

**First Report of the Collaborative Forum of Former Residents of
Mother and Baby Homes and Related Institutions**

**Report of the Inter-Departmental Working Group to examine
health-related recommendations**

December 2019

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1. Executive Summary

The Minister for Children and Youth Affairs, Dr. Katherine Zappone T.D, established a Collaborative Forum in June 2018 to facilitate dialogue and action on issues of concern to Former Residents of Mother and Baby Homes and related institutions. The First Report of the Forum was provided to Minister Zappone in December 2018 and contains forty-three wide-ranging recommendations across three areas of focus, including (1) Information, Identity, Terminology, and Mis-Representation; (2) Health and Well-being Supports and (3) Memorialisation and Personal Narratives.

Following Government consideration of the recommendations on 15th April 2019, it was agreed (amongst other actions) that the Minister for Health would develop proposals for a package of health and well-being supports, including access to any necessary health and social care measures, for former residents of related institutions.

A focused Working Group was therefore convened by the Minister for Health in May 2019 to undertake an extensive assessment of the twenty-one health & well-being recommendations contained in the First Report and to develop proposals for a package of health and well-being supports. In endeavouring to complete their assessment, the Group encountered some data limitations which presented a challenge to informed policy development. The Group sought to address these challenges by undertaking a process which included engagement with relevant policy and service functions in the Department of Health and the HSE, by extending an invitation to the Chair of the Collaborative Forum Subcommittee on Health and Well-being to present to the Group and share direct experience from a former residents perspective and by undertaking a rapid review of relevant academic literature, to help determine available research previously undertaken in relation to specific health requirements which could arise as a consequence of being resident in a State institution similar to Ireland's 'mother and baby' homes.

The Working Group has identified a dedicated package of health and well-being supports that it considers will directly assist and benefit the individual needs of former residents of Mother and Baby Homes and related institutions. The proposals now being recommended recognise a clear requirement to help ensure that former residents' mental health, and specific need for psychological support, is fully addressed. The proposals being made include an appropriate support mechanism to enhance awareness among former residents regarding availability of existing health services and to support their efforts to access services appropriate to their individual needs.

Finally, the Group also recommends that arrangements should be made to commence a targeted programme of health research for former residents of Mother and Baby Homes. It is envisaged that the more comprehensive understanding of specific profile and health needs to be derived from this research will later assist, if deemed necessary, in the development of future service responses appropriate to improving the overall health outcomes of former residents of Mother and Baby Homes and related institutions.

2. Introduction

2.1 Background to the Collaborative Forum of Former Residents of Mother and Baby Homes and related institutions

The Minister for Children and Youth Affairs established the Collaborative Forum to facilitate dialogue and action on issues of concern to former residents of Mother and Baby Homes and related institutions (which historically focused on services for unmarried mothers and their children). It should be noted that this Forum is separate from the independent Commission of Investigation, which is investigating the issues of significant public concern in relation to these institutions and due to report to the Minister for Children and Youth Affairs, Dr. Katherine Zappone by February 2020.

The purpose of the Collaborative Forum is to build upon the process of engagement and consultation with former residents commenced through facilitated meetings hosted by Minister Zappone in June and October 2017. Selection of members of the Forum was undertaken by an independent selection panel drawn from persons formerly in such Institutions, advocates and academics. The Forum consists of 19 representative members and a Chairperson and commenced work in July 2018.

The Collaborative Forum's Charter mandated the Forum to review and bring forward recommendations across three areas identified. These comprise of:

- Information, Identity, and Terminology
- Health and Well-being Supports
- Memorialisation and Personal Narratives

2.2 First Report of the Collaborative Forum

Consistent with its Charter, the Forum provided Minister Zappone with its first report within six months in December 2018. The recommendations reflect the output of the deliberations of the Forum and its subcommittees. In total, the report contains 43 wide-ranging recommendations across three areas of focus – Information, Identity, Terminology, and Mis-Representation; Health and Well-being Supports and Memorialisation and Personal Narratives.

The recommendations of the First Report of the Collaborative Forum were considered by Government on 15th April 2019, following which it was agreed (amongst other actions) that the Minister for Health would develop proposals for a package of health and well-being supports, including access to any necessary health and social care measures, for former residents of related institutions. It was also agreed that the Minister for Health would convene a focused Working Group and report back to Government to facilitate timely engagement with the Budget 2020 process.

Although it was not possible to publish the full report in April, due to a number of important legal considerations identified by the Attorney General, the Minister for Children and Youth Affairs intends to publish the report after the Commission of Investigation completes its work, subject to any further advices of the Attorney General at that time. In the interim, the Government has committed to advancing consideration of the report and a comprehensive analysis of all of the Forum's recommendations is underway across relevant Government Departments.

2.3 Collaborative Forum Subcommittee on Health and Well-being Supports

Membership of the Collaborative Forum Subcommittee on Health and Well-being Supports comprised of five former residents of Mother and Baby Homes and related institutions and one advocate. The Charter mandated the Subcommittee to consider the following areas:

- Assist support groups
- Peer to peer support activities
- Safe places to share experiences
- Professional counselling
- Consider needs of different groups
- Access to health and social services

Analysis undertaken by the Subcommittee included engagement with the HSE and the Department of Health and an online survey of one hundred former residents.

