Part of the Project Officer's induction to the role included introductions to key personnel.

6.2.6 Staff preparation

ACH Group developed a toolkit aimed at key staff. The kit included information about the process arrangements for individualised funding.

The Project Officer provided key supports to internal stakeholders directly involved in the project at both agencies. Though this has been described as mentoring, this term may understate any capacity already held by individuals at each agency. We suggest the role was along the lines of being a specific practice guide.

At Cara, the Project Officer initially undertook the role of facilitator/adviser assisting individuals to set goals and plans for their individual budgets. As the author of much of the methodology, the Project Officer educated herself, over and above any induction offered by the two (2) agencies.

ACH Group staff undertaking the facilitator/advisor role attended training sessions held jointly by the Project Officer, Better Practice Project (HACC funded) and by an ACH Group Senior Development Manager. The training opportunities were extended to other ACH Group staff not directly involved with the project.

Cara staff undertaking the facilitator/advisor role were provided with individual training from the Project Officer.

7.0 RESULTS #2: HOW PARTICIPANTS USED THE FUNDING

Prior to this project, HACC respite funding individuals received their allocation as a quantum of support hours to the family member living with disability or age-related support needs. The agencies typically organised these supports on a regularised, periodic basis. This would have meant there may have been times when individuals received assistance when perhaps they did not need it. However, the agencies report individuals opt-in to regular weekly services because it is what they are used to.

Participants were then introduced to the methodology. This included ensuring participants understood their responsibility for making sure they didn't over-commit their funds early on which would create the risk of having insufficient funds later. All participants engaged in an individual funding plan had their own individual expense logs. Some participants chose an arrangement where they sent staff timesheets directly to the agency payroll staff. This arrangement gave participants the opportunity to check the claimed hours matched their own record of support hours received: intuitively, this step helps reduce the likelihood of mismatches, ensuring the participant receives the full amount of support allocated.

"It works really well ... the family sees the hours written on a timesheet"

Project Officer.

In at least one case a participant organised their own contractors and did not require a staff management service from the agency.

All participants chose arrangements where they authorised invoices prior to the Project Officer and agency finance departments processing those invoices.

In at least one instance this resulted in a participant detecting an overcharge in a service invoice; they had it corrected by the vendor before authorising its payment.

The methodology used in the project encouraged participants to think beyond a regular weekly schedule, and instead to view their individual budgets in the context of the full year. This helped encourage participants to think beyond what is currently available.

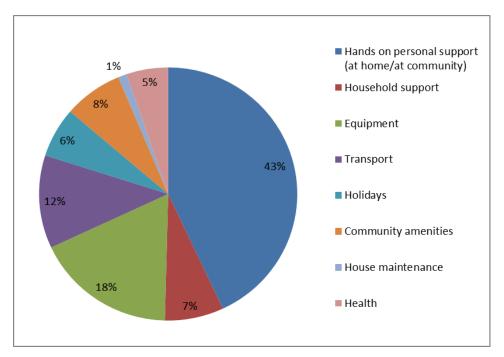
"We were encouraged to think big and were asked: if we had the money what would we do with it?"

Participant Stakeholder.

Some participants decided to continue to use their funds for hands-on personal support. However, across the population of participants enrolled in this project, there was a clear shift in the choices people made. Purchase decisions covered a range of lifestyle areas, including:

- Transport;
- Equipment;
- Household support;
- Holidays;
- Community amenities;
- House maintenance:
- Health.

The pie chart below shows the distribution of funding decisions made by partcipants.



Most participants included at least some variety in their purchases, moving away from an exclusive focus on hands-on personal support. Because of the small sample size we cannot report any further details of the items as this may identify individual participants, thereby compromising confidentiality. However, we can confirm, to the best of our knowledge, the items and services consumed were:

- Legal;
- Unlikely to be controversial in terms of any capacity to deepen or maintain social disadvantage;
- Selected by each individual on the basis of what would be most helpful
 to assist them to maintain personal capacity to provide support to a
 loved one with age-related support needs or living with disability.

On this basis, the expenditure may align well with South Australian HACC Service Principles which include a focus on:

- Maximising people's capacity and quality of life;
- Optimising people's choice and control;
- Providing services tailored and responsive to the needs of people;
- Supporting "community and civic participation that provide valued roles, a sense of purpose and personal confidence"⁵.

Once established, plans tended to run as set out by the participant, though in one case a family updated their funding plan after five months to enable them to utilise their remaining funding to meet additional needs.

Based on feedback from agency stakeholders, we note the arrangements included the capacity for participants to adapt their arrangements if things changed. Agency stakeholders reported that participants highly valued the flexibility.

Most participants have included various products in their funding plan or other services other than support workers. In all cases it supported the needs of the participant. Participants enjoyed having control and for some it financially assisted e.g. transport costs. Most participants had not used their full allocation and therefore had the opportunity to use any remaining funds for items they considered important in boosting personal and family capacity (which presumably are the goals of respite support).

We note that the Project Officer worked with some participants to help them avoid using their individual budget for items that were available via an alternate channel. For example, the Project Officer provided information on how participants with very high use of continence support could access extra free continence aids through Disability Services.

21 | Page

⁵ South Australian Department for Families and Communities 2011, *HACC Service Principles: South Australian Home and Community Care*, Government of South Australia, p. 4, http://www.sa.gov.au/upload/franchise/Seniors/Office%20For%20The%20Ageing%20-%20Corporate/HACC/HACC%20Service%20Principles%20Booklet%20 pdf

8.0 RESULTS #3: PARTICIPANTS' VIEWS OF THE PROJECT

JFA Purple Orange posed questions in the following areas to understand participants' views on the project:

- Supports you receive;
- Agency consultation;
- The planning you do;
- The people in your life;
- The things you do;
- Hope held for the future;
- Choice and control.

