Centre-Based Day Respite Project

Stage 1 Situational Analysis Report

Prepared for Brisbane North Primary Health Network

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COTA Queensland

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ACKNOWLEDGEMENTS

COTA Queensland acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the lands on which we walk, we work, and we live. We wish to pay respect to their Elders - past, present and future.

This project is an initiative of the Brisbane North Primary Health Network (BNPHN) heathy@home consortium, is funded by the Australian Government Department of Health, and has been undertaken by Council on the Ageing (COTA) Queensland.

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healthy@home members

EXECUTIVE SUMMARY

Changing demographics and family structures and shifts in policy and community attitudes are resulting in more people living in the community with increased need for ongoing care and support, including those living with dementia, more people without close family support, and increased pressures and demands on informal carers. Two significant consequences of these changes are social isolation and carer stress. Centre based day respite and group social support activity types are two major service activity types funded and delivered through the aged care system which respond to these needs for social connection and carer respite.

A range of innovative approaches to the implementation of centre based day respite and group social support is evident in both the Brisbane North CHSP Consortium group, healthy@home, and in the literature in Australia and overseas. A key element of current and emerging models and approaches is the focus on health and wellbeing, and the integration of centre and group activities with community life.

The place-based community setting for these services enables the following benefits for people as they age, in terms of supporting health, wellbeing and independence, and continued inclusion in community life:

a) a space that promotes inclusivity and diversity, and a sense of belonging and connectedness
b) an enabler of a meaningful life and engagement in conversations, activities and relationships which promote a sense of self-worth, dignity and purpose
c) a space that connects the person to their community, and to other health and support services
d) a place and relationship-based setting that enables early identification of health and social needs or changes and linking with assessments or interventions/responses
e) a gateway to knowledge, information and support for the 'client' and the carer
f) a gateway for intergenerational learning and sharing

Major issues raised during the consultations include the investment required by organisations in infrastructure and operational costs for service types that bring people together outside the home. A dramatic decrease in referrals has also occurred since the introduction of My Aged Care and there appears to be lack of knowledge and understanding of these group service types by assessors and the community in general. The very nature of these service types also adds complexity to the referral process in that they:

i. are group based and require thinking and logistics that a direct service to someone in their home does not require and
ii. require an understanding of the psychosocial impact of social isolation and/or intense dependence on a carer.

This means that the time, trust, knowledge and relationships required in making and supporting a referral are significantly different and an understanding of and responsive to these matters is key to success.

The need and value of this type of care and its cost effectiveness is even more important now as the number of people living with dementia and the preference and opportunity for people to remain living at home increases. The current reporting structure might not fully capture the value for money and cost-benefit to the community and health services as well as aged care system in terms of reduction in more intensive and costly care which this service type is potentially averting. This service type enables people to continue living well at home yet connected to their community; and potentially keeps people out of aged care homes.

In looking to the future, key policy and program decisions, particularly in relation to funding arrangements, assessment and referral, and understanding the differences between individual care and support and centre-based/group support responses are key considerations. Understanding and eliciting the needs and preferences for the community both now and in the future are also vital in moving forward, ensuring that the voices of currently 'hidden' individuals and cohorts are heard; that community knowledge, networks and support is optimised; and that equity of outcomes is achieved across the region.

1.0 INTRODUCTION

A number of key policy drivers and demographic changes are currently impacting on service delivery. These changes include new requirements under the single Aged Care Standards introduced July 2019; embedding and reporting on a Wellness and Reablement approach; recognition of increasing social isolation as a significant health determinant; and ensuring that Centre-based day respite services are inclusive of people from diverse backgrounds and people living with dementia. [1]

The concept for this project was developed by Brisbane North PHN, as a result of identification of need and the changing policy, service and community environment. Initial consultations and discussions were conducted by Brisbane North PHN through the healthy@home CHSP Consortium management group, and endorsement for the project received.

COTA Queensland submitted a proposal to BNPHN for engaging Centre-based day respite and group social support providers, consumers, carers and other key stakeholders to:

1. Identify and explore key priorities for these service types in the context of the policy drivers and demographic changes
2. Identify service referral issues and barriers and explore best practice approaches to support consumers and carers through the referral process and in accessing services which support their health and wellbeing
3. Map out Centre-based day respite and group social support and explore opportunities for improving coordination at a regional level and enhancing consumer engagement
4. Develop an outcomes measurement framework suitable for Centre-based day respite
5. Develop a vision for the future, given changing demographics and consumer expectations
6. Put forward recommendations for informing and influencing current and future aged care policy and service planning decisions

COTA Queensland was contracted on 31 October 2019 to undertake Stage 1 of this project, an initial exploratory project in order to:

- Capture existing knowledge and expertise in the sector through the healthy@home consortium member organisations
- Identify good practice models in Australia and overseas through a literature scan
- Identify key policy directions and opportunities for informing and influencing decisions at the regional and national level

This Stage 1 project commenced 4 November 2019 and concluded 20 December 2019.

[1] Brisbane North PHN Centre-based Respite Consultation Proposal Plan

2.0 METHODOLOGY

2.1 Project Approach

The approach implemented for this exploratory phase was as follows:

1. Face-to-face on-site consultations with healthy@home consortium members
2. Consultations with other key informants in particular the Brisbane North RAS Consortium coordinator
3. Brief literature and policy scan
4. Desktop mapping of Brisbane North PHN region centre-based respite and group social support service providers
5. Preparation of a situational analysis report for informing future work

2.2 Project Timeframe

4 November 2019 to 20 December 2019.

2.3 Project Scope

The scope for this initial exploratory stage was healthy@home consortium members providing CHSP Centre-based day respite and Social support group activities at centre-based locations in the Brisbane North PHN region.

2.4 Project Limitations

Several healthy@home consortium members have not contributed in the current consultation phase due to the limited timeframe and the organisations' capacity and priorities at this time. We are aware there are a number of other innovative models and approaches within the consortium group.

Sector conferences are another source of contemporary innovative practice. Access to these materials has been limited, however the BNPHN Healthy Ageing Team plans to follow up presenters from the recent LASA National Congress for their presentations.