2.4 Summary of Health and Well-being Recommendations from the First Report of the Collaborative Forum

Under Health and Well-being Supports, the Forum identified three priority areas:

1. Medical cards and Health Care Services
2. Health Assessment and Screening
3. New Health Care Organisation and Structure

The 21 recommendations made by the Subcommittee on Health and Well-being Supports can be broken down across these three areas as follows:

Healthcare

- 2.1 Health care programmes should reflect the dignity, privacy and human rights of survivors and the delivery of recommended health services should be expedited;
- 2.2 Provide comprehensive health care to all survivors of Mother and Child Institutions;
- 2.3 Survivors to be transferred to HAA Card;
- 2.4 Free access to private health services including any associated costs;
- 2.5 Free private health insurance with pre-existing health conditions covered;
- 2.6 Life time stipend for survivors living outside Ireland to cover health insurance costs;
- 2.7 Funding for academic research into the health of survivors to identify measurable health indicators to inform health policy and improve health outcomes of this Group;

Health assessment and screening

- 2.8 Free comprehensive private health assessment and screening for survivors by an accredited health organisation of their choice;
- 2.9 Funding for academic research into the long-term health effects and psychological impact of vaccine trials on survivors;
- 2.10 Tailored health screening and assessments to cover any specific findings of the research for survivors;
- 2.11 DNA genetic screening for survivors to identify medical history and family history;
- 2.12 A national repository for DNA screening;
- 2.13 Funding for legal process to identify or prove paternity for survivors to have amended birth certificates;
- 2.14 Immediate family of survivors to be included in family health care package;

Wider Policy including a New Healthcare Organisation

- 2.15** Develop a new National Survivor Strategy in collaboration with survivors under the remit of a single Minister;
- 2.16** Create properly resourced divisional structures within a central Department to ensure delivery of key health and well-being services and other wider objectives relating to this Institutional legacy;
- 2.17** A new Communications Strategy to inform survivors about the availability of health and well-being services, particularly those living overseas;
- 2.18** Support and provide sustainable funding for survivor led organisations and regional centres to deliver health and well-being services to their specific survivor Groups;
- 2.19** Funding for education and training of survivors in the specific area of health, counselling, therapy, management and other areas related to health and well-being;
- 2.20** State policies and actions to be put in place to ensure that no survivor is treated unfairly on account of their gender, religion, race, traveller ethnicity or disability;
- 2.21** An independent review into the operations and governance structure of Caranua and its impact on survivors to help inform decisions to be made on any future health and well-being organisations/structures developed for survivors of other institutions, such as Mother and Child Institutions.

3 Establishment of an Inter-Departmental Working Group to examine the health and well-being recommendations

Following a Government Decision on 16th April 2019, the Minister for Health convened a focused Working Group of officials in May 2019 to undertake an extensive assessment of the twenty-one health & well-being recommendations contained in the First Report of the Collaborative Forum and to develop proposals for a package of health and well-being supports, including access to any necessary health and social care measures, for former residents of related institutions. The Group, which comprised officials from the Department of Health, the Department of Children & Youth Affairs and the Health Service Executive met on seven occasions between May and September 2019. The Terms of Reference, as agreed by the Inter-Departmental Working Group and approved by the Minister, are attached at Appendix B to this Report.

From the outset, the Group identified two key issues which would require greater clarification to enable the Group to provide an accurate assessment of the scale and scope of healthcare supports required and an estimation of potential funding requirements, namely (i) the limitations of available data regarding the number and age profile of former residents, and (ii) the limited available information regarding specific health needs of this diverse group of citizens. These were significant challenges which the Group endeavoured to address in completing their assessment.

It should be noted that the proposals now being recommended by the Working Group are centred on an assessment of the recommendations relating to the Healthcare and Health Assessment and Screening priority areas. Certain other recommendations were considered outside the direct remit of the Working Group, and indeed beyond that of the Department of Health and would involve significant legislative, policy and resource issues - in particular, recommendations 2.15-2.21 regarding Wider Policy including a New Healthcare Organisation were deemed to fall outside the scope of the Working Group and therefore were not considered for detailed assessment as part of

the above proposals, given their requirement for a broader, cross-Departmental consensus regarding the appropriate policy approach for implementation.

3.1 Approach to Data Limitations Adopted by the Working Group

The Group recognised the limitations in available data regarding the number, age profile, socio-economic circumstances and health needs of former residents, being cognisant that the Commission of Investigation (Mother and Baby Homes and certain related Matters) is currently seeking to collate and analyse diverse sources of information at a level which has not been possible before. The Commission has reported that when cross-referencing of all records is complete, it should provide as comprehensive an account of former residents in these institutions as is possible to establish. The level and depth of this account and any related data will only become available when the Commission submits its final report - expected in February 2020.

In the interim, the emphasis in the Working Group's approach was to establish an estimate of the number of former residents, which could be used to inform deliberations regarding the Exchequer cost of any package of supports. The Minister for Children and Youth Affairs previously informed Government that preliminary data suggested that approximately 46,000 mothers and children (on an approximately 50:50 basis) spent time in the main mother and baby institutions from 1950 onwards. This data did not include the smaller mother and baby institutions, the county homes or any persons resident in these institutions pre 1950.

As part of its input to the Working Group, the Department of Children and Youth Affairs sought to develop a fuller picture of potential demand. The results of further analysis indicate that approximately 190,000 individuals (unmarried mothers and children as defined in the Commission's terms of reference) may have resided at some time in one of the 14 named institutions or in one of the County Homes. This data covers the entire period from 1922-1998 consistent with the Commission's remit. While the available data does differentiate between persons who were resident pre 1950 and post 1950 it does not readily assist in building a definitive age profile of the cohort of mothers or children.

In an effort to generate a more accurate estimate of potential demand for services in 2020, the Department of Children and Youth Affairs utilised the extensive data on life expectancy available from the Central Statistics Office to forecast a potential total population of residents who may come forward to avail of any package of health and well-being supports - on this basis, the Working Group proceeded on a working assumption of 57,000 former residents who may be alive today. The Working Group also noted the analysis of age profiles and related considerations as outlined in Appendix C.

3.2 Approach to Identification of Clinical Need Adopted by the Working Group

Key to the assessment process was the requirement for the Working Group to identify the appropriate clinical need for this population cohort. To help inform an objective analysis of the clinical need of former residents, the Group (i) engaged with relevant policy and service functions in both the Department of Health and the HSE, (ii) engaged directly with the Chair of the Collaborative Forum Subcommittee on Health and Well-being supports, that subcommittee being responsible for formulation of the specific recommendations being examined and (iii) arranged to undertake a rapid review of relevant academic literature, to help determine available research previously undertaken

in relation to specific health requirements which could arise as a consequence of being resident in a State institution similar to Ireland's 'mother and baby' homes.