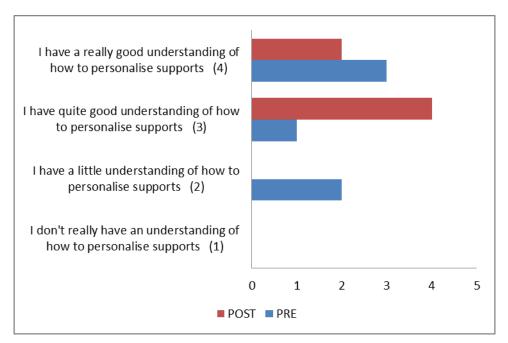
We note participant numbers were modest hence data sets are too small to be statistically meaningful. However we are reporting the data because it honours those who took the time to share it with us and it does contain some indicative signals.

To derive numeric data from the tables and produce average scores, we took the qualitative categories and assigned each a number. For example, in the first graph below, we assigned a score of one (1) for "I don't really have an understanding of how to personalise supports" through to a score of four (4) for "I have a really good understanding of how to personalise supports".

8.1 About the supports you receive

Understanding personalisation

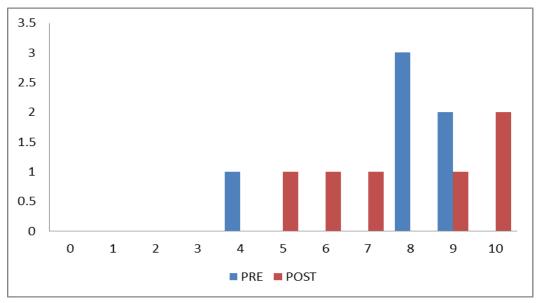
Initial results are inconclusive about the extent to which people increased their understanding of how to personalise supports as a result of their enrolment in the project. There was a slight positive shift in the average score from 3.17 to 3.33.



We consider this reflects the relative early stages of the scheme and relative low numbers of participants.

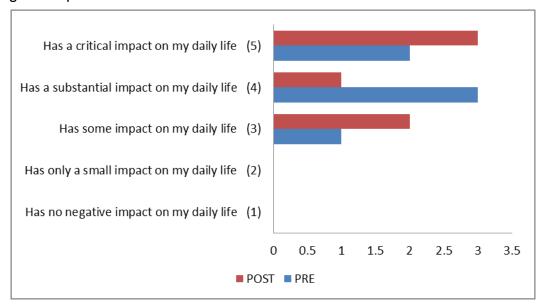
Rating the quality of support

Participants rated quality from zero (0) (very poor quality) to ten (10) (very high quality). Again, Initial results are inconclusive about any changes in perceived quality of support as result of the project. There was little difference in the average score prior to participation 7.67, and during participation 7.83.



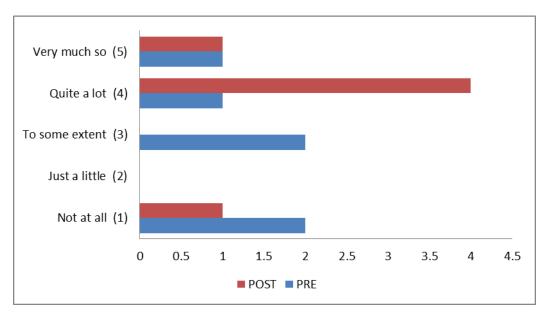
Impact of providing unpaid support

There was no difference in the average score of 4.17. As with all data reported, this reflects the early stages of the project and can be deemed inconclusive until a larger sample size is sourced.

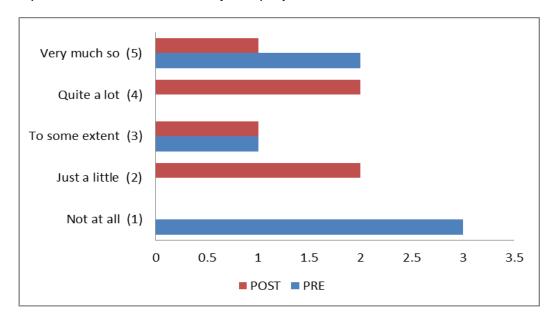


8.2 About agency consultation

Initial results show a positive shift in participant perceptions about agency consultation, with a change in the average score from 2.83 to 3.67 relative to consultation on overall agency service planning (where participants feel they have assisted the agency to strengthen its practice for people in similar situations).



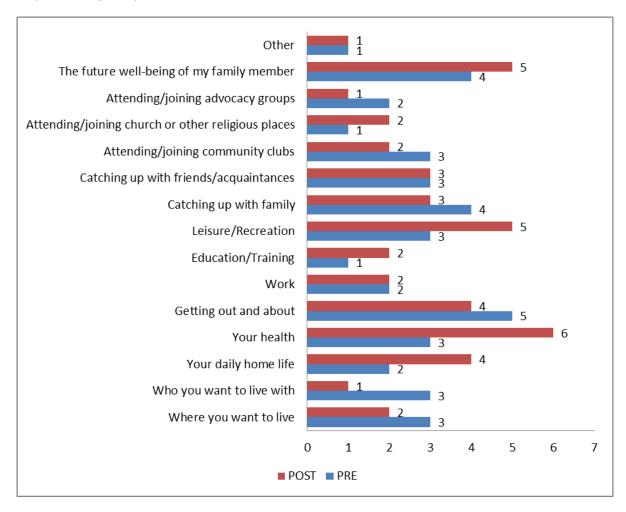
Similarly, there was a positive shift in average scores from 2.67 to 3.33 for participant involvement in the way the project ran overall.