The 2019 CHSP Innovation Grants may also be another source of current innovative practice within Australia; this information is not publicly available on the website at this stage. A request has been placed to seek access to this information however the listing is not available at the time of preparing this report.

3.0 Findings

Member organisations of the Brisbane North PHN healthy@home consortium were invited to participate in face-to-face interviews over the course of a few weeks. Interviews were conducted with a mix of management and staff members in varying roles. In total, 16 people directly participated across nine services and six organisations.

In addition, a semi-structured interview was conducted with the Brisbane North PHN RAS Coordinator, who had sought input from the team of RAS Coordinators according to the Interview Schedule. This schedule of questions had been developed following analysis of the previous Service Provider consultation phase.

The following broad themes emerged through analysis of the information shared through the service provider consultations, and the additional perspective provided through the assessor interview.

3.1 EXISTING SERVICES AND ACTIVITIES

3.1.1 Client Base Diversity

Service providers interviewed for this stage of the project provide support to a diversity of clients. Whilst services are open and available to all in the community, many of the services appear to attract a particular cohort that may be influenced by their history, their location, their particular niche or specialty and/or changes in the community as a result of funding or program changes, or closure of other services and programs.

Some or the more significant changes occurring which seem to be impacting or influencing most services include:

- Increasing number of people with dementia
- Increasing level of care need for people
- Mix of abilities and needs influenced by different funding streams (for example, Home Care Packages or people on Home Care Package waiting lists)
- Increasing stress, isolation and health risks for carers
- Increasing number of men
- Newly emerging CALD groups

Concern was raised that there may be a number of newly emerging or hidden population groups who could benefit from this service type and who are not reflected in the general cohorts currently using the services.

3.1.2 Community Based Setting

The importance of 'community' in both understanding of the client group, and the design and provision of services, was central in the service provider consultations. In some instances, the community has a specific CALD community or religious affiliation; in others, it was more place-based in that it relates to and connects with the geographically based community in which the users of the services live.

3.1.3 A Safe Place for Social Connection and Support

The centre-based and community-related nature of the service creates a safe gathering and meeting place for the person. It creates an environment in which people can share stories and interests, skills and knowledge, and goodwill and companionship. Laughter was a key component for many,

and a sense of fun was engendered through staff, volunteer and service user interactions. The setting, the approach and the people involved in these activities all contribute to fostering a sense of belonging, of value, of joy, and of connection.

The importance for people to feel safe was referred to a lot, and included physical safety, cultural safety and social safety. Respondents talked of the increasing number of people with dementia, and the need to adapt with dementia-friendly environments and appropriately trained staff, volunteers and students. The more frail and those with more advanced dementia are preferring and/or requiring the safe environment of the centre-based location.

It is an easier process for clients to consider attending if they feel the service reflects their community and/or they feel their cultural or social needs and preferences will be acknowledged and respected. Respondents provided examples of people who were at first reluctant to join or consider this type of support. A range of strategies were employed to work with the person to explore if this was something that would work for them, including 'soft referrals' in which another support worker who may be providing individual support attends with the person the first few times, for smaller periods of time, so they can 'test it and see'.

The centre-based day respite location is also for many in the community a trusted source of information about other services and supports. Some organisations provide information sessions on varying topics to participants of the services, as this is an identified need and gap. Others seek opportunities for external organisations and groups to provide this information and access to services and other supports.

3.1.4 Meaningful Activities, Relationships and Roles

A range of activities and experiences are being provided by Brisbane North services as shared through the consultations and in other conversations outside the formal consultations. Programs are generally planned in advance with active input and direction from users. This appears particularly to be the case for group outings.

<u>Connection with nature</u>
Some centres have adapted and transformed their environment to create more connection with nature, animals and the local environment

- One service reported having chooks which the attendees look after, and a vegetable garden, the produce of which is cooked onsite
- When the centre was being painted, clients took on roles of keeping an eye on the chooks, and designing and replanting the garden
- Another service has negotiated with Brisbane City Council and received funding to transform the dry unused park area adjoining the respite centre into a garden area that can be enjoyed by both the users of the respite centre and the community. This provides a setting for interaction between clients and with the community – both direct, and through quiet observation. The garden/park area is an exercise/walking circuit for those who are able to and want to build exercise or a walk outdoors into their day. Others assist in the plant nursery

Group bus outings to natural settings are also very popular, with trips for example to Maleny, the Sunshine Coast and the Toowoomba Carnival of Flowers. One service' men's group have a schedule of going to their favourite fishing locations.

<u>Music, artistic and creative pursuits</u>
A range of musical and creative activities are built into daily programs. The value of music was demonstrated with examples such as *'one woman who never speaks, sings'.* Another service

had encouraged a particular client for some time to consider joining the group activities at the centre, however he was very reluctant. A volunteer then joined the group and led a regular guitar playing and singing segment. Knowing the person had a love of guitar playing, he was encouraged again to 'give it a go'. He now attends weekly and joins the volunteer in leading this segment.

Another service has a *Sip and Paint* group, in which participants sip wine and paint. They also have a partnership with QPAC, go to the ballet and have joined in supper club nights.

Other examples included activities and partnerships such as linking men into the local Men's Shed, which participants enjoy for the hands-on activities and making of things, as well as the relationships and the more relaxed atmosphere, in comparison to the 'schedule' at the centre.

Dinner, dancing and date nights

Some of the services arrange a regular dance night which for some is the only time a carer and their spouse go out together in a safe and supportive environment to socialise. One person reported

This is the first time I've been out at night for 20 years.

Another man asked for a photo to be taken of he and his wife dancing, so they could send it to their children. This man died a short time afterwards.

Celebrations of key events and specific days

Special occasions and events are celebrated at most centres and tailored to the participants' interests and associations. Christmas decorations and celebrations were in full swing during the time of the consultations, and Melbourne Cup is said to draw out some interesting hats and competitive natures.

Flexibility with the environment and hours

The environment is adapted to be appropriate for different needs. A number of services have 'quiet rooms' or 'retreat rooms'; and the centre space will be used in different ways to meet the varying interests and comfort levels of participants throughout the day. Some services are adapting their activities and processes to be more comfortable for and inclusive of the growing number of men attending. Outdoor spaces are also used to create different environments in which people can interact, share, and learn, play bocce, or sit quietly by themselves.