The Working Group consulted with relevant service policy functions within the Department of Health and with HSE Community Health as a means to (a) identify and inform the typical health status, and needs which can generally arise, for an ageing and older population and (b) to establish a clear information base regarding the availability of existing appropriate services within the health system which could be of particular benefit to this cohort (for example mental health, GP, dental services etc.). The Working Group's assessment was greatly assisted by the valuable contribution of the patient voice. The Working Group, recognising the importance of the Collaborative Forum's approach of "nothing about us without us", invited the Chair of the Collaborative Forum Subcommittee on Health and Well-being to present at a Working Group meeting. This enabled the Working Group to hear first-hand the experiences of former residents of Mother and Baby Homes and to develop better understanding of the background to recommendations included in the Report. The presentation by the Chair also made clear to the Working Group the uncertainty and difficulty some former residents can experience when seeking to identify and access health services.

The rapid review of academic literature undertaken concluded, based on the limited amount of research available in this area that the identification of specific health issues relating specifically to residency in homes for unmarried mothers, as occurred in Ireland and some other countries (notably Australia and Canada), is difficult considering their unique experience, life course trajectory and other significant events. In addition, the secrecy and trauma associated with these forms of residency made establishing health issue commonalities among that cohort problematic.

The cumulative effect of the steps taken above confirmed to the Working Group the limited available information and evidence-base in support of specific, discrete health needs arising for former residents. Establishing additional health and social care needs that may be specific to this cohort was therefore a challenging task for the Group.

4 Eligibility and Access to Health Services in Ireland

Given the broad-ranging recommendations made by the Collaborative Forum for health services, the Working Group considered it would be appropriate in the first instance to clearly establish and acknowledge the range of services currently available within the Irish health system, with a view to aligning existing services with any needs identified as of particular relevance or importance to former residents.

The following sections outline existing health services which are relevant to the recommendations of the Collaborative Forum and eligibility for accessing such services.

4.1 Eligibility for Health Services

Ireland's public hospitals provide a wide range of emergency, diagnosis, treatment and rehabilitation services. Improving access to and reducing waiting times for patients for hospital operations and procedures is a key priority for Government. Eligibility for access to public health services is governed by the eligibility framework as set out under the Health Act 1970 (as amended). Under this framework, any person regardless of nationality, who is accepted by the Health Service Executive (HSE) as being ordinarily resident in Ireland has eligibility to public health services. A person is

deemed ordinarily resident if they are living in Ireland and have lived here, or intend to live here, for at least one year.

There are two types of eligibility for people who are ordinarily resident:

- Full eligibility for medical cardholders; and
- Limited eligibility for people who do not have a medical card.

The Irish Public Health System provides for two categories of eligibility for persons ordinarily resident in the country, i.e. full eligibility (medical cardholders) and limited eligibility (all others). Full eligibility is determined primarily by reference to income limits. Determination of an individual's eligibility status is the responsibility of the Health Service Executive.

Adults with full eligibility are entitled to a range of services including general practitioner services, prescribed drugs and medicines, all in-patient public hospital services in public wards including consultants' services, all out-patient public hospital services including consultants' services, dental, ophthalmic and aural services and appliances and a maternity and infant care service.

Other services such as allied healthcare professional services may be available to medical card holders. With the exception of prescribed drugs and medicines, which are subject to a €2.00 charge per prescribed item (maximum of €20 month per month per individual/family), these services are provided free of charge.

Persons with limited eligibility are eligible for in-patient and outpatient public hospital services including consultant services, subject to certain charges. The public hospital statutory in-patient charge is €80 in respect of each day during which a person is maintained, up to a maximum payment of €800 in any twelve consecutive months. There is also a charge of €100 for attendance at Accident & Emergency departments and other similar type services unless, inter alia, the person has a referral letter from their General Practitioner. Other services such as allied healthcare professional services may also be made available to persons with limited eligibility.

Accessing Medical Cards based on Financial Assessment

Medical Card provision is primarily based on financial assessment. In accordance with the Health Act 1970 (as amended), eligibility for a medical card is determined by the HSE. The HSE assesses each application on a qualifying financial threshold. This is the amount of money that an individual can earn a week and still qualify for a card. It is specific to the individual's own financial circumstances. The HSE conducts a financial assessment based on an applicant's household income after tax; PRSI and the Universal Social Charge (USC) have been deducted. Certain expenses are also taken into account. In addition, if a person's sole income is derived from a social welfare payment, even where this is more than the current means threshold, he/she will be awarded a medical card.

It should be noted that when a person attains the age of 70, the medical card income limits are €500 gross income per week for a single person and €900 gross income per week for a couple. Persons aged 70 or older, who are assessed as ineligible under the gross income thresholds, may also have their eligibility assessed under the means tested medical card scheme in the event that they face particularly high expenses, e.g. nursing home or medication costs. Almost 30% of all medical card holders are currently over 70.

Discretionary Medical Cards

Under the Health Act 1970 (as amended), having a particular condition in itself, does not establish eligibility for a medical card. However, every effort is made by the HSE, within the framework of the legislation, to support applicants in applying for a medical card and, in particular, to take full account of the difficult circumstances in the case of applicants who may be in excess of the income guidelines.

In certain circumstances, the HSE may exercise discretion and grant a medical card, even though an applicant exceeds his or her income threshold, where he or she faces difficult financial circumstances, such as extra costs arising from an illness. Currently 160,000 individuals hold a discretionary medical card. Social and medical issues are considered when determining whether undue hardship exists for an individual accessing general practitioner or other medical services. The HSE also affords applicants the opportunity to furnish supporting documentation to fully take account of all the relevant circumstances that may benefit them in assessment, including medical evidence of cost and necessary expenses. After examining all of the supporting documentation, in certain circumstances, a discretionary medical card may be awarded.

GP Visit Card

Approximately 10% of people in Ireland have a GP visit card. Individuals who are not eligible for a medical card may still be able to avail of a GP visit card, which allows card holders to visit a participating General Practitioner for free and also covers visits to GP out of hours service. The GP visit card is also means tested; however the income limits are higher than those for the medical card. It should be noted that the GP visit card is automatically available to everyone aged over 70. In addition, over 23% of all GP visit card holders are currently over 70.