8.3 About individual planning

Nature of goals set

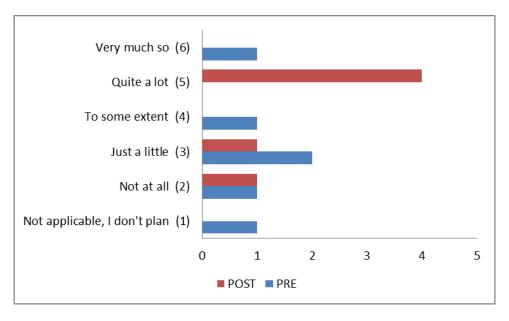
The next graph shows the lifestyle areas where people had set goals, prior to their participation (termed "pre") and again once they had enrolled in the project (termed "post").



There were planning activity increases in the areas of future wellbeing of family member, leisure and recreation, personal health, and in daily home life.

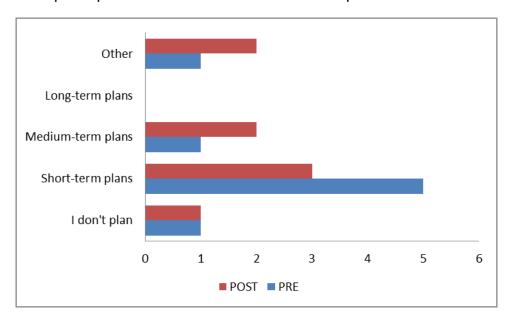
Extent to which arrangements reflect plans

There was a more noticeable increase in this area, with the average score increasing from 3.17 pre to 4.17 post, suggesting participants felt their support arrangements reflected their plans.



Types of planning that people undertake

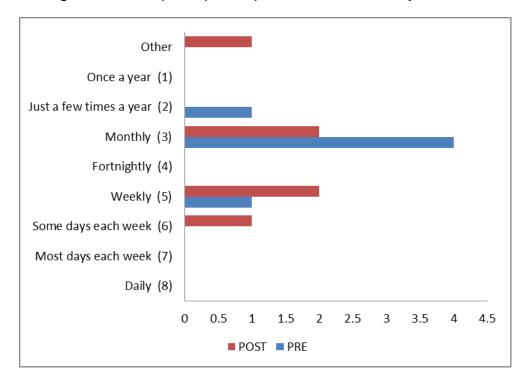
This graph shows the ways participants reported their approach to planning. Please note participants could select more than one option.



The sample size will need to increase before the data can be analysed in a meangiful way.

8.4 About the people in your life

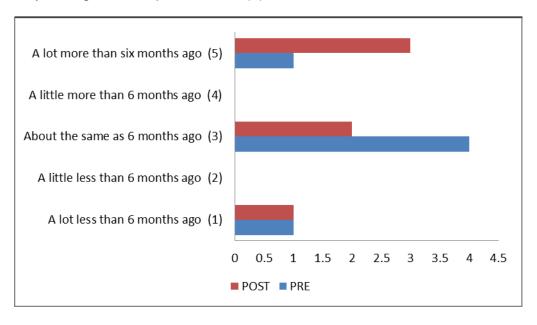
The following table shows participant reports of how often they met with friends.



Removing the "other" item as an outlyer, and assigning a score of one (1) for "once a year", a score of two (2) for "just a few times a year" ecetera, the data averages shifted from 3.17 pre to 4.4 post, suggesting participants enjoyed slightly more time with friends once they had enrolled in the project. Again, it is difficult to make conclusions because the sample size was small.

8.5 About the things you do

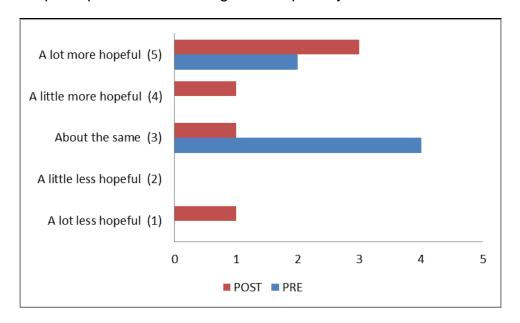
We asked participants about their involvement in community life and if there had been any changes in the previous six (6) months.



With a score of one (1) assigned to "a lot less than 6 months ago" through to a score of five (5) for "a lot more than 6 months ago" there was a positive shift from an average of 3.0 pre to 3.67 post. This suggests that for most participants there was an increase in their involvement in community life compared to six (6) months earlier.

8.6 About hope

We asked participants about the degree of hope they held for the future.

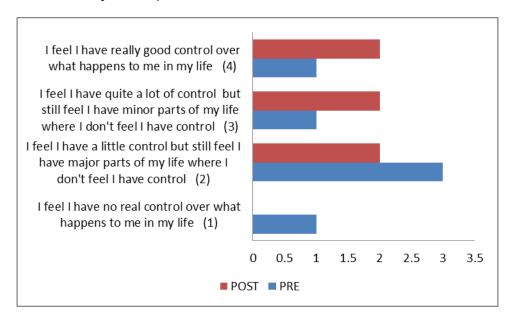


Assigning a score of one (1) to "a lot less hopeful" through to a score of five (5) for "a lot more hopeful", there was very little difference between the average scores from 3.67 pre to 3.82 post.