Many of the services offer flexibility in hours, enabling respite and social connection to occur outside Monday to Friday daytime hours. As one coordinator commented:

Saturday mornings are traditionally when we get our odd jobs done such as shopping, catching up with friends for a coffee, seeing the grandkids play sport. So, we make this time available for the carer to continue their social connections as much as possible.

Range and diversity of people involved in the daily routine

The collective nature of the activities results in a number of people/roles and relationships contributing to the health and wellbeing of the person. The roles ranges from the bus/transport drivers and cooks to staff, students and volunteers. Staff, volunteers and students are often teamed up with clients with common interests, for example fishing, gardening, knitting, or going for a walk or sit outside.

Continuity of relationships in the community

Continuity of relationships can also be enabled through the flexible, person-centred and responsive approach taken in and through this activity type. A couple of services illustrated how they do this:

Previous clients of the centre-based respite service continue to join in the Centre-based activities on a regular basis, after moving into a residential aged care home. They want to maintain the relationships and the connections. The client pays to attend as a private client, and the RACF provides the transport.

T*he Centre-based day respite men's group who play music and sing as a choir also attend the organisation's residential aged care facility and perform for and interact with residents*.

3.1.5 Maintaining and Creating Community Connections

The importance of maintaining community connections was clearly evident in a number of centre-based and group social support activities and the way people 'walk with their feet'.

Bus trips, short and long, are extremely popular. The trip to and from the centre is also an opportunity for people to see and stay connected to what is happening in their community.

Clients sometimes request to stay on the bus while others are being dropped off, so they get to do the circuit of their community.

Intergenerational activities are extremely popular and have been in place at most centres for some time, as a result of long-established relationships with local schools. The mutual benefit is not only intergenerational connection, understanding and appreciation. It also enables a sharing of knowledge and skills between the generations; and opportunities for leadership development and community service activities. The centre provides the connecting point for the community in accessing its elders.

3.1.6 'Wrap Around' Care and Support

Centre based respite is not 'just a day out' (service provider quote)

A purposeful end-to-end program is put together aimed at proactively contributing to the quality of life and quality of care outcomes for the variation of clients participating on any given day. The client would not be aware of the level of planning and review that occurs, and the various aspects of their health and wellbeing that is taken into account. System terminologies, structures and requirements are behind the scenes, while activities and services are designed to wrap around the person in as seamless a way possible.

Some respondents talked of case notes taken at the end of each day and how workers share their observations, both of a person's increased engagement or capability, or concerns re withdrawal or a deterioration in condition. The co-location in several instances of other services, such as nursing and allied health, including podiatry, enables reviews to occur within context and to understand any changes over time.

The organisations involved in the consultations work with particular target groups and as such have increased knowledge, understanding and expertise in providing services and supports that are tailored to the needs and preferences of that cohort. One provider described their end-to-end support for their clients who can feel socially and economically marginalised and isolated. *The day starts with a phone call to the person, providing a connection to give them courage and readiness to attend. They are then picked up in cars, and the conversation to and from the centre is a key component of understanding how the person is going and if there are any changes that may impact*

their health or future involvement in the group. The day involves a range of physical, social and mental activity as well as nourishing food and one-to-one 'check-ins'.

3.1.7 Wellness and Reablement embedded in planning and activities

Wellness and reablement is integrated in the service's planning and activities. Specific activities are programmed to support physical capabilities such as allied health led exercise activities. Yoga, tai chi and hydrotherapy are also offered at or through some locations, and one service's members actively participate in the Seniors Games, an organised and inter-community 'competition'.

Evidence of other activities which increases a person's motivation and capacity are also illustrated above, such as community dances, creative and artistic endeavours, walking in nature or caring for animals.

Knowledge of and relationships with the clients enable staff to develop a good understanding of the person and what is important to them. Using this understanding and their relationship and communication skills, staff gently support people to consider and undertake activities which support their physical and social capabilities in a safe and culturally appropriate way.

Partnerships with other organisations or services also enhances the service's capacity to provide safe wholistic programs. One service partners with the Mater and through their Falls Prevention program, healthy eating, safe exercise and strength and balance building is incorporated into regular activities.

3.1.8 Client Participation in Planning and Review of Services and Activities

Services actively seek clients input in the design of programs and activities, through a range of methods. Quarterly 'participation meetings' with the groups seem common, to hear general feedback and identify members' ideas and preferences for the next quarter's program including food and activities. One-to-one conversations and observations are conducted both formally and informally; and the value of criticism and complaints explained in terms of assisting the organisation to better understand and meet their needs.

In addition, the review with the client of their 'goals' (the term is not used) and support plans informs the design of the program and daily activities.

Some services are applying models that enable people to 'walk with their feet' in terms of which activities or approaches best meet their needs and values. This might be through providing a range of activities on any one day and the person choosing and moving as they feel comfortable; quiet areas and outdoor spaces to which a person can retreat and be alone or gather in smaller numbers; and the popularity of some activities such as bus trips to specific types of locations.

3.1.9 Workforce integration and development

Centres use a varying mix of staff, volunteers and students to deliver their programs. Organisations reported a strong commitment to training for staff, volunteers and students, particularly in relation to understanding dementia and working with a wellness approach.

Allied Health and nursing are often co-located in the centre and involved in physical exercise activities or for review if staff observe a change in the person's needs, capability or condition.

The centre-based programs also provide an occasional alternative experience for staff who work on the individualised programs. These staff report that involvement with clients in the group-based activities provides them with a different perspective and appreciation of the person and the program.

Coming here (to the centre) reminds me why I'm in this field of work.

The centre-based day respite programs provide a training ground for students in aged care, disability and community services, and allied health. GPs undertake community access training as part of their programs through one service with an indigenous focus and clientele base. This environment provides the opportunity for future GPs to get to know people in a more natural environment than a medical clinic, and where the older person has increased power over the story and conversation shared.

3.2 ISSUES AND CONCERNS

3.2.1 Referral Issues

Service providers identified lack of referrals since the introduction of My Aged Care as a major barrier. Previously referrals tended to occur through local knowledge and relationships, for example referrals from hospitals or people 'knocking on our door'. Currently many referrals occur through identification in other programs such as Home Assist or Domestic Assistance, or through Home Care Packages and NDIS referrals.