4.2 Community Drug Schemes

Individuals may also be eligible for the supply of approved medicines, aids and appliances, provided by community pharmacies through the community drug schemes. The main schemes are as follows.

- Under the Drug Payment Scheme (DPS), no individual or family pays more than €124 a month towards the cost of approved prescribed medicines. The DPS is not means tested and is available to anyone ordinarily resident in Ireland.
- Under the Long-Term Illness (LTI) Scheme, patients with a specified condition receive drugs, medicines, and medical and surgical appliances directly related to the treatment of that condition, free of charge. The only qualifying requirement is diagnosis of a condition covered by the LTI.
- The Discretionary Hardship Scheme allows medical card holders to obtain items prescribed by a doctor that are not otherwise reimbursable.

4.3 Mental Health Services

The HSE provides a wide range of community and hospital based mental health services in Ireland. The HSE National Counselling Service (NCS) is a professional, confidential counselling and psychotherapy service available free of charge in all regions of the country. Established in September 2000, the HSE NCS employs over 70 Counsellor/Therapists who are highly qualified and experienced in working with developmental trauma.

Since the inception of the NCS, its primary clients have been adults who experienced abuse whilst in the care of the state as children. Between 2000 and 2013 more than 30,000 people were referred to

the NCS for counselling in relation to experiences of childhood abuse. 11% of these clients identified that this abuse occurred in an institution. Counselling is available free at the point of delivery from dedicated counselling centres as well as primary care centres across the country. The NCS welcomes self-referral by clients as well as referrals from health professionals. The remit of the NCS expanded in 2013 with the development of the Counselling in Primary Care Service which offers counselling to adults for mild to moderate psychological difficulties.

In addition, Connect Telephone Counselling Service provides support for adults who have experienced abuse, neglect or trauma in childhood. The service was established to particularly support adults who experienced abuse in institutional settings.

4.4 Home Support Services

Home Support Services are an important component of the provision of service to older people with assessed needs and to support them in their choice of living in their own home and community. The HSE has sought to maintain and when possible to expand the range and volume of services available to support people to remain in their own homes, to prevent early admission to long term residential care and to support people to return to their homes following an acute hospital admission. The Home Support Service is used to its maximum effect as part of each individual recipient's care plan. It is a non-statutory service and access to the current service is based on assessment of the person's needs by the HSE.

4.5 Nursing Homes Support Scheme

The Nursing Homes Support Scheme is a system of financial support for those in need of long-term nursing home care. Participants contribute to the cost of their care according to their means while the State pays the balance of the cost. The Scheme aims to ensure that long-term nursing home care is accessible and affordable for everyone and that people are cared for in the most appropriate settings. Anyone who is assessed as requiring long-term residential care can avail of the Scheme, regardless of age, as long as the person's care needs can be appropriately met in a nursing home that participates in the Scheme. The applicant can choose any public, voluntary or approved private nursing home. The home must have availability and be able to cater for the applicant's particular needs.

Participants in the Scheme contribute up to 80% of their assessable income and a maximum of 7.5% per annum of the value of assets held. In the case of a couple, the applicant's means are assessed as 50% of the couple's combined income and assets. The first €36,000 of an individual's assets, or €72,000 in the case of a couple, is not counted at all in the financial assessment. The capital value of an individual's principal private residence is only included in the financial assessment for the first three years of their time in care. This is known as the three year cap.

A person's eligibility for other schemes, such as the Medical Card Scheme or the Drug Payment Scheme, is unaffected by participation in the Nursing Homes Support Scheme or residence in a nursing home.

4.6 Health Screening

The National Screening Service was established in January 2007. At present, population-based screening programmes are in place for cancer of the breast, bowel and uterine cervix and retinal screening for patients with diabetes.

These programmes aim to reduce morbidity and mortality in the population through early detection of disease and treatment, both of which greatly improve health outcomes. A screening test is designed for populations of individuals who do not have any symptoms of disease. It aims to identify those with a risk marker for a disease and ensure early treatment.

A screening test is not a diagnostic test, which is designed for individuals with symptoms of a disease or for those identified with a risk marker to assess whether they have it or to follow its progress. Screening programmes internationally and in Ireland are based on a call /re-call system, where eligible populations are invited to take part and clinical services are provided for the further investigation and treatment of people identified as at risk of having or developing a disease.

4.7 Genetic Testing

Genetic testing refers to a series of techniques involving molecular analysis of human nucleic acids (including DNA and RNA) and is performed clinically for a variety of reasons. The Department of Clinical Genetics at Our Lady's Children's Hospital (OLCHC) provides a public genetics service to referring clinicians for patients and families in the Republic of Ireland affected by, or at risk of, a genetic disorder. The Department of Clinical Genetics provides public diagnostic services for a broad range of hereditary disorders and, because of the familial nature of genetic disorders, serves both adults and children. Services offered include diagnostic screening and cascade screening to at-risk relatives, as well as carrier screening for couples with a family history of a genetic disorder.

4.8 Private Health Insurance

The private health insurance market in Ireland is a voluntary commercial free market, subject to Irish and EU law, based on a system of voluntary enrolment whereby consumers who wish to purchase health insurance from one of the open market providers are facilitated to do so.

5 Health Profile and Clinical Need of Former Residents of Mother and Baby Homes and related institutions

In recognition of difficulties already flagged, namely the absence of data regarding age, numbers and clearly defined health requirements of former residents, the Group endeavoured to identify as far as possible the typical health profile and clinical need which could arise for former residents.

The assessment undertaken by the Working Group was greatly assisted by the valuable contribution of the patient voice. The Working Group, recognising the importance of the Collaborative Forum's approach of "nothing about us without us", invited the Chair of the Collaborative Forum to present at a Working Group meeting. This enabled members of the Working Group to hear first-hand the circumstances experienced by former residents of Mother and Baby Homes and to develop better understanding of the background to recommendations included in the Report. The presentation by the Chair also made clear to the Working Group the uncertainty and difficulty some former residents can experience when seeking to identify and access health services within the State.

Engagement with representatives from the office of the Chief Medical Officer in the Department of Health and the HSE also provided the Group with information on the clinical need and typical service requirements which arise for cohorts of a similar age and background.