We note one participant reporting they felt a lot less hopeful about the future once they enrolled in the project. Because this response was generated via an anonymous online survey we cannot make further enquiry to identify if the response was due to enrolment in the project or due to an external factor.

8.7 About choice and control

We asked participants the question, "As a result of the support arrangements you have, please rate your sense of autonomy and independence (i.e. the control you feel you have over your life)?"



Assigning a score value of one (1) to "I feel I have no real control over what happens to me in my life" through to a score value of four (4) for "I feel I have really good control over what happens to me in my life", the average score shifted from 2.33 pre to 3.00 post. This suggests a positive shift in participant perceptions of control.

While the data sample is small, the additional comments made by participants were revealing:

Selection of comments from participants prior to enrolment:

"We cannot get support easily – for personal care or respite... I am hoping this exercise will increase our decision making capacity."

"I am involved but I have to comply... due to what staff are regulated to do... can't assist in making a lot more of the decisions as carers work for their superiors..."

"Living in the country makes it difficult as some staff will not travel the distance. It seems to me that staff has the privilege to decide who they would like to work with rather than where they are needed."

"Xxx gets funding for showering through [another agency] and they supply a worker and if you don't like the worker they say bad luck and have not anyone to

replace them. Have no comeback to go to another agency to find another worker. The funding goes to the agency."

"I arrange myself around when staff are available."

"We have the choice of who comes to us. If we don't like them we tell them. We need to trust the people who come into our house."

"We feel that we do have control and if we haven't we go about getting it. We are pretty assertive. We have our say. We tell people what has to happen. We are in charge."

"We are always here and cannot do things... feel trapped. We can't do what we want to do, it frustrates us."

"It is being organised for me and happens at that time each day".

"It is one thing to receive three hours respite every fortnight, at a time chosen by me, and another as to the practicality of it. It is not at times when it will most benefit me. Main reason for this was that it had to be a set time... it is not always possible to make appointments to fit into this time. Also there are other days when I desperately need respite, but it is not just available."

"We had people supporting us; they did what they thought was right. Very grateful for everything that we have got."

"You are so grateful that you get anything and take what you get."

This selection of comments reveals participants have varying experiences of control and choice in conventional support arrangements. Given both agencies have a clear interest in personalising supports it is perhaps not surprising that some participants report they have at least some positive experience of choice and control. Overall, the comments convey the potential for arrangements to be strengthened to better suit people's circumstances.

Selection of comments from participants six (6) months after enrolment:

"[We were] given the opportunity to say what we wanted."

"We were involved in daily decisions about staff we want and changing days around.... and being flexible."

"I used to have a lot of depression but with this new set up with the outcomes to me it has relieve a lot of pressure."

"If you have your health and not stressed... your mind is a bit clearer."

"We never used to use [the funding] that much... now because [we] have choice and use money for other things [it] has relieved a lot of pressure."

"We could purchase equipment that no one else was going to fund."

"[It's] given us more freedom. Helped us financially as well. Support is changing."

"[Feel I am participating more in community life] because of having more time to do things... more freedom and flexibility."

"Simplicity – financial side [has worked well]. Have not found troublesome or a problem. Their willingness to help with any queries. They provide this support... making information available."

"It's giving people independence."

"[They] supported us to use the resources for what we needed and not what they thought we should use it for."

Even though there were positive reports about the impact of the project on people's lives, some people still reported that providing unpaid personal support has a critical impact on their lives.

"Can't do what we want all the time."

At least in part, this will be due to the broader problems of the current disability support system in Australia, as charted by the Productivity Commission inquiry report⁶.

⁶ Productivity Commission report on Disability Care and Support released 10 August 2011, http://www.pc.gov.au/projects/inquiry/disability-support/report

9.0 RESULTS #4: THE EXPERIENCE OF CHANGE WITHIN THE AGENCIES

"We can't think of a good reason why not"

HACC Funder.

We spoke with senior staff at ACH Group, Cara and the HACC Development Team from the Department for Communities and Social Inclusion, and asked for their perspectives on the project. Stakeholders were interviewed prior to the commencement of the project, and then a second time prior to completion of this report.

These conversations generated the following themes.

9.1 On advancing agency commitment to individualised supports

"I think we will continue with consumer directed care regardless of the type of funding."

From the information supplied at interviews, it is clear both service agencies entered this project with a strong interest in extending their knowledge of how to provide individualised supports. Their experience with the project has consolidated their commitment to individualised approaches, and has augmented any previous experience in providing individualised supports.

This suggests that if a service agency approaches the topic of individualised supports with a positive attitude, the agency is more likely to have a positive experience overall.

9.2 On supporting individuals to have real choice and control

'We had a really strong principle ... it's not our place to choose; we put it on the table and then it's their choice."

Again from interviews, there is little doubt both agencies were committed to supporting participants to have real choice about their supports. In pursuit of this, the agencies moved through a range of practical considerations covered below.

9.2.1 Developing a community of practice

"From a partnership point of view I think we've derived a lot of benefit."

Both service agencies spoke very strongly about their mutual regard. Each agency saw there was a great opportunity to learn from the other, particularly because of what were seen as differing characteristics between the disability and aged care sectors.

"We learnt a lot about the older people services, the way services value older people and what they are doing to [support] older people to keep control of their lives."

"[The Project Officer's] experience in disability has helped us because ... in disability as a field, there is [sic] not as many barriers and restrictions and the same degree of perception around risk as there is within aged care generally... The norm is you know risk averse, tread carefully, consult widely. So I think [the Project Officer] came with a set of preconceived learnings from the disability sector which were really useful for us."