Lack of knowledge and understanding of these CHSP group-based service types appears to be a major reason for the lack of referrals from the assessors' perspective. Confusion regarding the differences between the two service activity types - centre-based day respite and group social support - was also evident. In addition, assessors require further information to assist in understanding if the referral is appropriate for the person, with additional or different considerations required as compared to individual service types. For example, information is required such as transport availability and arrangements; wheelchair accessibility; and additional supports that a person might require if away from home for the majority of the day.

Providers recognise they need to 'sell' what they have to offer, and the benefits/outcomes from participation in these activity types. This is not only to assessors, but also to the community in general.

Providers also talked about the need to intensively support some people to consider participation in group settings, particularly for someone experiencing social isolation or who has not participated in group settings as part of their previous life. A 'cold referral' to a group activity for someone would require a huge leap for the person if they do not have the support and encouragement to 'give it a go'. Soft referrals are identified by both providers and assessors as appropriate and effective means for these service types and client needs. Examples were provided of the Ozcare dementia support worker attending with the person in the beginning; or the personal support worker bringing the person into the centre to observe and have a cup of tea. This can take considerable time and effort, however the outcomes for the person for their short-and longer-term health and wellbeing can be significant.

The term 'respite' was also raised as a barrier or deterrent for people and is used with caution or not referred to at all. Some examples used by participants are 'I'm going to the centre' or 'I'm going to the club'.

3.2.2 Capacity to Respond to More Complex Needs

Many providers talked of the increasing complexity and level of need of clients attending the services and the impact this is having on staffing ratios, skills and knowledge; the appropriateness of the physical environment; and program planning for appropriate activities and supports.

Some are needing to increase staffing ratios for parts of the day when some clients may require additional attention or support with personal care; or on days when smaller group sizes are offered to enable a more supportive environment for people with dementia.

This increasing complexity or level of need is also resulting in changes and adaptations to physical infrastructure such as making the centre more dementia-friendly and including hoists in transport vehicles.

Factors suggested as possibly contributing to this increasing level of need include the increasing need for carer respite and support as people are encouraged and supported to remain living at home, with increasing needs for example related to their loved ones dementia condition, or increased reliance due to physical frailty or mobility or sensory issues. The flow-on effect from the Home Care Package waiting list situation was also identified as a key factor in the increasing level of need for clients currently utilising CHSP type services. Some services are available for people from a range of service types and funding streams including NDIS and Home Care Packages.

3.2.3 Need to Also Support the Carer

The need to support the carer was named by services as an important component relating to health and wellbeing for both the client and the carer. Some services are supporting the carer indirectly – yet substantially – through making available hairdressing and washing, showering, collection of bloods by pathology and access to podiatry appointments and other nursing and allied health support.

Some services are establishing carer support groups and activities that are resourced by other programs and positions through the organisation. Others are looking to experienced volunteers/peers to run support groups and get-togethers. Respondents talked of the flexibility in timing and location required to support carers, and the need for access to appropriately qualified staff.
One organisation talked of their plan to set up Memory Cafes in which both the person and their carer can join with others, not necessarily to refer to or talk about dementia. Locations can be in existing cafes or other locations in which people feel comfortable and their activity is 'normalised'. One example shared was of *a carer who now feels confident for her husband to stay in overnight respite, after hearing others' stories at a carers' get-together over lunch.*

3.2.4 Connections to Support Personal and Family Dynamics

Some services talked of the critical need for access to social work type support for clients, carers and families. One organisation previously self-funded a full-time social worker for ten years. This can no longer be sustained; now a reduced amount of social work/social welfare type support is being provided through another program and in-kind contribution by the organisation.

Another organisation talked of changes in Queensland Government community health funding and programs some years ago, and the subsequent loss of access to social work services and support.

3.2.5 Need for Information on Other Matters Impacting the Client and Carers' Lives

Participants talked of the role the Centre-based program plays as an information source for the clients, carers and community in general. People request information on a range of matters impacting their lives. The centre is seen as a trusted and accessible provider or linkage point for this information. The organisations are not funded for this service however still attempt to have information available, link people into services, and/or arrange community education and information sessions.

3.2.6 Infrastructure Costs

A major issue expressed through the consultations related to the ongoing infrastructure costs for enabling this type of community and centre-based activity to occur. These costs include establishment, maintenance, replacement and operational costs for the buildings and transport fleets. It also includes modifications to buildings and vehicles as client needs change.

All the services interviewed are supported by large well-established backbone organisations which appear to provide significant in-kind contributions through buildings, additional staffing and management support, and other costs. Sustainability however is of a key concern Concerns were raised for smaller organisations without this support, and the additional vulnerability for these smaller organisations to funding and payment changes.

Some services reported being approached by other organisations who were wishing to broker a place in the organisation's centre-based activities. These were often higher care clients on Home Care Packages, and the organisations reported that given the high cost and investment by the organisation itself in making this service viable, and the challenge of appropriate staffing to meet the needs levels, they often do not have capacity to consider the request.

3.3 LOOKING TO THE FUTURE

Service providers were asked about their thoughts and experiences regarding changing community needs, values and preferences, and what this means for service responses moving forward. Some of the responses are outlined below according to changing demographics of likely user groups and possible models of care to consider in thinking about adaptation and the future. All expressed a keen interest in hearing more about what others are doing and thinking in relation to these types of supports, both in the region and elsewhere.

3.3.1 Changing demographics

When asked to reflect on likely future trends and models for meeting community needs, participants identified that – even though the current models had good uptake and responses – it was quite likely that people may look for smaller, less formal and more flexible ways to gather in the future. Some participants reflected on their ageing parents and thought about what is currently meaningful for them in terms of social connection. An example provided was of a father/grandfather who, every morning, walks to pick up the paper and milk and have a coffee at his local coffee shop. How might this look if that person has more advanced dementia and was needing support to continue to connect with others and in locations in which they are comfortable and feel connected?

Others talked of the growing numbers of men attending the activities, and how they are adapting their service to be more attractive and amenable to this cohort. Some find that the bus outings are popular and achievable; others provide different hands-on type activities and design the physical space to enable smaller groupings and quieter less verbal interactions.