In the absence of available academic literature specific to the discrete and unique health needs and circumstances of former residents, the Group also relied on findings of similar research and reports regarding survivors of institutional abuse.

5.1 Profile of Need of the Older Population

Central to contributing to an understanding of potential needs of this specific cohort is an understanding of the clinical need and typical service requirements of persons of a similar age and background. An individual's health status is determined by a complex interaction of the main determinants of health which include the social and economic environment, the physical environment and the person's individual genetic characteristics and behaviours. The section beneath sets out information on the typical health status and needs which can generally arise for an ageing population.

Life expectancy is continuing to increase in Ireland, currently standing at 83.6 years for women and 79.9 years for men. Life expectancy for women is higher than for men, as in most countries. However, this gap has narrowed in the past decade, and male life expectancy in 2016 was 3.7 years below female life expectancy compared to 5.6 years in 1996. By 2031, it is estimated there will be one million people over the age of 65 in Ireland. The greatest gains in life expectancy have been achieved in the older age Groups reflecting decreasing mortality rates from major diseases. This decrease is particularly strong for mortality rates from stroke (-39%), breast cancer, (-16%), suicide (-26%) and pneumonia (-39%).

The Irish Longitudinal Study on Ageing (TILDA) is a large-scale, nationally representative study of people aged 50 and over in Ireland. The following highlights some of the key findings of the TILDA study in relation to the health needs of older people generally:

Behavioural and physical health of older people

- Three-quarters of older Irish adults rate their health as excellent, very good or good but this rate declines with age.
- Both cardiovascular and non-cardiovascular diseases are common in older adults with the prevalence of most chronic conditions increasing with age.
- Hypertension, angina, and stroke are more common in men; osteoporosis, arthritis and high cholesterol are more common in women.
- One in five older Irish adults is a current smoker; the highest rates of smoking are seen in the poorest and those with lowest education levels.
- Half of those aged 75 years and older report low levels of physical activity.
- Screening for cancer varies significantly by age, education and wealth. Older, poorer, less educated adults are less likely to screen for prostate or breast cancer.
- One in five older adults takes five or more medications (polypharmacy). This proportion rises to almost one in two for those aged 75 years and older. Polypharmacy is more than twice as likely in medical card holders compared with adults without cover or with medical insurance.

Mental health and cognitive function of older people:

- Depression is common among older adults in Ireland, with 10% of the population reporting clinically significant depressive symptoms with a further 18% reporting 'sub-threshold' levels of depression.
- Anxiety is more common than depression among older adults. Among older adults 13% report clinically significant anxiety symptoms while 29% report sub-threshold levels of anxiety.
- There is evidence of under-diagnosis and hence under-treatment of depression and anxiety. Of older adults with objective evidence of depression, 78% do not report a doctor's diagnosis of depression. Similarly, 85% of older adults with objective evidence of anxiety do not report a doctor's diagnosis of anxiety.
- Depression is associated with disability. Nearly two-thirds of older adults with depression have a longstanding illness or disability compared to one-third of people who are depression free.
- Depression is associated with increased medication use. Of people aged 75 and over with depression, 56% are taking five or more medications compared to 36% of adults without depression.
- Increased health service utilisation in people with depression. Depressed adults aged 75 and over have an average of 7 visits to their GP in the past year compared to an average of 4 visits among the non-depressed older population.

Health and social care utilisation

- Nearly 60% of people between 50 and 69 have private medical insurance, dropping to 46% for those in their 70s and 32% of those over 80.
- The likelihood of being a user of GP care rises slightly with age, but is similar for all those over 70.
- The likelihood of having a hospital admission is similar for different ages over 60, but the length of stay increases slightly with age, and people over 80 are lower users of outpatient services than those in their 60s and 70s.
- The prevalence of disabilities rises with age from less than 10% of those between 50 and 64 to nearly 30% of those over 75.

5.2 Information on the profile and needs of Former Residents of Mother and Baby Homes and related institutions

The Chair of the Collaborative Forum Subcommittee on Health and Well-being provided a comprehensive presentation to the Working Group which included key survey findings from a survey undertaken by the Subcommittee. The Subcommittee surveyed 100 people in Ireland and overseas and the following findings are a snapshot of their findings on the value and need of health supports to former residents:

- 80% found genetic screening to identify unknown inherited illnesses as important
- 36% found provision of private care very important
- 73% found Dental services and appliances are very important
- 80% found Ophthalmic services and appliances are very important

- 50% found Aural services are very important
- Home Support and Home Nursing is very important for 44% and 37% respectively

The overall survey findings, and the valuable insight provided by the Chair of the Collaborative Forum Subcommittee as part of his presentation, emphasised the desire felt by former residents for their needs to be recognised in the first instance and consequently that assistance can be provided to access relevant health services and information.

5.3 Rapid Review of academic literature on profile and needs of Former Residents of Mother and Baby Homes and related institutions

The Working Group also undertook a rapid review to identify relevant academic research concerning health requirements that could arise as a specific consequence of being resident in a State institution similar to Ireland's Mother and Baby Homes. While there is some limited research in this area, a specific focus on health and social care needs was found to be uncommon.

Limited literature was identified from the jurisdictions of Australia and Canada where government commissions of inquiry into residences for unmarried mothers were established. The Australian and Canadian committee heard accounts of post-traumatic stress disorder, acute mental health problems, depression, and anxiety, as well as identity and abandonment issues. In particular, both Committees heard of the urgent need for appropriate counselling services.

The review concluded that the identification of specific health issues relating to residency in homes for unmarried mothers, as occurred in Ireland and other countries, is difficult considering their unique experience, life course trajectory and other significant events. In addition, the secrecy and trauma associated with these forms of residency renders cohort identification to establish health issue commonalities problematic. Individuals may not be forthcoming, and the people who are forthcoming may not be able to provide the full picture of health and social care needs for the entire cohort. Therefore, the academic literature review found establishing the additional health and social care needs that are specific to this cohort, over and above the needs of other individuals who did not have this experience, a challenging task.