"The collaboration showed how services/agencies can work together and share resources."

This two-agency community of practice was anchored on sharing the Project Officer resource and joint membership on the project's Steering Committee and Reference Group. These arrangements helped to ensure there were strong lines of communication between the two agencies as they advanced their respective methodologies and their appreciation of the benefits of working collaboratively.

"[Because] we are continuing to push the boundaries, we've had some fresh eyes that have helped us to do that; I think it's really good to work in partnership ... It's good for us to work with people who we don't usually work with."

The project is still in its early stages. While there have been some initial efforts to share learning more widely with the aged care sector, there is still work to do to establish a strong momentum beyond the two agencies.

Agency stakeholders noted the marketplace is likely to have competitive aspects for some time to come, and this may make collaboration more difficult if some agencies feel there is commercial sensitivity in the way they share information. However, in this project, the agencies clearly built a very strong habit of collaboration.

"The trust is pretty complete I think between the two agencies."

9.2.2 Capacity of Project Officer and facilitators

"People that can have that initiative to get things happening, get decisions made, don't worry about barriers, the ability to do the hard slog around writing policies, procedures, doing spread sheets; good project officer skills are hard to come by... They are what really make the project happen."

Both agencies have a high regard for the work of the Project Officer. Based on stakeholder feedback, it seems clear the Project Officer's approach to the role made a big difference. Key elements of the Project Officer's practice included:

- Being an honest, straight communicator with all stakeholders, including challenging existing practice "she is just a straight shooter";
- Having a strong value base about people's right to choose;
- Having a strong outcomes focus in terms of what 'respite' means in people's lives, giving rise to a highly flexible approach to people's plans;
- Strong willingness to assist agency staff with practice, including presentations and training;
- Extensive industry experience (in disability);
- Being well informed;
- Acceptance that agencies have differing traditions "she's tried to understand our culture and our different styles";
- Interest in people "personal networks ... have been built up", "informal networks have been working well".

The Project Officer had less experience in the aged care sector so had to invest time in getting to know stakeholders within ACH Group and the issues within the industry.

We note that while strong interpersonal skills are important to the success of the Project Officer role, it is also important that the post holder has sufficient seniority within the agency to make decisions quickly.

Feedback suggests the 'facilitator' role was a key ingredient in the success of individualised funding for any person, and the Project Officer modelled this well in the project. Facilitator practice is as dependent on the person's value base and outlook as it is on any specific practice guidelines.

"The facilitator role is a role that not everybody can do."

"How do you get the right people with the right values to become facilitators; we have guidelines but they are open to interpretation."

"What you recruit for is a person that has substantial experience in the field, very resourceful networks, that's very important, has the right values, you need to find out what they think about whose money it is; people have to have the right way of thinking."

Agency stakeholders noted the importance of allowing sufficient time to get to know individuals and their circumstances, to talk about the possibilities, and to assist the individual to develop a plan that is right for them. For some individuals this might feel like a rare opportunity to have an in-depth conversation about their current life.

"Every individual plan in the beginning takes time so I say don't put two hours in your diary, you probably will have to have three to five hours [because] people are isolated, they don't have the peer support, and suddenly they will rattle off everything in their life."

"They didn't even know how the system worked."

"I thought it would take long, when you make changes and people haven't done it before and they can't touch and feel it, you've got to allow time."

Agency stakeholders were mindful of the challenge of building workforce capacity. An approach based on individualised funding demands changes in the way staff feel, think and act.

"We are still left with the challenge about how to roll it out further; you might have one or two people trained up but we've had a turnover of staff. We don't have a full system and we don't have the quantum of staff ... to deliver consumer direct care. I think the challenge is how do we take this and then take the next step."

9.2.3 On changing business support systems

"You don't have to be as prescriptive about the future."

Agency stakeholders reported a number of practical considerations that relate to business support systems in each agency. These considerations included:

- Setting up individual accounts and monthly statements for participants;
- Resolving transparent fee structures for the agency's work in support of individuals, and when those fees are applied. In particular, we note agency interest in:

- Clarity for individuals on the range of service and administrative assistance offered by the agency, and what these elements cost
- Clarity of understanding of the time involved for a facilitator to properly support an individual to understand their options and explore what's possible;
- Resolving levels of delegations within agencies, so that decisions can be made quickly;
- Recalibrating business supports (and accounting practices) to accommodate a person-driven, annualised schedule for their supports (for example where an individual can 'bank' resources to take a more significant respite opportunity later in the year), rather than a servicedriven weekly/fortnightly schedule of assistance that is less sensitive to an individual's circumstances;
- Exploring different methods to support individuals in spending their funds, including the potential for a credit card arrangement or cashing out into people's bank accounts, and understanding these in the context of funder policy;
- Resolving business software platforms that can support individualised funding relationships between individuals and the agencies;
- Resolving accountability, risk and insurance considerations associated with the choices individuals wish to make, for example employing their own staff;
- Resolving data accuracy, both within the agency and between agency and government funders, and the need to adapt funder reporting tools to capture the correct data (for example reporting consumption of dollars instead of units of time).

"It's a kind of really big mindset change."

10.0 SPREADING THE WORD: COLLABORATION WITH THE WIDER SECTOR

Over the year of the project, local presentations have been delivered at the Western Linkages HACC Regional Collaborative Forum ^{7 8}. One unsuccessful abstract for a national conference was submitted. Both agencies have committed to future conference presentations including at the South Australian HACC Forum in June 2012.