The changing face of CALD communities was also raised. The generation of older CALD populations who are currently using services may be different to what subsequent generations who have been born and raised in Australia will want and expect. Newly emerging migrant communities are also seeking understanding and entry into the aged care support system for their ageing members. The different systems and expectations of care – including who is responsible for providing that care – is vastly different for many non-English speaking communities. In addition to language and cultural barriers, trust is a major issue, and exacerbated for those communities who have experienced torture and trauma. One CALD service provided examples of being approached by new communities to support them in understanding and providing care, as they see them as a 'culturally safe' partner in this journey.

An Afghani women's group approached us to provide services for them …we recruited two members from their communities to coordinate that group and it's centered around tradition and cooking…and they all get together and feel connected to what we are able to provide. We understand and respect how to nurture that, how to nurture these women and that's a dynamic program.

The centre-based day respite and group social support programs enable this kind of early intervention and support for marginalised groups who might not otherwise know how to or trust accessing the aged care system directly for their ageing members. It also provides an avenue for established and experienced service providers to assist and partner with other community groups and networks in developing and providing responsive, appropriate and safe services.

3.3.2 Different Models

Service providers were asked about their knowledge of or thoughts about different models that may be of relevance now or in the future. Some of these are listed below:

- 'Home environment' type models that may suit people with more advanced dementia
- Small group activities that enable people to participate in and interact with community life
- Additional individualised care and support available for the person and/or the carer as part of their relationship with the centre-based service
- More integrated service and setting within the community rather than a separate place/'respite centre' to which the person comes
- More flexibility in hours, number of hours, types of activities, how people access the activities and support
- Increase integration of allied health professionals for supporting the wellness focus and for undertaking wellness-based research that measures outcomes for participants
- Community hubs where people not only access group type support or day respite, but also other support services such as allied health and also community education for example about dementia, elder abuse and other matters impacting people's lives; and for all interested (clients, carers, family and community members, others)
- Creation of and support for 'village' type settings

3.4 LITERATURE SCAN

Several key models were identified in the literature scan and are outlined below. It is interesting to note that the Brisbane North services are implementing many aspects of these models, even though they may not give the model or approach a specific name. At least one however is specifically pursuing accreditation with an internationally accredited model, the Eden Approach.

3.4.1 Meeting Centres Support Programmes

The Meeting Centres Support Programmes (MCSP) centres are popular in Europe, with 163 MCSP centres in the Netherlands, and centres in 25 other countries. [2]Attendees at an MCSP are offered:

- meaningful recreational, creative, and therapeutic activities in the Meeting Centre (their "club")
- the caregivers can attend informative meetings and discussion groups, and
- both can participate in social activities and utilize individual consultation

(Dröes et al., 2019, p. 1528).

MCSPs commenced over 25 years ago and have been the focus of numerous research studies. According to Morton et al (2019):
Research has demonstrated that, compared with regular day-care, attending a meeting centre has a positive effect on mood, behaviour, self-esteem and delay of institutionalisation of the person with dementia, and on sense of competence, burden, psychological and psycho-somatic complaints of family caregivers (p. 2).

In the last decade, further attempts have been made to individualise the MCSPs. Dröes et al (2019) compared individualised MCSPs (iMSCPs) with regular MSCPs and No day care support and found promising results for use of iMCSPs. The iMSCPs incorporate three interventions within existing MSCPs for people with dementia and their carers:

- DemenTalent: a volunteer project [that] meets the needs of people with dementia for autonomy, being useful by contributing to society as a volunteer and to maintain dignity. Practice shows that people [with dementia] feel they have value again and that this promotes social participation and more independent functioning. The project also contributes to a more positive image of dementia and counters stigmatization (p. 14).
- Dementelcoach: offers informal caregivers tailored telephone support for the problems they experience as caregivers, in which a great deal of attention is paid to the burden experienced by caregivers and methods for reducing stress and transgressive behavior toward the person with dementia. (p. 14).
- STAR e-Learning: a course recently developed in a European project and accessible via the Internet (www. startraining.eu). The course consists of 8 modules for informal caregivers and volunteers (in addition to 6 advanced modules for professional caregivers) and is aimed at increasing their knowledge and skills in order to provide the person with dementia with person-oriented care, to deal with behavioral changes, to prevent or decrease neuropsychiatric problems, and to take good care of themselves as caregiver (p. 14).

3.4.2 Eden Principles

There are 10 Eden Principles, which collectively espouse creating and maintaining environments that promote 'antidotes' to loneliness, helplessness, and boredom. The 'antidotes' include:

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- companionship
- having an opportunity to give as well as receive, and
- having meaningful activity.

Applications of the principles at Hawthorn House in Albany, Western Australia, the first Australian day care respite setting to achieve full registration by Eden, include:

- having resident animals (dog, canaries, chickens) for attendees to interact with and care for
- encouragement of attendees to assist with food preparation and washing-up
- a weekly playgroup for pre-school aged children
- a weekly mother and baby group, and
- inclusion of family members and carers of attendees.

Downes (2013)

3.4.3 Montessori

Montessori-based approaches used and studied in residential aged care facilities have been associated with some positive outcomes (increased client engagement and ability to perform activities of daily living, and decreased behaviours of concern), and are now being implemented in centre-based respite. The principal tenet of Montessori-based approaches is "to foster independence and encourages the client and all involved to collaborate in establishing meaningful roles for the individual in his or her community" (Hanna et al., 2018; p. 25). Allen (2017, p. 27) describes how to successfully implement activities using a Montessori-based approach:

- Create meaning and purpose through knowledge of the individual's life story
- Match the individual's strengths and abilities to activities and roles
- Offer choice
- Talk less and demonstrate activities more
- Create routine and use repetition
- Create supportive environments
- Take the activities from simple to more complex
- Ensure activities are error free
- Honour the person by inviting them to participate in an activity and, on completion, ask if they enjoyed it and would like to do it again at another time.

