Dementia Needs Analysis Framework to Support Local Service Development

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FOREWORD

We are starting at a relatively low service and support base in relation to dementia care in Ireland. Generic services need to ensure that they are dementia inclusive, responsive to the needs of people living with dementia. While at the same time we also need to develop appropriate and targeted dementia-specific supports.

A recent mapping project which the National Dementia Office (NDO) undertook with the Alzheimer Society of Ireland (2017) shows that dementia services are patchy and uncoordinated in many areas. This must change as our population ages and the number of people living with dementia increases. So too must supports for family carers who provide the main bulk of support to those living with the condition.

The NDO is therefore pleased to present this Dementia Needs Analysis Framework to support dementia service planning and development across the country. We are moving forward with the implementation of the National Dementia Strategy and while work is progressing there is much more to be done. This framework is a mechanism to help us direct time, energy and resources into dementia care that most appropriately meets people's need. The current situation of under-developed supports must certainly change but we also have an opportunity to develop services and supports that are important to people with dementia and their family carers.

Central to the framework is the engagement of people with dementia and their families. Those with the lived experience are an essential key to helping us design systems of care which support people to live as well as possible and a life of their choosing. This type of involvement is being increasing recognised as a critical component of inclusive and outcomes driven services.

This Framework, and it's six step approach, should make dementia service development more responsive and consistent across the country; helping to strengthen our response to dementia and more appropriately meet people's needs.

Sincerely

Dr Emer Begley

Senior Project Manager
National Dementia Office

SIX STEP SUMMARY

STEP 1
Know your Target Audience

- How many people with dementia are living in the region?
- How many people with dementia are aged over and under 65 years?
- Where are the areas that have high numbers of older people?

STEP 2
Know your Available Resources

- What dementia-specific services and supports are available in the region?
- What generic services are available which people with dementia and their families could use?
- What are the other assets in the community which could support wellbeing?

STEP 3
Know the Needs of People Living with Dementia

- Do you know that people with dementia are experts in what their needs are and can help develop and design services?
- What are the best ways to engage people living with dementia?
- Can you adapt ways to facilitate their inclusion, such as running focus groups or carrying out interviews?

STEP 4
Know the Needs of Dementia Family Carers

- Do you know that family carers provide the main bulk of care to people living with dementia and are best placed to tell you what they need?
- How can you know the types of services and supports they need?
- How can you include and consult with family carers to support the design and delivery of services?

STEP 5
Know the Views of Other Key Stakeholders

- Do you know that other service providers have insights into what services and supports are needed in a region?
- How can you engage these key stakeholders such as home care workers, meals on wheels providers, day care workers, health and social care professionals etc.?

STEP 6
Know the Priorities

- Using the above information you can determine priorities

Section 1:
INTRODUCTION

1.1 What is this Dementia Services Needs Analysis Framework?

The overarching principles of personhood and citizenship which underpin the National Dementia Strategy (2014) focus on enabling people with dementia to maintain their identity, resilience and dignity and by recognising that they remain valued, independent citizens who, along with their carers, have the right to be fully included as active citizens in society. Translating these principles into practice requires the refocusing of current service delivery to address the needs of people with dementia and their carers in a way that is responsive and flexible. To achieve this it is necessary to review health and social services for people with dementia. This Needs Analysis Framework is a tool to assist in the collection of information to identify:

☑ The supports and services that are currently in place to support people with dementia and their family carers;

☑ The supports and services that fit with the needs and preferences of people with dementia and their family carers;

☑ Gaps in existing provision;

☑ The key priority areas for action in accordance with resource availability, with priority being given to the most urgent deficits that can be addressed within available resources.

The Framework includes **SIX STEPS:**

1. Know your target audience
2. Know your available resources
3. Know the needs of people with dementia
4. Know the needs of family carers
5. Know the views of other key stakeholders
6. Know the priorities.

Following these steps will enable you to gather all relevant information, manage this information and prioritise areas for action.

PERSONHOOD

Supporting personhood means services:

- Take an individualised approach recognising the uniqueness of each person;
- Listen and respond to develop services;
- Asserts the value of all human life;
- Understand the world from the perspective of the person.

WHO IS THIS NEEDS ANALYSIS FRAMEWORK FOR?

Anyone involved in the planning, design and delivery of services which people with dementia and/or their families/carers might use.

At the end of each step you will find a list of useful resources which will help you in gathering the required information. You can create an Excel Dementia Services Needs Analysis Workbook using the worksheets as your templates. There are six worksheets to manage the collected information. They are included as separate appendices in this document and are:

- **Worksheet 1** – 'Demographics'. Recording of information collected during Step 1.

- **Worksheet 2** – 'Services and Supports Available'. Templates for recording dementia specific services, general health and social care services and community assets collected during Step 2.

- **Worksheet 3** – 'Services and Supports Identified by Stakeholders'. Those are the services and supports identified through engagement with people with dementia at Step 3, family carers at Step 4 and from other key stakeholders at Step 5. The services and supports identified can be recorded as available or unavailable on this worksheet also.

- **Worksheet 4** – 'Review What is Missing with What is in Place'. The review worksheet focuses on the potential of services and supports currently in place to be adapted or reconfigured and the potential to provide any new services.

- **Worksheet 5** - Probability List. Services and Supports that could be developed from current resources.

- **Worksheet 6** – Possibilities List. Services and Supports that require new resources.

1.2 Understanding dementia

WHAT IS DEMENTIA?

Before you start it's important to understand dementia and know how it affects those living with it and those in a caring role. Dementia is an umbrella term which describes a number of conditions that cause changes to the brain. These changes affect the ability of brain cells to communicate with each other. When brain cells cannot communicate normally the ability to remember, plan, use language, find your way around and regulate mood and behaviour may be affected. The most common causes of dementia are:

- Alzheimer's disease

- Vascular dementia

- Mixed dementia (a combination of Alzheimer's disease and vascular pathology in the brain)

- Lewy Body Dementia.

Dementia is not a normal part of ageing. In fact there are over 4,000 people under the age of 65 years living with dementia in Ireland. However the risk of developing dementia does increase with age. It is estimated that dementia affects one in 14 people over 65 and one in six over 80. This may be due to factors associated with ageing such as high blood pressure, heart disease, weakening of the bodies natural repair system and changes in the immune system. Our risk of developing dementia can also be affected by smoking, by a lack of physical activity and by what we eat. So 'What's good for your heart is good for your head'. You can learn more about dementia by following the links to resources at the end of this section.