The most significant development in the early stages of the project was the creation of an online SharePoint portal - a facility for eight (8) participating agencies of the Alternative Models Workgroup⁹ (all of whom were exploring the potential of consumer directed care and/or active service delivery approaches, including the two agencies in this evaluation) to post resources (such as methodology documents) and questions for discussion. The Project Officer for this project was the most active contributor to the SharePoint portal; we note some agencies may have been less forthcoming with information due to considerations of commercial sensitivity.

Such sensitivities are predictable in a market that has been shaped by competitive tendering processes. However, this does not appear to have deterred individual practitioners across agencies from finding ways to be helpful to each other.

Importantly, each agency involved in the project reported great value in the learning they could access from the other agency; ACH Group deepened their understanding of disability sector considerations and practices while Cara reciprocally deepened their understanding of aged care sector considerations and practices.

⁷ The Western Linkages HACC Regional Collaborative Forum brings service providers together to share knowledge and experiences to progress the goals and focus of the HACC program and improve supports for people living with disability and age-related support needs - http://www.westernlinkages.org.au/about-us.aspx 8 Collaborative projects are funded through the HACC program in the north, east, west, south and Adelaide Hills regions to improve community services, consumer outcomes and community supports for people with age-related support needs, people living with disability and carers -

 $[\]frac{\text{http://www.sa.gov.au/subject/Seniors/Corporate+and+business+information/Home+and+Community+Care+(HACC)/HACC+Service+Principles/HACC+Service+Prin$

⁹ The Alternative Models Workgroup was one of three groups created as part of the 'Innovative Ideas' Project to discuss learnings, share and develop information and resources.

11.0 DISCUSSION AND IMPLICATIONS FOR FUTURE ARRANGEMENTS

11.1 Considering the first strategic goal: transformational change to a consumer-directed funding model

The data set is too small for any meaningful statistical analysis, and it will be interesting to see further data in six (6) months' time with a larger sample size. However, the data does reflect the stories of a small number of participants who wanted to explore the possibilities of individualised funding.

The patterns of spending suggest participants considered a broader range of options than just conventional hands-on personal supports, which generated a profile of supports markedly different to that in place for the participants prior to the project.

Even though the amount of public funding was relatively low, in some instances less than \$2000 of public funds, there was positive movement in every metric except one (which remained the same). Positive changes were reported in people's understanding of personalised supports, rated quality of support, experience of consumer input to agency services and the project, seeing friends, participating in community life, feelings of hope for the future, and having control.

While the project is in its early stages, in terms of participant numbers, the data is encouraging, and suggests the agency methodologies have brought early benefits.

Some of the changes were small but give encouraging signals about the potential of the project for individuals.

At this point, we make some comments on the availability of information to participants, and the nature of ordinary life as a context for fulfilling respite needs.

11.1.1 On the need for information

A number of participants have shared stories about information including what they did and did not know. To further advance this project and its capacity to transform, the agency stakeholders may want to explore how they can continue to strengthen the arrangements for getting information to participants about what might be possible. In addition to the endeavours of the facilitators (who also need to stay well-informed about the possibilities and about community resources) a strong source of information will be other individuals involved in the project, whose early stories of progress may be highly encouraging to others.

11.1.2 On a good life

We note an anchor-point for the funder's support of this project was the South Australian Home and Community Care (HACC) Service Principles, which articulate values in quality of life, personalised supports, personal choice, responsiveness and community participation.

"We developed the service principles and innovative projects were a tool to start embedding the Service Principles into practice"

HACC Funder.

The South Australian Government is to be commended for subscribing to these values and for reflecting them in the selection of this project.

There is little doubt that all agencies involved in this project were interested in supporting people to live a good life. This has included a shift in thinking about the nature of respite. Participants made choices that reflected their personal circumstances (and were less likely to buy classic types of respite support) as a result of the project. From the qualitative data collected from participants, the arrangements have had a positive contribution to their wellbeing. This suggests that having control over an individualised budget can have a positive impact in people's lives, even when the funds are modest.

Moving forward, the practical challenges will include continued enquiry into the nature of respite in people's lives, especially outcomes, and how these outcomes might be achieved through markedly different purchasing habits compared to traditional service arrangements.

11.2 Considering the second strategic goal: agency change management that supports ongoing and sustained implementation

The participant experiences reported above suggest that each agency introduced changes that have brought benefits to the participants. No significant issues of agency change management were reported.

Because the project is in its early stages it is not possible to conclude whether the changes made in each agency will be sustainable.

However, the main agency stakeholders (i.e. people in senior leadership roles) are resolved in their intentions to continue and consolidate this work. This is good news for ongoing implementation though, as with any organisation's endeavour, the momentum of that implementation may be at risk if key leaders/practitioners move on.

A further review of agency practice change in six (6) to twelve (12) months time will provide additional information about momentum and sustainability, including culturally, within each agency.

We have identified several areas for additional discussion in this section of the report. They relate to:

- The difference in approach to change undertaken by each of the agencies;
- The implications for agency practice of a move from population-based funding to individualised funding;
- The importance of individual staff member values and practice:
- Changing business supports.

11.2.1 Differences in approach to change

As mentioned earlier, Cara undertook an approach characterised by habits of *action research*, whereby initial information was gathered to provide a skeleton methodology then initiated and refined based on feedback from participants.

By contrast ACH Group undertook an approach characterised by habits of *reflective practice*, whereby the agency sought to review its current practice, consolidate a comprehensive body of knowledge, and then implement this as a complete methodology.