3.4.4 Farm-Based Day Care / Nature-Based Day Care / Animal Assisted Therapy

Day respite care that offers clients an opportunity to be in nature or to interact with animals has been the focus of research in Norway, the Netherlands, and Japan. Farm-based/nature-based day care is offered in some European countries. In Norway, this provision of day care aligns with the following municipal obligation: "By 2020, all Norwegian municipalities will be obliged to offer day care to people with dementia" (Ibsen et al. 2019, p. 350). A manual has been written about delivering farm-based day-care in Norway (English title is Care farming – Day care services designed for people with dementia. National Manual) (Strandli et al., 2016). Ibsen et al. (2019) conducted interviews with service providers of farm-based day care (FDC) in Norway. The providers reported they offer a range of activities that can be individually tailored to each client.

Hassink et al. (2019) conducted interviews with providers of urban nature-based adult day services (ADS) in the Netherlands, and identified five types of urban nature-based ADS:

1. Social entrepreneurs offering nature based ADSs, either by
    a. Using their own facilities
    b. Participating in existing facilities (e.g., city farm, city garden, park);
2. Nursing homes opening their gardens to people with dementia living at home;

3. Social care organization setting up nature-based activities (e.g. green maintenance, walks in green environments, visit to a children's farm or city farm);
4. Community garden set up by citizens;
5. Hybrid initiatives: Care organizations initiating nature based ADSs together with other actors:
    a. Either other institutional partners
    b. Or social entrepreneurs (p. 4)

In Japan, animal assisted therapy has been evaluated for its impact on people with dementia attending a day respite centre (Kanamori et al., 2001). The clients chosen for the research had pets at their home (five had dogs, two had cats). Outcomes were assessed quantitively and suggested some improvement in 'problem behaviour' (as measured on a standardised questionnaire) and some decrease in a salivary stress marker after the 6-week therapy at the day centre.

3.4.5 Host Home Program

At the Alzheimer's Association National Conference in Sydney in 2005, Sue Leake presented outcomes of what she coined 'Australia's first ethnographic host-home program' and described as 'family day care'. The program was developed through partnerships between Commonwealth Carer Respite Centre Southern Metropolitan Region, the Flexible Respite Program, and Fronditha Care. Features of the model include respite is offered in the carer's home rather than in a centre, clientele are people with dementia, up to six clients can attend at a time, respite periods can be up to 6 hours. The program described by Leake (2005) was for people of Greek origin. Hosts were selected carefully, because they needed to be bilingual (English and Greek) and able to provide food and activities that would appeal to clients of Greek origin.

The host home program was also implemented by the Brotherhood of St Laurence at the Banksia Centre in Frankston, Victoria (Holm & Ziguras; 2003), with funding from the Commonwealth Department of Health and Aged Care. Positive outcomes of the program were that it "provided an accessible respite option for those unable to use centre-based services [and] it enabled more individually tailored activities, greater socialisation and greater attention from staff than possible in centre-based services." (p.1).

3.4.6 Exercise

Some studies have incorporated physical activity into day respite centres. Clark et al. (2008) reported an initiative called the Seniors' Games that has been run in Queensland since 1995. The participants in the Seniors' Games are aged, on average, 85 years old and are attendees of day respite centres in South East Queensland. To encourage inclusivity, participants who choose to not participate in physical activity on the day can design banners and team flags. In addition to promoting physical wellbeing and self-esteem among participants, the Seniors' Games are also seen as offering intergenerational benefits to the older participants and younger organisers.

Interested attendees of a Blue Care day respite centre in Queensland participated in a program of weight-bearing exercises that was run over 20 weeks (Henwood et al., 2013). Only physical benefits to the participants were assessed; however, the study findings indicated that day respite centre staff taught by an exercise physiologist can be trained to confidently deliver exercise programs independently.

3.4.7 PALZ – Professionals with Alzheimers initiative (Australia)

Individuals with dementia who have worked in high-powered positions often lose the mental stimulation of their workplace as well as their social network, which may contain likeminded individuals from their workplace. An initiative called PALZ—Professionals with Alzheimer's

(http://palzglobal.org.au/) has been rolled out in Australia and the UK to ease loss of identity and dignity that former professionals may experience following their diagnosis. PALZ is a non-profit organisation that offers:

1) interactive bimonthly corporate-style presentations run by professionals where attendees are encouraged to participate,
2) industry-based meetings (e.g., for teachers, accountants, lawyers) to discuss topics relevant to their industry, and
3) an annual conference.

The organisation "provides an environment that fosters that mental stimulation, but further, is able to do so whilst ensuring the social focus is on the 'Who I am' not the 'What I have'." (Roth, 2017).

This literature scan identified programs that have been developed specifically for centre-based day respite and that are exploring different models, approaches and partnerships, both in Australia and overseas. The literature scan also identified a growing body of high-quality evidence-based research about centre-based respite; and noted protocols of planned literature reviews or studies that are likely to be of relevance when completed and published.

A reference list of 65 sourced articles and three protocols of planned literature reviews or studies are included in Attachment C.

3.5 POLICY ENVIRONMENT SCAN

3.5.1 Policy Reports

ACFA Report on respite for aged care recipients Oct 2018 [3]

The Minister for Senior Australians and Aged Care, the Hon Ken Wyatt AM, MP requested that ACFA undertake a study of respite care, including its use and the appropriateness of current arrangements and funding structures. The ACFA Report supports the status quo in terms of how CHSP respite services are offered. Recommendation #18 (on page 40) states: 'ACFA does not consider there is a need for any major changes to how CHSP respite services are offered, noting they continue to provide a useful mixture of support services (such as the Commonwealth Respite and Carelink Centres) and direct respite assistance. Fee issues should be considered as part of broader consideration of how fees should operate, including integrating fees between CHSP and home care.' This is a useful policy document in terms of fee structure issues, including individualised funding vs block funding for centre-based respite.

Royal Commission into Aged Care Quality and Safety, Interim Report (October 2019) [4]

The amending Letters Patent extended the date for delivery of the Final Report until 12 November 2020. The Interim Report notes on p.16 that the extension of time gives it the chance to inquire further into a range of matters, including respite care. (Note that references to respite care are interspersed throughout the Interim Report; however, it does not contain policy prescriptions for respite care.)