SIGNS AND SYMPTOMS OF DEMENTIA

It is important to remember that dementia affects everyone differently.
There are a number of common signs and symptoms which include:

- Memory loss, particularly for recent events;
- Problems with language e.g. difficulty finding the right word;
- Changes in mood and behaviour;
- Becoming confused in familiar surroundings or situations;
- Difficulty in following conversations, TV programmes or reading;
- Difficulty managing money and everyday tasks;
- Difficulty solving problems or doing puzzles;
- Loss of interest in hobbies and pastimes;
- Lack of initiative to start something or go somewhere;
- Repeating a question or story several times without realising.

1.3 Why is it important to carry out a dementia services needs analysis?

In 2016, the number of people with dementia was estimated to be 55,266. The majority of whom live in the community and are supported by family members. Approximately 60,000 family carers provide care for people with dementia living in the community in Ireland. The number of people with dementia is expected to grow at an average rate of 3.6% per year. This means that by 2036, the number of people with dementia in the country will have doubled; by 2046, the number will have almost trebled[1].

People with dementia have an equal right to participate and be included in society. However, having dementia can make it more difficult to claim these rights. Legislation and policy now firmly places the rights of people with dementia at the centre of service development and provision. The United Nation's Convention on the Rights of Persons with Disabilities (UN CRPD) outlines how people with disabilities, including people living with dementia, have the right to live independently and be included in the community; the right to liberty and to security of person; to freedom from torture, inhuman or degrading treatment and to legal personhood and to autonomy. It is imperative therefore that we review current services to ensure that they are being used and made available to people with dementia; meeting their requirements and those of their family carers.

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[1]. http://cesrd.ie/wp-content/uploads/2017/12/Developing_and_Implementing_Dementia_Policy_in_Ireland.pdf

The availability of information on the needs of people with dementia and their family carers will enable the development and prioritization of appropriate dementia services and supports informed by people with dementia, family carers and other stakeholders. The availability of a range of person-centred, flexible and responsive services will ensure respect for the will and preferences of people with dementia from diagnosis through to end-of-life, which is a priority action in the National Dementia Strategy.

EXAMPLE 1: GLOUCESTER PARTICIPATION IN DEVELOPMENT OF DEMENTIA CARE

By hearing and responding to the views of people with dementia in the UK, commissioners have developed services that make a difference and offer value for money. In this video Helen Vaughan, Commissioning Development Manager for Dementia Services, Gloucester NHS, speaks about how involving people with dementia and their carers is fundamental to planning and developing services.

https://www.scie.org.uk/dementia/supporting-people-with-dementia/participation-in-development.asp

1.4 What should this Framework be used for?

The framework offers a blueprint for collecting information on what resources are available and what services are required to support people with dementia and their family carers to live with dignity as valued, independent citizens included in their community. This information will not alone provide direction when developing new services and supports but will also highlight existing resources which could be reconfigured or adapted to support and maximize their inclusion. It could also inform national and local operational plans. Make sure to discuss the findings at management meetings and include it on the agenda for discussion at planning meetings.

The framework provides guidance on:

- Carrying out an audit of the assets/resources available to people with dementia in the area;

- Engaging people with dementia in identifying what is important to them and what care and support they need;

- Engaging family carers to identify the services and supports that can address their particular needs;

- Finding out from other stakeholders, including colleagues, community and voluntary organisations about the supports and services they see as important to people with dementia and family carers;

- Identifying and prioritizing the development of services and supports to meet the identified needs.

1.5 How to use the framework

Each region will be starting from a different baseline and have different resources available to carry out the Dementia Services Needs Analysis. You are not expected to undertake all of the tasks outlined in this framework, but to pick, choose and adapt the suggested approaches to fit within your capacity and ways of working.

Undertaking this Dementia Services Needs Analysis offers the potential to make savings as evident in the UK, see example 2 below. Where co-production, which involves people with support needs, family carers and service providers working together to create services, is a key concept in the development of public services. The approach is value driven based on the principle that services do not produce outcomes, people do; so those who use a service are best placed to design it.

> **EXAMPLE 2: NESTA'S PEOPLE POWERED HEALTH PROGRAMME**
> This programme focuses on ways to improve practice in health services, including peer support and co-design/co-delivery with people who use services. Nesta's analysis of the programme shows that where these approaches are used with people with long-term conditions, they deliver savings of approximately 7% due to reduced and shorter hospital admissions and fewer visits to casualty departments. They also argue that these savings would grow to 20% as the different parts of the programme support each other. Details of Nesta's People Powered Health programme can be accessed here: https://www.nesta.org.uk/project/people-powered-health

1.5.1 HOW TO GO ABOUT IT

- Supporting people with dementia to live well in communities is everybody's business, so all stakeholders have a role to play in identifying the resources available to support people with dementia and their families and identify where there is a deficit in available supports.

- However, designated persons or a team will be needed to take overall responsibility for organising the collection of the different pieces of information to give a clear picture of needs. This should ideally be undertaken by a consortium of key personnel, senior management or equivalent. The consortium could fulfill the dual purpose of implementing the framework and creating greater integration of services.

- This Framework should be used as a structure to document findings and conclusions in a systematic way and thus support and guide decision-making on setting priorities. Some of the information may already be available to your organization and not all of the steps will be relevant.

REFLECTION: BEFORE YOU START IT MAY BE HELPFUL TO REFLECT ON THESE QUESTIONS

- How are the voices of people with dementia, their family carers and other stakeholders, including staff working with people with dementia and organisations delivering support to people with dementia, being heard within your organisation?

- How accessible is it for people with dementia to share their ideas, views and opinions on services and supports with those responsible for the provision and development of services?

Be aware that consulting and involving people with dementia and family carers brings with it an expectation that their experiences will be acted on. It is therefore important from the start to manage these expectations by being clear about the purpose of the engagement; being honest about expected outcomes and always giving feedback and letting people know what has happened as a result.