5.4 Information on the profile and needs of other survivors of institutional abuse

As an aid to the steps above undertaken by the Working Group, available research and findings on the profile and needs of other survivors of institutional abuse was sought from and provided to the Group by the Department of Education and Skills.

The Commission to Inquire into Child Abuse (CICA) commissioned a study in 2005 on adult survivors of institutional abuse in industrial and reformatory schools who appeared before the CICA. Key findings include the following:

- It is estimated that 80% of survivors of institutional abuse today are aged over 58, just over half of these are over 70 and 7% are over 80.
- All participants had experienced one or more significant life problems, with mental health problems, unemployment and substance use being the most common.
- More than four fifths of participants had an insecure adult attachment style, indicative of having problems making and maintaining satisfying intimate relationships.

- Approximately four fifths of participants at some point in their life have had a psychological disorder including anxiety, mood, substance use and personality disorders.
- The overall rates of psychological disorders among survivors of institutional living, for most disorders, were double those found in normal community populations in Europe and North America.

In addition, a recently completed report on “Consultations with Survivors of Institutional Abuse on Themes and Issues to be addressed by a Survivor Led Consultation Group” also found that survivors concerns in order of priority include:

- An aging profile and increased health needs
- Fear of institutionalisation in old age (hospitals, nursing homes etc.).
- Adequate and suitable housing
- Poverty – inadequate income
- Fear of isolation and the need for social supports
- Neglecting the needs of ‘hard to reach’ survivors
- The restrictions on obtaining counselling services
- Support in managing bureaucracy to access services
- The unequal treatment of survivors who didn’t receive redress and therefore couldn’t access services and funds through Caranua.
- Lack of educational support for survivors and for their children and grandchildren
- Lack of access to information and files on their own and their families’ histories
- Being seen as ‘helpless victims’ rather than ‘resilient people’ who survived despite the lack of adequate support
- Resettlement options for survivors who returned to or wish to return to Ireland.

6 Outcome of the Assessment of Health and Well-Being Recommendations

The Group recognised the limitations in available data regarding the number, age profile, socio-economic circumstances and health needs of former residents, being cognisant that the Commission of Investigation (Mother and Baby Homes and certain related matters) is currently seeking to collate and analyse diverse sources of information at a level which has not been possible before. The Commission has reported that when cross-referencing of all records is complete it should provide as comprehensive an account of former residents in these institutions as is possible to establish. The level and depth of this account and any related data will only become available when the Commission submits its final report, which is expected in February 2020.

In the interim, the lack of data presents a challenge for informed policy development. However, the engagement with relevant service providers, the interaction with the Chair of the Forum Subcommittee and the research review conducted over the past number of months have highlighted various complex policy issues arising for consideration. The assessment process made clear to the Working Group the uncertainty and difficulty some former residents can experience when seeking to identify and access health services within the State. Recognising the importance of taking appropriate actions to address this, the Group sought to focus on identifying appropriate health services which could help mitigate or alleviate such previous difficulties experienced and would also fulfil specific health needs arising for assistance. Further detail on the relevant package of health and well-being supports which are expected to assist and benefit the individual needs of former residents are set out in section 6 (Conclusions and Subsequent Actions).

In addition to this, the process of engagement confirmed to the Group that in relation to recommendations made under the headings of *Healthcare*, and *Health Assessment and Screening*, there were valid reasons why it may not be appropriate to implement the full range of recommendations in the manner sought.

6.1 Survivors to be transferred to HAA card

Recommendation 2.3 of the Report calls for former residents to be transferred to a HAA card. Individuals who contracted Hepatitis C through the administration within the State of contaminated blood and blood products are entitled to healthcare services under the terms of the Health (Amendment) Act 1996. The HAA scheme is specifically for persons who contracted Hepatitis C as a result of contaminated blood transfusions or blood products. These provisions were put in place in what the Government at that time deemed to be very special circumstances in which the persons concerned had clear health and social support needs as a result of having contracted a very serious and indeed life-threatening condition.

The Collaborative Forum, as part of its recommendation to be transferred to the HAA card added that provision should be made equivalent to the proposals made in Judge Quirke's Report on the establishment of an ex gratia Scheme and related matters for the benefit of those women who were admitted to and worked in the Magdalen institutions. Following this report, the Redress for Women Resident in Certain Institutions Act 2015 (RWRCI Act) made specific provision for a range of primary and community health services in Ireland for women who qualify under the Department of Justice & Equality Magdalen Restorative Justice Ex-Gratia Scheme.

Individuals who are eligible under the RWRCI Act are not entitled to the same type and level of access to healthcare services as provided for under the HAA Act. The health status of Magdalen women and those who contracted Hepatitis C was not identical, with both cohorts considered to face very different circumstances. Both schemes are provided for in primary legislation and only those persons who meet the conditions laid out in the legislation are eligible to avail of the prescribed services.

6.2 Recommendations relating to Private Healthcare Access

Recommendations 2.4 - 2.5 and 2.10 - 2.12 are related to the provision of free access to private health services including private health insurance, health assessments and genetic screening. From a public policy point of view, it is considered most appropriate to meet people's needs through the public healthcare system. Private health insurance is a regulated free market, subject to relevant Irish and EU law. Availing of private health insurance is a choice made by individual's, and as such, is not a State-provided or State-funded arrangement. Implementation of the Forum's recommendation could potentially pose significant legal and competition issues.

Recommendation 2.11 seeks DNA genetic screening for former residents to identify medical history and family history. Genetic screening is typically only carried out on individuals where a predisposition to a particular condition is suspected, based on physical signs and symptoms. There is a paucity of clinical evidence supporting genetic screening on individuals not already displaying clinical symptoms of disease. It can be noted that, conversely, opportunistic testing has the potential

to increase psychological distress and anxiety around the probabilities and uncertainties associated with genetic findings.

Evidence-based health screening programmes are already currently in place on a targeted basis for cancer of the breast, bowel and uterine cervix, and there is retinal screening for patients with diabetes. The public health service does not include untargeted and non-evidence-based health screening programmes and overall policy in this regard is unlikely to change.