Reasons for this might include, but are not limited to:

- Differing degrees of risk tolerance between the disability and aged care industries;
- ACH Group's previous experience testing individualised funding methodologies, on an action research basis;
- Possible differences between people living with disability and people living with age-related support needs in their desire to be involved in action research as 'co-designers'.

There is nothing inherently better about either methodology; in fact, they may reflect natural changes during the longer-term carriage of individualised funding. For example, in the very early stages of the design and implementation of individualised funding, there may be strong merit in trialling methodology with intended beneficiaries to get their feedback on its suitability (this would be comparable to 'beta testing' in the field of IT, where draft versions of software are released to intended beneficiaries whose feedback then informs the final version).

This is likely to result in a significant number of changes to the methodology to help strengthen its impact for intended beneficiaries. Over time, the methodology begins to settle into itself, as larger changes give way to smaller refinements and the intended beneficiaries might then expect a greater degree of stability in the methodology.

Both approaches add value to the work and reflect a desire to learn from experience. For any agency wishing to design and grow its methodology for assisting people into good lives, the *action research* approach is a reminder of the fundamental soundness of involving the intended beneficiaries in the design of the system intended to benefit them. The *reflective practice* approach is a reminder of the importance of making sure an agency is properly learning from its experiences so that beneficiaries can have confidence that helpful practice is identified and preserved, and unhelpful practice is replaced.

11.2.2 Shifting from population-based funding to individual funding

In considering the momentum and sustainability of transformational change in agencies, the results suggest at least two system characteristics have altered for one or both of the agencies in this project. In our view, how each agency manages through these and similar issues will determine the sustainability of transformational change.

The changes relate to agency practice in response to the block contract model of service procurement. In human services there has been a tradition over the past twenty (20) to thirty (30) years of block contract funding, whereby a service agency receives an aggregate sum of funding to provide aggregate services to an aggregated client population. This gives rise to certain agency practices to help manage client demand within the overall budget. Some of these practices have to change, or cease, when an agency moves to an individualised funding model. Two such practices are termed here as 'use it or lose it', and 'unders and overs'.

Use it or lose it

Typically in human services when agencies receive aggregated funding for an aggregated population they tend to regularise support arrangements as this ensures predictability for staff, managers and clients. This may translate to an individual receiving a particular type of support at a particular time on a particular day. If the individual does not need to use this, or is not in a position to use it because of a change in circumstances, the opportunity is lost. Such arrangements could be termed *use it or lose it*.

By contrast, a move to individualised funding means an individual has an individual budget with the capacity to change arrangements to suit any changing circumstances. This removes the 'use it or lose it' practice, and instead demands the support agency has the capacity to track and support such flexibility.

Unders and overs

Because a support agency is working with individuals on a regular basis, it is likely to notice changes in support needs. These changes can result in alterations to the level of service absorbed within the overall funding. In other words, some individuals may receive a higher level of service than that originally assessed, and this is compensated by other individuals receiving a lesser level of service. These 'unders and overs' are not transacted as 'robbing Peter to pay Paul' but simply reflect relative demand.

This arrangement gives a service agency some flexibility to respond to a individual's changing circumstances without having to initiate a potentially complex process of reassessment and government involvement. However, such flexibility takes place within a block contract that is inflexible across the population.

By contrast, a move to a model of individualised funding does not allow for such 'unders and overs' management because a quantum of funding is allocated to each individual. This gives much greater flexibility and control to the individual, but if their circumstances warrant a higher degree of funding support, the service agency will have to refer the individual back to the funder.

In this project some participants chose not to proceed because their individual funding allocation was lower than the value of their current services because they were beneficiaries of the 'unders and overs' approach.

In our view, this does not suggest a block contract funding model should be retained because of the 'unders and overs' option; instead, the individualised

funding methodology needs to include a timely and accessible process for reevaluating an individual's level of funding support.

In the meantime, the implication for a service agency is that as it advances its methodology for individualised funding, it will likely have to dismantle its 'unders and overs' approach to demand, and some individuals may see this as an unwelcomed reduction in service. If so, this is unfortunate; an agency's 'unders and overs' approach can be viewed as a well-intentioned effort to make the inflexible block contract model more sensitive to the needs of individuals.

11.2.3 People are more important than systems

A methodology sympathetic to beneficiary circumstances and ordinary life goals is an important element in any system for individualised funding and personalised supports. However, people bring it to life. In this project, the agencies have attributed much of the helpful progress to the work of the Project Officer and the character of their approach.

This is a reminder that people with a helpful skill set, anchored upon a coherent and passionate value base, can help beneficiaries make genuine advances in their lives, even when methodologies or resource levels are not optimal.

This suggests agencies may wish to undertake a thorough and thoughtful approach to the selection of workers undertaking coordination and facilitation roles.

11.2.4 Changing business supports

The early stages of this project already reveal a range of system challenges for an agency adopting individualised funding to personalise supports. This finding is neither new nor startling, but is a reminder that agencies need to expect to review, refine or design almost every organisational process.

This is a challenging but worthwhile endeavour, and critical to its success will be the extent to which the agency has resolved its own true values (i.e. those values most reflected in an agency's behaviour rather than those values that happen to be written down). It is these values that will help the agency navigate the complex range of system challenges resulting in a comprehensive and coherent set of business support arrangements that fit the goals of client-driven personalised supports.