Resources for learning more about dementia

- HSE Understand Together - www.understandtogether.ie

- The Alzheimer Society of Ireland - www.alzheimer.ie

- Dementia Services Information and Development Centre - www.dementia.ie

- Alzheimer Society UK - www.alzheimers.org.uk

Section 2:
THE DEMENTIA SERVICES NEEDS ANALYSIS FRAMEWORK

The framework outlines SIX STEPS to identify the services, at regional and local level, that can support the well-being of people with dementia and family carers. Information gathered using the six steps can be recorded in the different worksheets provided in this document's appendices. Alternatively you may prefer to use your own method of data recording.

2.1 STEP 1: Know your target group

As a first step information about the target group is important for service planning and developing new services and supports. Research has been carried out on the estimated prevalence of dementia and you can find figures pertaining to your area from the Centre for Economic and Social Research on Dementia Report 'Developing and Implementing Dementia Policy in Ireland' (2017: p. 33).

Table 1: Sources of data

In my Region/Locality	Data Sources	Links
• Number of people aged 65 and over • Number of people aged 85 and over	• Census Data (CSO.ie) • County Council Local Economic and Development or Community Plans include demographics relating to the local population.	www.cso.ie/en/census/ www.cso.ie/en/census/census2016reports/census2016smallareapopulationstatistics/
Approximate number of people with dementia by CHO and LHO: • Aged 65 and over • Aged under 65	Centre for Economic and Social Research: 'Developing and Implementing Dementia Policy in Ireland' (2017). See pages 28 and 33.	http://lenus.ie/hse/handle/10147/622755
Gender and living arrangements	• Census Data • County Council Local Economic and Community Plans	See list of local authority websites, click through to search for local plans www.housing.gov.ie/local-government/administration/local-authorities/local-authorities

Where do people 65+ live	• County Council Local Economic and Community Plans • All Island Observatory Data, data mapping resources	http://airo.maynoothuniversity.ie/mapping-resources/airo-research-themes
Areas with a high prevalence of people with dementia	Centre for Economic and Social Research: 'Developing and Implementing Dementia Policy in Ireland' (2017)	http://lenus.ie/hse/handle/10147/622755

This information can be recorded in Worksheet 1 'Demographics' (Appendix One).

2.2 STEP 2: Know your available resources

Whilst there will be deficits in terms of services and supports that can meet the needs of people with dementia and family carers in every region/locality, there will also be resources and assets that can be used to support them to maintain their interests and use their strengths to continue to live as well as possible in their community. When planning dementia services, it is therefore important to know what dementia-specific services and supports are in place, but also what other services and resources in the community are used or have the potential to be used by people with dementia and family carers.

2.2.1 DEMENTIA-SPECIFIC SERVICES

A mapping exercise carried out by the National Dementia Office and the Alzheimer Society of Ireland (2017) identified dementia-specific community-based services and supports across Ireland. Information on dementia services in your area is available on the on-line service finder on http://www.understandtogether.ie/ and the mapping project report is also available on the website. The information you gather can be recorded on Dementia Specific Services template on Worksheet 2, 'Services and Supports Available'. See Appendix Two.

2.2.2 GENERAL HEALTH AND SOCIAL CARE SERVICES

People with dementia access health and social care services that are not dementia-specific such as home care, aids and appliances, primary care services, public health and community nursing, generic day services etc. These services are crucial in keeping people with dementia well, therefore it is important to look at availability and access for people with dementia to these services in your local area. To collect this information:

- Make an inventory of the different health and social care services for adults in your local area. A lot of this information is already mapped on the HSE website. You could combine the information on the dementia-specific services and general services to give a visual representation of where all services are located.

- Arrange to speak with the managers of each of the services to get information on the approximate number of clients who have dementia and criteria for accessing these services. This information could also be gathered as part of the engagement process with stakeholders outlined at STEP 5.

- Having gathered the information note the following beside each service: (i) the approximate number of people with dementia using the services; (ii) if there is a waiting list operating; (iii) if so what are the waiting times and (iv) ease of access as viewed from the perspective of health and social care professionals.

The list of generic health and social services which are available in the locality can be recorded on the general health and social care services template on Worksheet 2 'Services and Supports Available'. See Appendix Two. Different colours can be used to indicate ease of access, for example yes in green indicates easy to access, yes in red indicates waiting list.

2.2.3 COMMUNITY ASSETS

People with dementia, like anyone else, enjoy and are involved in various community activities. Supporting people with dementia to stay connected and to participate in their hobbies and groups maintains their social inclusion.

Community assets are the collective resources which individuals and communities have at their disposal; those which can be leveraged to develop effective solutions to promote social inclusion and improve the health and well-being of citizens. Assets include organisations, associations and individuals.

COMMUNITY ASSETS

These are anything that improves the quality of community life. For people with dementia it can include:
- The capacities and abilities of community members;
- A physical structure or place;
- A business that is dementia inclusive;
- Community Associations and groups;
- Local private, public, and non-profit organizations.

A list of community assets could include libraries, health centres, citizen information services, education centres, leisure centres, family resource centres, Gardai stations, local bus services and GP practices. Businesses such as banks, post offices and shops. Voluntary and community groups such as faith groups, sports clubs, yoga and meditation groups, support groups, residents' association, Men's sheds, craft groups, Active Retirement groups and charities such as Vincent de Paul, Meals on Wheels, Alone, Senior Helpline and Age Action.

Assets also include individuals such as volunteers, families and community leaders, as well as the physical environment such as parks and public buildings.

Knowing about these different assets will give you an idea of the strengths and resources within the community and can help uncover potential resources that can be enhanced to address the identified support needs of people with dementia and family carers.

Collecting information on community assets

- To start, make a list of the different resources in the community that are widely used, for example supermarkets, churches, leisure centres, Citizens Information Services etc. The questions asked in the reflection box below will help you think about community assets.

- Information on organisations providing services and supports to citizens may also be available to you. For example Section 38 organisations, who are funded to provide a defined level of service on behalf of the HSE, and section 39 organisations, who are grant-aided organisations to provide services, usually complete yearly returns on activities and target groups.

- Community directories and County Council Age Friendly directories of services for older people are another good source of information on different resources within a community.

- Local newspapers, parish newsletters and community noticeboards are also sources for this type of information.

EXAMPLE 3: LOCAL ASSET MAPPING PROJECT (LAMP) is a project that mapped the social, public, and health services, sports and fitness centres that promote health in St. James's Hospital catchment area of Dublin. Over time, the range of services has been expanded to include businesses and community groups.