6.3 Recommendations outside the remit of Working Group

The proposals recommended below by the Working Group are centred on an assessment of the recommendations relating to the Healthcare and Health Assessment and Screening priority areas. Certain other recommendations were considered outside the direct remit of the Working Group, and indeed beyond that of the Department of Health, and involve significant legislative, policy and resource issues - in particular, recommendations 2.15-2.21 regarding Wider Policy including a New Healthcare Organisation were deemed to fall outside the scope of the Working Group and therefore were not considered for detailed assessment as part of the below proposals, given their requirement for a broader, cross-Departmental consensus regarding the appropriate policy approach for implementation.

7 Conclusions and Subsequent Actions

The Working Group sought to undertake an assessment process which adequately and appropriately considered the specific need of former residents and, importantly, involved a compassionate and holistic response to their health and well-being concerns. A core objective in the work undertaken was to identify services which could assist people to meet the typical needs which emerge in their daily lives. For example, persons affected by stress and trauma which may be related to their experience in institutions may be potentially more vulnerable and may require additional assistance in accessing services to meet their health and other needs. Key to improving access to relevant services therefore was to seek to adopt a systemic approach that could target the often-interrelated difficulties experienced by former residents in a coherent and strategic manner. In this respect, the Working Group cautioned against an approach that relied upon an assumption that provision of medical cards would have the desired impact in terms of addressing real needs and ensuring appropriate service provision.

The Group recognised that a significant number of former residents are likely to be in, or approaching older years and in many cases the services being sought may be a reflection of their desire for support that their needs will be met in a manner which facilitates independent living for as long as reasonably possible. An important part of this is an assurance that services will be available if and when required. In this context, the Group noted that the Government has made improved access to home support services a priority in Budget 2020 with an additional investment of €52 million, providing over 19.2 million hours of home support next year. This brings the overall home support budget to over €487 million and represents a substantial increase of one million hours more than the 2019 target.

In addition, approximately 75% of those over 70 in Ireland currently hold a medical card. Budget 2020 also provided that medical card gross income limits for those over 70 will be increased to €550

per week for a single person aged over 70 (currently €500 per week) and to €1050 for a couple aged over 70 (currently €900 per week).

In the context of finite resources available, and taking account of other policy measures already being developed or to be commenced by Government next year, the Working Group considered that the greatest benefit for the needs of former residents would derive from the provision of a targeted package including additional mental health support services, the establishment of a dedicated patient advocacy liaison service and the commissioning of a targeted research study. This focussed approach and seeking to identify and maximise the greatest benefit for former residents in service provision terms, is particularly relevant in the context of wider challenges facing the health service around Government funding, eligibility, workforce capacity and additional associated costs attaching to on-going Brexit contingency planning.

7.1 Proposals for a Package of Health and Well-being Supports

Over the course of the past number of months, the Group undertook an extensive assessment of the Report's twenty-one ambitious and wide-ranging health & well-being recommendations. The Group sought to take into account the appropriateness and feasibility of the various recommendations, the scale and scope of healthcare supports which may be provided (including the potential funding implications) and considered potential mechanisms which could provide any health and well-being supports identified.

Notwithstanding the two key challenges encountered by the Group in completing their assessment, namely (1) a lack of clear data regarding the specific number and age profile of former residents, and (2) the limited amount of available information regarding specific health needs of this diverse group of citizens, the Group identified a dedicated package of health and well-being supports that is envisaged would directly assist and benefit the individual needs of former residents of related institutions:

Enhanced Health Services – Counselling Supports

The assessment undertaken has demonstrated a clear requirement to help ensure former residents' mental health, and specific need for psychological support, is recognised and prioritised. Dedicated funding to enhance existing services is therefore proposed. It is envisaged that such services may be provided by the National Counselling Service (NCS). As outlined in Section 4.3, the NCS is a well-established and integrated service within the HSE with a proven track record of providing counselling and psychotherapy to a wide range of clients including those who have experienced psychological difficulties as a result of time spent in institutions. It is envisaged that this additional service offering could provide telephone and face-to-face counselling by appointment through an established nationwide network of counselling locations.

Patient Advocacy Liaison Supports

The Working Group process identified that there may be an awareness deficit among former residents regarding availability of existing health services and identified a consequent need for an appropriate mechanism to address this gap. In recognition of this need, a dedicated patient advocacy liaison service, providing a direct contact point of support for former residents, could be

established. This service would help ensure that individuals can have an appropriate point of contact within the health system and that individuals are signposted to access necessary health services.

This service offering could provide a single named individual as a point of contact, who would respond appropriately and directly to former residents. The liaison officer would listen to their discreet and unique health needs, advise of available and appropriate health service options and assist with accessing the most appropriate health services to his/her need. This signposting and information service could include a dedicated Freephone number, email and web chat along with a suite of online, easy to understand accessible information on a range of health services and health and wellbeing topics tailored to former residents.

Targeted Health Research Study

The work of the Group further re-iterated a significant information deficit regarding both the age profile and the specific clinical need of former residents. Any process of targeting a response to the needs of any population or group should be informed by a clear understanding of their specific needs. The availability of this information is critical in informing the development of any further services or arrangements that may be introduced in response to clarification of specific health needs.

Recognising this deficit, and in acknowledgement of the Collaborative Forum's approach of "nothing about us without us", a targeted programme of health research will therefore be commissioned to help identify measurable health indicators which can inform health and well-being policy and improve the health outcomes of former residents.

In addition, it is envisaged that additional specific needs may emerge from the services to be established/research to be undertaken which could be further considered at that time – this study will help identify measurable health indicators and additional information derived from the study may assist, if deemed necessary, in the development of service responses appropriate to improving the health outcomes of former residents.

Finally, as outlined earlier in this Report, certain recommendations were outside the direct remit of the Working Group and will require broader, inter-Departmental assessment.

7.2 Next Steps

Following Government approval for the provision of funding, the Department of Health will engage with the HSE to oversee the effective implementation and timely provision of the package of supports for former residents.

In tandem with this, arrangements will be made with the Health Research Board to commence the targeted programme of health research. It is envisaged that this study will identify measurable health indicators and that additional information derived from the study may assist, if deemed necessary, in the development of service responses appropriate to improving the overall health outcomes of former residents.