11.3 Considering the third strategic goal: disseminate learning and strategies to assist transformation by other agencies

The results suggest the two agencies have not yet had significant opportunity to systematically engage the broader sector. This does not suggest any reluctance to share. Indeed, in interviews with agency stakeholders, we gained the strong impression that they wanted to contribute to the advancement of consumer-centric practice across the sector.

Given the activities of the project so far, the limited work in this strategic area appears to be solely an issue of timing.

However, we note the two agencies have benefitted greatly from their collaborative relationship, and in that sense have modelled how agencies can

assist other agencies to transform. In their support for this project, the HACC funder is also a contributor to this collaboration.

There is little doubt that both service agencies benefitted significantly from their collaboration. Agencies carry differing skills sets and traditions, and the two-agency collaboration doubled the learning that would otherwise have been available to each agency. Given the importance of knowledge capital in the lives of individuals and organisations, such learning benefits need to be pursued as the broader disability and aged care sectors continue their move towards more individualised funding arrangements.

While public funders may want to consider how to create incentives within the marketplace that make it easier for service agencies to collaborate on their learning, this is not necessary for it to take place; agencies so inclined can initiate and build communities of practice. This is evidenced by the two agencies in this project.

We note the support of the public funder who selected the project and funded it. We also note the funder visited the project early on, especially to check agency comfort with goals given the tight timeline for reporting.

Funder staff have spoken very positively about the progress of the project, and they are to be commended for selecting the project for funding.

Based on stakeholder feedback, there are challenges lying ahead in how these public monies might be arranged in the future; individualised funding creates a range of questions about system flexibility and accountability, and sets up a dynamic tension between the beneficiary's desire for flexibility and the funder's desire for accountability.

Hopefully, what they have in common is an interest in value-for-money, in terms of positive outcomes in each individual's life. As this particular project goes forward and indeed for any project that seeks to advance individualised funding and personalised supports, one way to manage this tension and extend the experience of collaboration would be for the public funder to find ways to participate in some of the key meetings and moments of the project and to meet with participants; the shared stories may assist it work through some of the resulting sector policy challenges.

11.4 Two considerations for the public funder

As stated elsewhere in this evaluation report, we believe the funder is to be commended for supporting this project, which has made an encouraging start.

In conducting this evaluation, we have identified two broader system issues that may be of interest to the public funder.

These are:

- Options for transferring funds;
- Evolving the relationship between needs and funding.

11.4.1 On the options for transferring funds

Some of the participants on the scheme also receive other government monies because of their circumstances, such as income support or carer benefit payments through Centrelink. These payments are paid directly into the person's bank account for them to use as they see fit.

Even though the HACC respite funding is attending to similar pressures, there are far greater constraints around their expenditure and a greater degree of accountability on the recipient. We can foresee increasing numbers of people wishing to enrol in the project given the encouraging data about wellbeing, echoing much larger studies in other jurisdictions¹⁰. The public funder may want to explore a broader range of options for how beneficiaries can receive their funding, such as via direct payments into beneficiaries' bank accounts, given the value people placed on flexibility.

We note the funder's observation that public policy has been advanced since the project commenced. There has been much discussion in Australia regarding commitment to a National Disability Insurance Scheme (NDIS), while in South Australia the Government recently gave a commitment to systematically rollout an individualised funding model for eligible people living with disability. Had these public announcements been in place prior to the commencement of this project, the funder's operational policy coordinates may have been different regarding beneficiary range of choice, and the extent to which funding could be transacted via beneficiary bank accounts (or proxies such as credit cards).

11.4.2 Evolving an understanding of the relationship between need and funding

We have yet to encounter a funding system that is perfect in the way it charts support needs and translates that to a quantum of individualised funding. The HACC funding arrangements are no exception. This is evidenced in this project by some of the differences in allocated funding between individuals that might have manifestly comparable levels of need.

This is not a criticism of the funder, and this matter will need to be more fully charted as part of the move towards wide availability of individualised funding and personalised supports in South Australia.

The advantage of a shift towards an individualised funding model is that it gives the funder the opportunity to collect data that reflects people's personal circumstances (as opposed to blunt, population-based data). Data opportunities could include:

- An assessment of the distance between a person's current circumstances and ordinary life chances, rather than just attempting to measure functional impairment;
- Longitudinal changes to this distance as a result of individualised funding and personalised supports;

Leadbeater, C, Bartlett, J & Gallagher, N 2008, Making it personal, Demos, London, UK, http://www.demos.co.uk/files/Demos PPS web A.pdf?1240939425



12.0 CONCLUDING REMARKS

When the two service agencies proposed this project, they included a commitment to provide an evaluation report. Because of the impending government changes in responsibilities for aged care funding and disability support funding, the timeframe for the evaluation report tightened. Together with the slower-than-expected rate of enrolment, this has meant there is a modest amount of data available for evaluation.

However, the available data gives encouraging signals of progress, with participants enjoying emotional and practical benefits from their involvement in the scheme; benefits which are the natural goals of 'respite'.

In this sense, the project signals the potential to reconceive the nature of 'respite' by reducing assumptions that it exclusively constitutes formal supports. The goals of 'respite' – for example to recharge batteries, reclaim hope for the future, take a break, spend quality time with loved ones – can be advanced in any number of ways, limited only by people's imagination of what might be helpful, and by any reasonable constraints applied by public policy.

Importantly, the project has shown participants value the opportunities for control and choice over their support arrangements, and service agencies learn from these endeavours, especially when working in collaboration with the people involved and other agencies with a kindred spirit.

We look forward to the opportunity to remain involved with the evaluation of this project, and preparing a further report once the number of participants in the project has increased.



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