The objective of the programme is to integrate the hospital into the community by using the data to socially prescribe local services and activities to improve health and wellbeing. Social prescribing is where GPs and primary care professionals link people with sources of support and social activities within their community that can enhance their well-being.

A description of LAMP can be accessed from http://www.ehealthireland.ie/Case-Studies-/Local-Asset-Mapping-Project-at-St-James-Hospital/. To see how the programme operates, visit http://locidokey.com/.

The information collected from your community assessment can be recorded on the Community Assets template on Worksheet 2, 'Services and Supports Available'. See Appendix Two.

REFLECTION: ANSWERING THESE QUESTIONS MAY HELP YOU IDENTIFY ASSETS IN YOUR AREA

1. Who are the faith-based and community organisations serving people in the community/region?
2. What services are they providing and are they dementia inclusive?
3. What services are local public bodies providing? Are they dementia inclusive?
4. What organisations are funded by HSE, government agencies and charities for older people, people with disabilities and are these dementia inclusive?
5. What are the various intervention strategies being used in the community to support people with dementia and family carers?
6. Who in the HSE, local government and the community are involved with local dementia service development?
7. What local volunteer groups serve the community, are they dementia inclusive?
8. What community organisations are involved in supporting people with dementia and family carers?

Approaches to identifying community assets are outlined in the guide Conducting a Community Assessment which can be accessed from http://strengtheningnonprofits.org/resources/guidebooks/Community_Assessment.pdf

To gain a better understanding of the services being provided by different groups and to determine whether they are dementia inclusive may mean contacting those involved in organising the different group(s) or those who provide services. You may find it helpful to send a short questionnaire to all groups and organisations identified to get this information or by speaking directly to those involved by phone or arranging to meet (see survey tools, STEP 4 and 5 resources). Information on community assets that are important to people with dementia and family carers can be collected as part of STEP 3.
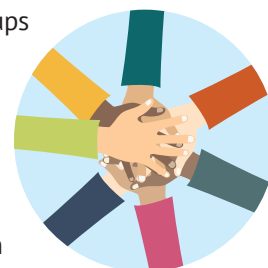
Resources that may be useful for undertaking Step 2

- Conducting a Community Assessment
  www.strengtheningnonprofits.org/resources/e-learning/online/communityassessment/default.aspx?chp=0

- Asset Based Mapping
  www.assetbasedconsulting.net/uploads/publications/A%20glass%20half%20full.pdf

- Co-producing services using community assets - 'We're Here Too'
  http://otbds.org/wp-content/uploads/2016/07/Were-Here-Too-Report-2015-and-16.pdf

- Building Community Based Supports with Older People
  www.otbds.org/wp-content/uploads/2016/07/buildingcommunitybasedsupportwitholderpeople23.pdf

2.3 STEP 3: Know the needs of people with dementia

People with dementia are in a unique position to share what it is like to live with dementia; they are experts by experience. Listening and learning from people with dementia ensures resources are appropriate and can be used effectively to enable them to live as well as possible in their community. The best way to find out what people with dementia want and need is to connect with them and ask.

REFLECTION: OPEN QUESTIONS ARE USEFUL IN HELPING PEOPLE WITH DEMENTIA TO THINK ABOUT SUPPORTS FOR EXAMPLE:

- In your life, what are the activities that are important for you to do?
- What helps you to do these things?
- What makes it more difficult for you to do these things?
- Are there things that you used to do, but have stopped doing?
- If so, why have you stopped doing them?
- What might help you to start doing them again?

An example of a questionnaire using open questions is available from the Dementia Friendly Hampshire guide. Finding out what a 'dementia-friendly community' means to people with dementia, (page 18) and can be accessed at

http://www3.hants.gov.uk/2012-dementia-friendly-communities-toolkit-engagement.pdf

A person with advanced dementia may find it more difficult to communicate with speech. However, this does not mean that they cannot express their views and preferences in other ways. Non-verbal communication, such as gestures, touch and facial expression, accounts for 90% of all communication. There are different ways your organisation can engage with people with dementia to find out what supports and services they require as shown below.

2.3.1 TALKING TO PEOPLE WITH DEMENTIA ONE-TO-ONE

One-to-one conversations are useful for exploring the views and attitudes of the person living with dementia. Having these conversations enables greater insight into the lived experience. Opportunities for engagement on a one-to-one basis can take place as:

- Part of routine interactions between health and social care professionals and the person with dementia, for example through a home visit by the community public health nurse, dementia advisor, GP, home help, OT assessment and/or a visit with the pharmacist. These intermediaries routinely interact with people with dementia as part of their work.

- Set-up interviews with people with dementia to collect their views on services and supports.

Engagement through Conversation

- Think about who are the key Health and Social Care Intermediaries locally who interact regularly with people with dementia, e.g. GPs, PHNs, Home Helps, Pharmacists etc.

- Seek buy-in from the key intermediaries by focusing on how working together in this process can bring more effective outcomes for the wellbeing of people with dementia.

- A number of HSE initiatives such as 'What Matters to You' and 'Make Every Contact Count' could be adapted to be used in the community when engaging with people with dementia. For example health and social care workers in the community could ask people with dementia what is important to them when taking medical history or discussing support needs. As part of the 'Make Every Contact Count' people with dementia could be asked about things they need to support them to live as well as possible with dementia.

- The information on types of supports identified are documented and shared with the designated person/persons.

COMMUNICATION

Communication is the basis of engagement.
- People with dementia may experience difficulties with communication.
- Harness the expertise within the HSE and other stakeholder organisations to build effective communication skills among key intermediaries, for example from Speech and Language Therapy, Occupational Therapy, Dementia Nurse Specialist.
- See links to communication resources at end of STEP 3.