Royal Commission Background Paper Number 6 *Carers of Older Australians* (July 2019) [5]

This paper provides an overview of the role of carers in supporting older people, the impact of caring and carer needs, and the available supports and services. It was prepared by staff of the Office of the Royal Commission into Aged Care Quality and Safety, but it does not represent the Royal Commission's position or direction. The Background Paper does not contain policy suggestions; however, it does highlight issues related to carers' reduced health and wellbeing, and financial difficulties.

The Australian Department of Health Wellness and Reablement Report Outcomes (2018) [6]

'The introduction of the annual report on wellness and reablement approaches to service delivery is designed to assist the department to better understand how wellness approaches to service delivery are being implemented by individual CHSP service providers and whether there are any specific gaps in understanding.'

This Report notes, on p.7, that there are trials of a 'reablement focussed assessment model' around Australia in 2019.

The Report highlights some barriers and challenges to implementing a wellness and reablement approach across organisations. Of particular relevance to this project is client's, carer's and family's lack of understanding of wellness and reablement (see page 5).

The next annual wellness report was due by 31 October 2019. This report was not available at the time of preparing this document.

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[3] https://agedcare.health.gov.au/acfas-report-on-respite-for-aged-care-recipients Accessed 20.11.2019

[4] https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf Accessed 19.11.2019

[5] https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-6.pdf Accessed 19.11.2019

[6] https://agedcare.health.gov.au/sites/default/files/documents/07_2019/outcomes-for-the-wellness-and-reablement-report-v3.pdf Accessed 20.11.2019

UNSW Social Policy Research Centre 2016 report – *Transitioning Australian Respite*.[7]
This report examined the costs, benefits and impacts of the transition to consumer-directed care (CDC) markets for respite outputs and outcomes. The focus is on the major reform processes of the National Disability Insurance Scheme (NDIS) and the Commonwealth Home Support Program (CHSP). The report concludes that policy changes in other countries that recognise the needs of carers 'in their own right' are not currently evident in the Australian Government policy frameworks of the NDIS or CHSP.
Without such recognition, it warns, the benefits of support which aims to achieve respite effects for both participants and carers may be lost. (Note that p.43 has comments on block vs individualised funding.)
Some of the issues that this report raised seem to have been addressed by the establishment of the Carers Gateway and the recently announced Integrated Carer Support Service model.

3.5.2 Key Opportunities for Informing Policy and Program Development

The following list might not be comprehensive and due to the limited timeframe, has not been further informed by other key policy stakeholders. It does however include some upcoming changes in the system that directly relate to this service type.

- CHSP contract negotiations for 2020 – 2022: early 2020 for service providers and BNPHN
- Reablement trials in progress: BNPHN RAS and CHSP Consortium leads are involved in discussions; consideration/inclusion of centre and group-based service type activities and outcomes
- Royal Commission into Aged Care: submissions until 30 April 2020
- New Single Assessment Agency: the tender process will occur in 2020 and the new arrangements will commence April 2021
- New Carers Gateway Regional Delivery Partners with increased funding and focus on carer support: commence 1 April 2020
- Expedited access to online referrals for some services by GPs and by clients and their representative
- Discussions regarding future of CHSP and Home Care Packages (care at home programs)

Communication of the outcomes and impact achieved through centre-based day respite and group social support is essential as we approach decisions of a new single assessment model and agencies, and discussions in terms of possible integration of CHSP and Home Care Packages in the future. The benefit of group programs which connect people with the community cannot be underestimated; nor the cost-benefit ignored.

[7] https://pdfs.semanticscholar.org/a2db/7da7279bc76a30fabdb37c12f6f525114d73.pdf?_ga=2.28031033.445765580.1576467005-2144338575.1576467005 Accessed 27.11.2019

4.0 DISCUSSION

The longer-term objective of developing a shared vison for the future and an outcomes measurement framework relevant for centre-based respite and social support groups guided the inquiry in this exploratory stage of the project. In the service provider consultations, it was clearly evident that a number of outcomes are achieved for the client and the carer, as well as the broader community and the health and aged care systems. These outcomes are in some instances captured and reported upwards within an organisation and highlighted in organisational reporting structures such as annual reports and social media. However, it is unclear how effectively these outcomes are being reported through Funded Agreements and other aged care system consultations and reviews. In addition, it was evident that assessors and the community in general (which includes potential clients, carers and their networks) are not aware of the programs and benefits available through these activities.

Consultations with healthy@home consortium providers and a scan of the literature identified similar themes and approaches emerging in responding to social isolation and carer respite. Providers did not generally refer to specific models however aspects of their approaches and programs reflected key models in the literature, such as the Meeting Centres Support Program model in Europe, and the Eden and Montesorri approaches. Integrating nature and animals into programs was also evident in the literature and for some of the services.

The growing need for more targeted approaches for supporting people living with dementia was evident in the literature and in the consultations, as was the need for ongoing dementia training for staff and volunteers. In addition, the need for more proactively and deliberately supporting the carers of clients with intensive support needs was named and some organisations are looking at how they might do this in the future. Given the growing need for and focus on engaging with and providing suitable environments for people living with dementia, a number of articles have also been sourced through the literature scan to inform this work.

In addition to person and carer outcomes, many centres have partnerships or arrangements with kindergartens, primary schools, secondary schools, and particular community, leadership and workforce development programs. The centre-based activity type provides a safe community gathering or meeting place for people of different ages and abilities to come together and learn and share from each other. The engagement of young people and trainees in this way has the potential to make a significant impact on actively addressing ageism and diminishing discrimination, as these young people will be the decision makers, the aged and health care workforce, and the family members and carers of the future.

Healthy@home consortium centre-based day respite and group social support services are having impact across a range of areas, not only increasing quality of life and quality of care for the person receiving the service. The current reporting structure might not fully capture the value for money and cost-benefit to the community and health services as well as the aged care system in terms of reduction in more intensive and costly care which this service type is potentially averting. The need and value of this type of care and its cost effectiveness is even more important now as the number of people living with dementia increases and the preference and opportunity for people to remain living at home is supported.

5.0 CONCLUSION AND RECOMMENDATIONS

5.1 CONCLUSION

The centre-based day respite activity type provides opportunity for service providers to design a creative and tailored response for people who are socially isolated and/or dependent on their informal carer for support. A range of models and approaches were demonstrated through the consultations and identified in the literature which place the person requiring support at the centre of the care, with meaningful activities and relationships, and demonstrable health and wellbeing benefits and outcomes for both the client and the carer.