EXAMPLE 4: CONSULTING THROUGH CONVERSATION

- 'What Matters to You' is a HSE quality improvement initiative with the aim of enhancing person-centred care in acute hospitals in Ireland. Instead of just focusing on the physical status of the patient, hospital staff ask what is important to each patient when taking their medical history. A summary of the 'What Matters to You' initiative can be found here: https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/%E2%80%9Cwhat-matters-to-you%E2%80%9D-enhancing-compassionate-person-centered-care-.pdf

- 'Make Every Contact Count' is a HSE Health and Wellbeing programme where health professionals, using their routine consultations have short focused conversations with people about their lifestyle risk factors, highlighting healthier choices and supporting them to make these choices to achieve positive health outcomes. Details of the programme can be accessed from https://www.hse.ie/eng/about/who/healthwellbeing/making-every-contact-count/making-every-contact-count-framework.pdf

Using One-to-One interviews to get the views of people with dementia

There are various settings where people with dementia meet, for example social clubs and Alzheimer Café's. People with dementia attending these settings could be approached and asked if they would like to take part in a short interview looking at the different services and supports they use and those they would like to avail of. This approach requires;

- A facilitator with some skills in interviewing and communicating with people with dementia. The stakeholders responsible for running the clubs or café may have these skills and may be willing to support the process.

- The provision of clear information in an accessible format on the purpose of the interview.

- That consent is informed – this means that the person understands the nature of what they are engaging in and can withdraw from the interview at any time.

- Consideration and assurance around confidentiality.

- The interview guide consists of short questions. Discussions could be supported with visual aids for example each question written on separate sheets of paper, pictures or 'talking mats', may be helpful where the person has a more advanced dementia (see link to DEEP and other resources at end of STEP 3).

MAKING ENGAGEMENT ACCESSIBLE

The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. They have produced a number of guides including
- A Guide to Collecting the Views of People with Dementia
- A Guide to Writing Dementia- Friendly Information
See the list of resources at the bottom of this section for more information on these guides.
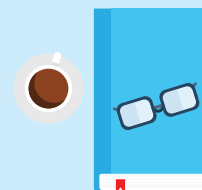
2.3.2 TALKING TO PEOPLE WITH DEMENTIA IN A GROUP

Group discussions or focus groups can be particularly useful for exploring views and attitudes on broad subject areas. The number of people in a focus group can range from 2 to 10, depending on the individual's support needs.

People with dementia involved in existing networks, such as social clubs, support groups and Alzheimer Café's, could be invited to take part in a discussion group focused on dementia services and supports. Similar to the one-to-one interview, this approach requires:

- Visiting the group at an earlier meeting to introduce yourself and the discussion topic.

- The provision beforehand of clear, straightforward information about the purpose of the group meeting.

- A facilitator with some skills in interviewing and communicating with people with dementia such as HSE colleagues or the stakeholders responsible for the group activities.

- The use of visual aids where possible to help people connect with the discussion topic. Voting cards with 'yes' or 'no' (or thumbs up, thumbs down) can be useful to gauge opinion of a particular service; providing opportunities for people to talk about services in an indirect way, for example speculating on how another person is experiencing the service.

- Simple short questions to guide the discussion; taking it slowly, being careful not to overwhelm people with too much information.

- A process for providing feedback on the findings is outlined.

EXAMPLE 5: THE IRISH DEMENTIA WORKING GROUP

People with dementia came together to form the Irish Dementia Working Group with support from the Alzheimer Society of Ireland. The group engaged as a key stakeholder to inform the development of the National Dementia Strategy. Among other things they have also been involved in drafting guidelines to inform design to make homes more accessible for people living with dementia. Details of the aims of the group and the activities they have been involved in can be found here:

http://dementiavoices.org.uk/group/irish-dementia-working-group/

To facilitate people with dementia in local areas to participate in formal discussions about the delivery and development of services on an on-going basis, consideration could be given to setting up a Service User Reference Group. This approach requires:

- Identifying people with dementia in local areas interested in joining the User Group. Support and social groups already established in an area, may have members who would be interested in joining.

- Staff or volunteers to support the group.

- Making the processes accessible to people with dementia. See link to DEEP Guide Involving People with Dementia as members of steering/ advisory groups at the end of STEP 3.

EXAMPLE 6: LIVERPOOL SERVICE USERS REFERENCE GROUP (SURF)

This is a group of people who represent the views of people living with dementia, their carers and families across the City of Liverpool with the aim of improving services and care; providing a voice for people with dementia; influencing decision-making. Actions taken by the group include supporting Liverpool City Council in reviewing respite services; developing information resources for people with dementia at GP Practice level; advising on the development of Liverpool Council Housing Strategy. For details of the group see https://surfdementia.org/

**EXAMPLE 7: SHEFFIELD DEMENTIA INVOLVEMENT GROUP (SHINDIG)**

SHINDIG is a city wide forum that meets four times a year. The group is jointly organised by Sheffield Alzheimer's Society and Sheffield Health and Social Care NHS Foundation Trust. Staff help facilitate small group discussions among people with dementia; family carers or a mixed group of people with dementia and carers who prefer to work together. Details of SHINDIG and their activities as outlined in their annual reports can be accessed on this website:

https://shsc.nhs.uk/about-us/get-involved/sheffield-dementia-involvement-group-shindig/

Other less structured approaches to collecting the views of people with dementia include providing a forum, a couple of times a year, where people with dementia living in the locality (and their family carers) can come to share ideas, views and opinions on local services and developments.

2.3.3 ASKING PEOPLE TO COMPLETE A QUESTIONNAIRE

A survey could be used to collect the views of people with dementia on current services and supports; establish if currently available services are fit for purpose and identify supports and services people with dementia may need. However, this approach is unlikely to provide a deep or indepth insight into experiences. The paper survey can be distributed through established networks or posted out to people. A link to an on-line version (for example using SurveyMonkey see link after STEP 5) could be included in local newsletters. A survey approach to collecting the views of people with dementia gives time to think about responses and can be completed over a couple of days. They also preserve anonymity. However, difficulties may arise in getting completed surveys returned. A survey approach requires:
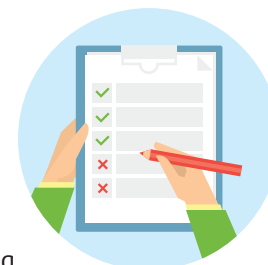
- Clear and precise introduction to what the survey is about, e.g. a frequently asked questions format can work well.

- Questions are set out under themed headings.

- Questions are short and unambiguous, use large and plain font.

- There is an opportunity to add comments.

- Clear instructions on where to return completed questionnaires.

- Information on where to get the results of the survey are provided.

EXAMPLE 8: DEMENTIA ACTION ALLIANCE SURVEY FOR PEOPLE WITH DEMENTIA

To mark the fourth year of the National Dementia Declaration, Dementia Action Alliance (DAA) conducted a survey to find out how the UK is doing in improving the lives of people with dementia and those that care for them. The survey is quite long but the lay-out is useful, and is available at: https://www.dementiaaction.org.uk/assets/0001/0975/ Survey_for_people_affected_by_dementia.pdf

2.3.4 ADVANTAGES AND DISADVANTAGES OF THE DIFFERENT METHODS

Engaging people with dementia on a one-to-one basis can provide a person-centred approach that is more likely to meet their specific needs. For example, it provides an opportunity to use different communication aids, particularly important when the person has more advanced dementia. However, group discussions, particularly where the group knows each other, can generate insight into issues that might not be divulged in a one-to-one situation.

2.3.5 REVIEWING THE INFORMATION COLLECTED

After completing this Step you have engaged with people with dementia and listened to what they have said. Some of the supports identified may seem unrelated to traditional health and social care service provision and you might not consider including these. However, it is really important that all identified supports and services are noted and can be recorded on Worksheet 3, 'Services and Supports Identified by Stakeholders'. See Appendix Three.

REFLECTION: ETHICAL ISSUES TO CONSIDER WHEN ENGAGING PEOPLE WITH DEMENTIA

These issues include:

- Talk to the person with dementia, not through a third party;
- Ensure that people understand the nature of the processes they are engaging with and have all the information needed to participate;
- Ensure the person has given informed consent to participate;
- Ensure that people can express their views freely without fear or risk of any adverse response relating to service provision;
- Maintain confidentiality and protection of individual identities in any reports;
- The process is not tokenistic and the information gathered will be used for service planning and influence decision-making;
- You appropriately manage people's expectations and provide feedback where they have engaged in the needs analysis.

Resources that may be useful in supporting you to undertake STEP 3

Engaging people with dementia

- Strengthening the Involvement of People with Dementia A Resource for Implementation
  https://dementiapartnerships.com/wp-content/uploads/sites/2/strengthening-involvement.pdf
  https://dementiapartnerships.com/wp-content/uploads/sites/2/strengthening-involvement-supplement.pdf

- Dementia 2020 Engagement Programme
  https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/564973/Dementia_toolkit.pdf

- Meaningful Engagement of People with Dementia, Alzheimer UK
  http://www.alzheimer.ca/sites/default/files/files/national/meaningful-engagement/meaningful_engagement_e.pdf

- Dementia without Walls – reflections from people with dementia on how people with dementia have been involved
  https://www.jrf.org.uk/file/48408/download?token=z6PfoN3e&filetype=summary

Communication

- 'Talk to Me' leaflet
  https://www.dementia.org.au/sites/default/files/TalkToMe_Brochure_FoldedDL_HR.pdf

- Enhancing Communication – Murray Alzheimer Research and Education Programme
  https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides/enhancing-communication/introduction

- The Alzheimer Society of Ireland has a useful communication guide
  https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Fundraising/Camino/2014/Dementia-Friendly-Language-Final-for-Web-Aug-15_2.pdf

Dementia Empowerment and Engagement Project (DEEP) Resources

- Guide to Writing Dementia Friendly Information
  http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf

- Guide to Collecting the Views of People with Dementia
  http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf

- Involving people with dementia in an advisory or steering group
  http://dementiavoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf

- Including People with Dementia in Service Design
  https://www.genio.ie/system/files/publications/GENIO_DEMENTIA_INCLUSION_SERVICE_DESIGN.pdf

2.4 STEP 4: Know the needs of dementia family carers

In Ireland, the vast majority of people with dementia are primarily cared for by a family member. Engaging family carers in identifying the services and supports that can address their particular needs is essential if family carers are to provide care. The approaches for collecting the views of people with dementia as outlined above can also be used to get input from family carers.

Family carers often accompany the person with dementia to social groups and/or Alzheimer Café's. Discussion groups could include people with dementia and family carers, however bear in mind that the views of a relative or friend, no matter how caring, can be subjective rather than objective. To ensure people with dementia and family carers get an opportunity to articulate their own perspective, consider running a session for each group simultaneously. Information on services and supports from a family carer's perspective can be collected using questions like:

- What services do carers access most?

- What services are carers currently using?

- What services have they used in the past 2 years?

- What do they need to support the person with dementia they care for?

- What services do they need to support them in their caring role?

- What services would they like to see developed?

Information gathered can be recorded on Worksheet 3, 'Services and Supports Identified by Stakeholders'. See Appendix Three.

EXAMPLE 9: ONTARIO DEMENTIA CAREGIVER NEEDS PROJECT

This was a large multi-phased project focused on identifying the needs of community-based carers of persons with dementia, examining the extent to which community health and social support services were meeting their needs. The 'In their own Voice' project used a survey of caregivers of people with dementia to develop a profile of caregivers including assistance provided, perception and use of formal community support services and informal social resources. The project used focus groups to identify the issues and concerns of carers. The outcome of the project was the Dementia Supportive Environment Framework - an alternative model of dementia care developed by and for carers of people with dementia supported by care providers, planners and policy makers. For more information see: https://uwaterloo.ca/murray-alzheimer-research-and-education-program/sites/ca.murray-alzheimer-research-and-education-program/files/uploads/files/InTheirOwnVoices1-SurveyResults.pdf

2.5 STEP 5: Know the Views of Other Key Stakeholders

2.5.1 HEALTH AND SOCIAL CARE PROFESSIONALS

ASK FOR HELP

To assist in gathering information, enlist the help of a representative from each of the professional groupings within your organisation e.g. Nursing, OT, Speech and Language, home care workers etc. This can promote interest and engagement in the needs analysis process.

Health and social care professionals connect with people with dementia and family carers on a daily basis, building relationships with them. These professionals have a depth of knowledge about the person, their story and experiences of how current services and supports are meeting needs and where there are support deficits. A number of approaches can be taken to collect this information:

- Organise a lunchtime chat table in the coffee room inviting colleagues to take part, outlining the topic you wish to explore. Using a roundtable discussion approach, begin by asking colleagues to share a time when they were able to offer/provide support to a person with dementia that helped the person do something that was important to them (focus is on 'high point' stories). After everyone has an opportunity to contribute their story, ask 'what if we had unlimited resources, what services and supports would make a difference to people with dementia you meet to enable them to continue doing things that are important to them'.