The 'centre' is also a meeting or gathering place through which a range of people's needs are being met, beyond the direct consumer and carer outcomes. These places and spaces provide a connecting point through which a person's role and contribution in the community can be tapped and for others to join, learn and share. This was evidenced through intergenerational relationships and activities as well as the involvement of volunteers, students and trainees in centre and group life.

The cost-benefit of this type of group service activity would seem to be significant in terms of individual and system outlays. The investment by the organisations involved however is also potentially a key element to the current success of this activity type. The services involved in the consultations are all supported by large long-established backbone organisations. Interviewees all raised the issue of ongoing infrastructure and operational costs; and the various ways their organisations currently or have previously subsidised, provided or partnered to cover those costs. The changing environment and increasing need to adapt, particularly in terms of responding to increasing support needs of people living with dementia, is of concern for existing large organisations, who are also concerned for how smaller organisations are or will manage.

The introduction of My Aged Care has also had a dramatic impact on service providers, with a dramatic drop in referrals through the system. Lack of knowledge and understanding of the group service activity types by the contact centre, assessors and the community in general appear to be a key reason for this major issue. In addition however, the physical and social supports that need to be considered and included in encouraging and supporting a person who is currently socially isolated or who has become heavily dependent on their carer are key matters that need to be built in to the referral. New referrals for those most in need – particularly those who are not already in the system or within the organisation's network - take time, patience, relationships and knowledge.

The role of Centre-based activities is unique in our community and within the aged care system. The way in which organisations deliver the Centre-based respite and group social support activity types results in significant outcomes not only for the person and their carer. These centres also demonstrate outcomes in terms of training and influencing attitudes of the future health and aged care workforce, in being a safe place for the community to seek information and support, and in optimising community assets and linkages. Major matters relating to infrastructure costs, referrals, and knowledge and understanding of these service types however requires consideration; as well as an understanding of the changing demographics, needs and preferences of people who could most benefit from this type of support in the future.

5.2 RECOMMENDATIONS

The following recommendations are formed as a result of an analysis of the current situation as identified through this Stage 1 project and report; and with the objectives identified by Brisbane North PHN in its vision for Centre-based day respite in the Brisbane North region.

1. Conduct a participatory inclusive engagement activity with community members to identify current and future needs and ideas, with particular attention to 'hidden' cohorts and newly emerging target groups.

2. Showcase and share current models, activities and outcomes being delivered in the Brisbane North region and possibly further afield. Ensure community, assessment workforce, and key policy and program decision makers are involved in addition to service providers.

3. Collectively develop a shared vision of the future as an outcome of engagement, collaboration and communication activities undertaken above.

4. Collectively identify shared outcome measures and a framework that enables the cost-benefit of this service type to be demonstrated and continuously improved.

5. Inform and influence key system, policy and program decisions through collective and evidence-based information sharing and reporting.

ATTACHMENT A: Consultation Participants

Healthy@Home Consortium: Consultation Participants

November to December 2019

Organisation	Name	Position
CoAsIt	Dina Ranieri	Chief Executive Officer
Centacare	Desley Chorlton	Area General Manager Brisbane North
	Ann Donaghy	Manager Dementia Strategy Centacare Community Services
	Linda Abbott	Service Delivery Manager Northgate
	Sandra Jaynes	Service Delivery Manager Aspley
	Leah Randall	Service Delivery Manager Enoggera
	Helen Long	Operations Manager Moreton Bay
	Felicity Arnold	Service Delivery Manager Woominda (Ningi)
GOC Care	Angela Andronis	Director
Footprints	Jade Cronan-Thompson	Manager Aged Care, Disability & Community Services
	Arthur Hadaway	Social Support Groups Coordinator
Communify	Karen Dare	Chief Executive Officer
	Georgina Holloway	Aged Care Services Manager
	Victoria Judd	Team Leader Paddington Day Respite Centre
Burnie Brae	Vicki Neumann	Community Services Manager
	Wendy Him	Team Leader Day Respite Centre

ATTACHMENT B: Brisbane North Services

Brisbane North Primary Health Network region
Providers of Centre-based Day Respite and Group Social Support services.

The information listed in this table has been derived from a search on My Aged Care using the key centres listed on the BNPHN region map and respective providers websites. Determining which services are actually available would need to be verified with each provider.

Service Name	Centre based Respite	Group Social Support
All About Living Caboolture	Yes	Yes
Alzheimers QLD Gordon Park Multi Service Centre	Yes	Yes
Anglicare Southern Queensland Kilcoy Community Services	yes	yes
BallyCara Home Care Caboolture	Yes	Yes
BallyCara Home Care BrisNorth	Yes	Yes
Burnie Brae	Yes	No
Blue Care Caboolture Community Services	Yes	Yes
Blue Care Redcliffe Community Centre	Yes	Yes
Blue Care Sandgate Community Services	Yes	Yes
Bolton Clarke Caboolture	Yes	Yes
Bribie Respite and Support Services	Yes	Yes
Centacare Aspley	Yes	Yes
Centacare Caboolture, Bribie and Morten Bay Region	Yes	Yes
Centacare Enoggera	Yes	Yes
COASIT Albion	Yes	No
Communify	Yes	
Institute for Urban Indigenous Health Caboolture	Yes	Yes
Nambour and District Care (Range Care)	Yes	Yes
Ozcare Day Respite Centre Clontarf	Yes	Yes
Wesley Mission Balmoral Uniting Community Centre	Yes?	Yes?
Wesley Mission Haden Place (Specialised dementia respite)	Yes	No
Wesley Mission Highland House	Yes	Yes
Wesley Mission Pine Rivers, Aran Hills	Yes	Yes
Wesley Mission Sinnamon Village Jindalee	Not clear	Not clear

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This literature scan identified published protocols of planned literature reviews or studies that are likely to be of relevance to the broader study planned by Brisbane North PHN, when completed and published. These published protocols are:

- Morton, T, Atkinson, T, Brooker, D, Wong, G, Evans, S, Kennard, C (2019) Sustainability of community-based interventions for people affected by dementia: A protocol for the SCI-Dem realist review. BMJ Open 9, e032109.
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