- Draft a short on-line questionnaire and distribute to colleagues, seeking feedback on how current services and supports are meeting the needs of people with dementia; their views on the types of services and supports their clients want and what service and supports should be developed.

- Designate a 'What People with Dementia Need for their Well-Being' month, asking colleagues, who interact with people with dementia as part of their work, to participate by taking a note of supports and services identified by people with dementia and family carers that are important to their well-being. For example, the Public Health Nurse notes any requests for supports and services identified by persons with dementia and family members as important to their wellbeing that could not be accommodated. Provide participating colleagues with a special notebook or on-line folder where they can log these observations.

- The 'What Matters to You' and the 'Make Every Contact Count' initiatives could also be used on and on-going basis to gather information on supports and services people with dementia and family carers need.

2.5.2 OTHER STAKEHOLDERS

Consulting with other stakeholders such as home help providers, home care coordinators, Meals on Wheels, voluntary groups running social clubs and support groups for people with dementia and carers will also provide an insight into how current services are meeting need. Other stakeholders can also point to ways of adapting or developing services to address gaps people with dementia and carers have identified. Providing an understanding of what is important and how things work in a particular locality is critical to developing appropriate services and supports. Organisations working on the ground with people with dementia and carers brings knowledge of the issues, needs and priorities in local communities. This knowledge can be accessed in a number of ways:

- Where the HSE has a service level agreement with an organisation (an agreement to provide certain services), conversations around the types of supports their clients with dementia require, could take place before or after scheduled meetings.

- To gain a more in-depth knowledge, community and voluntary organisations involved in supporting people with dementia and family carers could be asked to undertake small focus groups with their staff, clients and/or members. For this approach put together a focus group pack for each organisation containing an information leaflet for participants on the topic for discussion; a discussion guide containing short, jargon free, open ended questions e.g. what do you think about the supports available to people with dementia in this area?; consent forms and a template for recording responses (see link to resources on running a focus group at end of STEP 5).

- Surveys could also be used to collect information about the kind of services currently being provided and get opinions on what supports and services are required to meet the specific needs of people with dementia and family carers. Simple questionnaires can be designed using SurveyMonkey. It is a good idea to use open-ended (how or why questions) and closed questions (prompt yes or no answer) and to include questions that require people to prioritise using a ranking system. Likert Scales can also be useful (see link to resources on designing a survey at end of STEP 5).

2.5.3 CAPACITY AND RESOURCES

Capacity, resources and networks will determine what approaches can be used for knowledge building about dementia services and supports in an area. A large scale project, such as a concern survey (see below) and public meeting are ways of engaging with the whole community (including people with dementia family carers, all stakeholders and wider community) at one time and these maybe an option. However this type of process will probably require input from outside specialist agencies.

Concern surveys are a form of community assessment in which people are asked to help identify what they see as the most important issues facing their community, in this case the focus would be on the most important services and supports for people with dementia to maintain their identify and stay part of the community. Community members define what they see as the problem and identify the most pressing concerns. It can build awareness of dementia and get people thinking about what barriers exist in a community for those living with the condition. It builds consensus. The method can be a reliable, systematic and an easy to use way to tap into information. A public meeting may be held to review the strengths and problems identified in the survey and explore ways of solving the problems through enhancing the strengths identified and using the resources available (see link to undertaking a concern survey at end of STEP 5). Special attention should be given to adapting the process to support people with dementia to actively participate, for example as co-producers of the survey and speakers at the public meeting.

2.5.4 WHAT NOW?

You will now have collected information from the different stakeholders. The information may be in surveys, notes from focus groups or interviews/conversations. Don't worry if you feel a bit overwhelmed by all the information you have collected, just remember the scope of the Dementia Services Needs Analysis is to identify the services and supports required by people with dementia and family carers. To do this read through the information collected and note all the different services and supports stakeholders identified as important to people with dementia and family carers (include services and supports currently in place and those which are not). You record this information on Worksheet 3, 'Services and Supports Identified by Stakeholders' (Appendix 3), noting also who made the recommendation.

Resources that may be useful in undertaking STEP 4 and 5

Surveys

• MonkeySurvey https://www.surveymonkey.com/

• Conducting a Survey http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-surveys/main

Focus Groups

• Running a focus group http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/conduct-focus-groups/main

2.6 STEP 6: Know the priorities – Using information gathered to determine action

Having collected and recorded all of the information in different worksheets, you will need a way to examine this information and determine priorities which will help ensure that services are developed and available to people with dementia and family cares based on what they see as important to their lives.

THE VISION is to deliver and develop dementia appropriate services and supports at regional and local level that are informed by the needs of people with dementia, family carers and other key stakeholders.

2.6.1 PROCESS FOR PRIORITIZATION

The person who collected the information for the Dementia Services Needs Analysis framework along with members of the consortium (if one has been established) and/or colleagues responsible for service provision should meet to review the data collected and undertake the prioritization process. The process involves:

- Using a weighted scoring system, rank services and supports identified by stakeholders on Work Sheet 3, 'Services and Supports Identified by Stakeholders' (Appendix Three). This will be done by importance to the person with dementia. A score of two is allocated to a service or support identified by people with dementia, with a score of one allocated to a service or support identified by other stakeholders. Total the scores for each service and support identified and this will give you some indication as to priority needs. On Worksheet 3, you can also record whether the service or support is available or not in your locality.

- Services and supports important for people with dementia but unavailable are listed across Worksheet 4, 'Review What is Missing with What is In Place'. Services and supports in place as listed on Worksheet 2, 'Services and Supports Available', are listed in Column One of Worksheet 4. The group review and evaluate the potential of services and supports in place to be adapted or reconfigured to provide the new service (Appendix Four).

- New services that could be potentially developed from existing services and resources are listed on Worksheet 5, the Probability List (Appendix Five).

- Services that will require new or extra resources are listed on Worksheet 6, the Possibilities List (Appendix Six).

2.6.2 RECONFIGURING, ADAPTING AND UTILISING EXISTING RESOURCES AND COMMUNITY ASSETS

You may be wondering how community assets can be tapped into to support people with dementia and family carers. For example in feedback from people with dementia, a person may say how important going to 10 o'clock religious service is to them. This may seem totally outside your remit, but enabling the person to go to daily service ensures the person with dementia is socially engaged, maybe getting some exercise if they can walk there; it gives them an opportunity to have a cup of tea afterwards if they forget to eat breakfast, etc. These activities maintain the person's cognitive and physical well-being, preventing the need for more intensive interventions such as residential care. In thinking about how services and supports identified as important to people with dementia can be developed within the resources available in the community, see if there are any partnering opportunities with community organisations?

EXAMPLE 9:

Carnew Community Care
As part of the Wicklow Dementia Friendly programme, people with dementia were asked about things that were important to them. Many attended the Day Centre, had lunch there and participated in social activities. However the staffing capacity could not accommodate all of the people with support needs. To support people with dementia to continue to participate in social activities such as arts and crafts, local volunteers received training to take on the role as Activity Pals, supporting the person with dementia to continue attending the centre.

My Day My Way

Another example is 'My Day My Way' where people who have dementia are helped to have more choice and control in their lives through the use of self-directed support. It builds more participation and choice into existing services and is developing new models of day opportunities that are flexible and work around each person. It is a partnership between Scottish Care, Dementia Scotland and local authorities including Falkirk Council and details of the programme can be assessed from: http://otbds.org/wp-content/uploads/2016/07/Were-Here-Too-Report-2015-and-16.pdf

Community Connectors

Community Connectors played a key role in developing links with community organisations to facilitate individuals engaging with previous and new activities in the community in the Living Well with Dementia projects piloted under the HSE & Genio Dementia Programme . A summary of the Community Support Model can be accessed from: https://www.genio.ie/system/files/publications/DEMENTIA_SERVICE_DESIGN_SUMMARY.pdf

2.6.3 DECISION-MAKING ON PRIORITIES

In making decisions on priorities, consider bringing together a group of stakeholders in your local area e.g. people who engaged in the data collection processes, to review the Probabilities and Possibilities Lists (Appendix Five and Six). To assist in decision-making on which services and supports should be prioritised, the following key elements should be considered:

- Consensus as evident from Worksheet 3 'Services and Supports Identified by Stakeholders' (Appendix Three).

- Promotes personhood as defined in Box 2.

- Is grounded in the real lived experience of people with a dementia as evident from engagement with people with dementia and family carers (STEP 3 and 4)

- Is important TO people with dementia and not important FOR them (STEP 3 and 4)

- Implications for capacity and resources are known (STEP 2 and 5)

2.6.4 WELL DONE

You now have identified where priorities should be given in the development of person-centred services and supports for people with dementia. One final point, involving people with dementia in designing and developing services should not be regarded as a "project" or one-off activity. If involvement is to be effective it must be thought of as an ongoing and evolving process that becomes embedded in the organisation's culture and day-to-day practice. It's important to feed back to the people who have engaged, being transparent and open with them.

Appendix 1:
WORKSHEET 1 'DEMOGRAPHIC'

Information collected at STEP 1: Know your target group can be recorded in the Demographic Template. The template can be expanded to include information, such as gender and living arrangements of the population aged 65 and over and aged 85 and over.

Demographics	CHO area, Locality or Region			
	Number of people in [insert area]	Number of people [insert area]	Number of people [insert area]	Number of people [insert area]
People with dementia aged 65+				
People with dementia <65				
All people aged 65 +				

Appendix 2:
WORKSHEET 2 'SERVICES AND SUPPORTS AVAILABLE'

Information collected at STEP 2: Know your available resources including dementia specific services, general health and social care services and community assets can be recorded here.

Type of Dementia Specific Services e.g. day centre; dementia social club etc.	CHO Area, Locality or Region			
	Name of service and location	Name of service and location	Name of service and location	Name of service and location

Type of Community Assets	CHO Area, Locality or Region			
	Name of service and location	Name of service and location	Name of service and location	Name of service and location

Type of General Health and Social Care Services	CHO Area, Locality or Region			
	Name of service and location	Name of service and location	Name of service and location	Name of service and location

Appendix 3:
WORKSHEET 3 'SERVICES AND SUPPORTS IDENTIFIED BY STAKEHOLDERS'

Information on services and supports that most appropriately meet people's needs collated from engagement with people with dementia (Step 3), family carers (Step 4) and other stakeholders (Step 5) are listed in column one.

To prioritise by importance, each service and support identified can be scored, with a score of 1 allocated for each stakeholder that identified the particular service. For feedback given by people with dementia the score is 2. The scores are then totalled for each suggested service/support.

Indicate whether the service or support identified is currently in place (if available or unavailable).

Services & Supports Identified by Stakeholders	Score - Person with Dementia	Score - Family/ Carer	Score -HSE Staff	Score - Other Stakeholders Community/ Voluntary	Total Score	Indicate Yes or No if the service in place

Appendix 4:
WORKSHEET 4 'REVIEW WHAT IS MISSING WITH WHAT IS IN PLACE'

Services and supports that are currently in place/available are listed in the first column, as listed from Worksheet 2 'Services and Supports Available'. Services not in place but desired are listed across columns 2, 3 and 4. Review and indicate under each new service where there might be potential to create the new service or support from an existing service by adapting, reconfiguring or making it dementia inclusive.

Services and Supports Available (dementia specific, general and community assets)	Services and Supports, currently not in place or available, identified as important for living as well as possible with dementia,			
	Description of Service/ Support	Description of Service/ Support	Description of Service/ Support	Description of Service/ Support

Appendix 5:
WORKSHEET 5
'PROBABILITY LIST'

Services and supports that are important to living as well as possible with dementia and have the potential to be developed within current resources by either reconfiguring existing services or adapting other supports to be dementia inclusive, are listed as probabilities and included in this worksheet.

Probability List: Services and Supports that could be developed from current resources.	CHO area, Locality or Region			
	Area	Area	Area	Area

Appendix 6:
WORKSHEET 6 'POSSIBILITIES LIST'

Services and supports that have been identified as important to living as well as possible with dementia but do not have the potential to be developed within current resources, are listed as possibilities and included in this worksheet.

Possibilities List: Services and Supports that can only be developed with new resources.	CHO area, Locality or Region			
	Area	Area	Area	Area