Recommendations outside the direct remit of the Working Group - in particular, recommendations 2.15 - 2.21 regarding Wider Policy including a New Healthcare Organisation will require broader,

cross-Departmental assessment. Such assessment, in conjunction with the findings of the Commission of Investigation into Mother and Baby Homes and related activities, which is due to publish its final report in February 2020, will also likely have a significant contribution towards the future development of appropriate policy and actions in this area.

Appendix A

Charter for a Collaborative Forum of Former Residents of Mother and Baby Homes and Related Institutions

Minister Katherine Zappone is to establish a Collaborative Forum to facilitate dialogue and action on issues of concern to former residents of the institutions which historically focused on services for unmarried mothers and their children.

The Minister recognises that a significant number of people have been deeply affected by the experiences which they, or family members and relatives, may have had in these institutions.

The establishment of the Collaborative Forum is a new approach in the State's response to the theme of *"nothing about us without us"* which has emerged from the former residents who have participated in consultations to date. Open and consistent engagement between the State and former residents will provide a strong voice for former residents in the decisions which affect them.

This Forum is separate from the independent Commission of Investigation which is investigating the issues of significant public concern in relation to these institutions.

The purpose of the Collaborative Forum is to:

- 1) Build upon the process of engagement and consultation with former residents commenced through the facilitated meetings hosted by Minister Zappone in June and October 2017;
- 2) Enable former residents to identify, discuss and prioritise the issues of concern to them;
- 3) Facilitate the active participation of former residents in recommending actions and solutions to address their concerns, including those issues raised in the reports of the facilitated meetings;
- 4) Focus on persons who were resident for a time in a mother and baby home and those with comparable experiences in a County Home;
- 5) Have a role in monitoring the implementation of measures designed to support former residents;
- 6) Enhance public understanding and appreciation of the impact of their experiences on the lives of former residents and their families;
- 7) To provide reports to the Minister for Children and Youth Affairs in relation to these matters;

Membership

- 8) Will consist of 20 representative members including a Chairperson appointed by the Minister;
- 9) An independent panel will select representative members from those persons who express an interest in participating in this process;

Sub-committees

- 10) Three sub-committees, each with a unique focus, will be tasked with examining specific issues on a modular basis to facilitate the Forum in making recommendations to the

Minister. In addition to its members, the Forum may nominate additional persons to sit on these sub-committees. The three sub-committees are as follows:

a. Terminology, Identity, and Representation:

Develop respectful and inclusive language which represents former residents and their experiences; develop strategies to undo stigma and raise awareness around the use of appropriate language; design an awareness programme for public bodies to assist service providers in their interactions with former residents; examine the arrangements for the provision of information and communication with former residents;

b. Health and Well-being Supports:

To examine how best to assist the advocacy and support work of national and local groups; identifying and sharing good practice in peer to peer support activities; providing safe spaces to discuss and reflect on experiences; examine the type of professional counselling support required and how best to enhance access to such support; consider the separate needs of different groups and make recommendations to facilitate access to specific health and personal social services;

c. Memorialisation and Personal Narratives:

Examine the potential use of memorialisation in its various forms to acknowledge and recognise past events, and most significantly to inform how people perceive history; to consider the development of a scheme to fund permanent and lasting local memorials to honour and commemorate the children who died in each of the named institutions; to consider the establishment of oral and digital memories projects to ensure an archive of material is created and preserved. This could include interviews with mothers, children and others with relevant knowledge.

In conducting its work the Forum will:

- 11)** Be a participant-centred process which adopts a consensus-oriented decision making approach in its deliberations;
- 12)** Ensure consistent communication and meaningful engagement with former residents, their families and advocates during this collaborative project;
- 13)** Develop a strategy to facilitate wider public communication of its work;
- 14)** Facilitate the full and equal participation of all members;
- 15)** Ensure the specific and separate needs of different groups are identified;
- 16)** Have access to expertise and advice through an Inter-Agency Support Panel
- 17)** Have access to administrative resources through the Department of Children and Youth Affairs;
- 18)** Conduct its activities in a manner which does not impact upon or pre-empt the outcome of the statutory investigations being conducted by the Commission of Investigation (Mother and Baby Homes and certain related Matters);
- 19)** Provide its first report and recommendations to the Minister for Children and Youth Affairs within 6 months of its establishment.

Appendix B

Terms of Reference of the Inter-Departmental Working Group

Overall Goal of Working Group:

The Working Group is being established to undertake an assessment of the report's health and well-being related recommendations, given their range and complexity, and will develop proposals for a package of health and well-being supports, including access to any necessary health and social care measures, for former residents of related institutions.

Objectives:

1. The Group will assess the recommendations on health and well-being supports contained in the report, consider the appropriateness and feasibility of those health-related recommendations identified, and examine the accessibility of such services within the current health system;¹
2. The Group will seek to identify the scale and scope of healthcare supports which may be provided, as well as the potential funding implications and the impact on existing health services of providing same;
3. The Group will consider potential mechanisms to provide proposed health and well-being supports identified, including the appropriate legal basis and determination of eligibility for the provision of such supports;
4. The Group will report to the Minister for Health so as to facilitate the Minister reporting back to Government by September 2019.

¹ The work of the Group will have a particular focus on recommendations which are within the remit of the Department of Health, and will seek to take account, where appropriate, of input and expertise from other relevant stakeholders.

Appendix C

Department of Children and Youth Affairs Summary on Data Analysis of Former residents

Firstly, the Working Group was cognisant of the limitations in available data on the number, age profile, socio-economic circumstances and health needs of former residents. Indeed, the implications of this limitation and the necessity for an innovative approach to assessing service needs were clearly signalled by the Minister for Children and Youth Affairs in bringing the Collaborative Forum's recommendations to Government.

Information from the Collaborative Forum: The Forum's report provided a brief overview of the health status of survivors and refers to published research, testimony collated by advocacy Groups, its own surveys, and the report of the initial consultative processes facilitated by the Minister for Children and Youth Affairs. Their ages range from under 50 to over 80 years, so the profile of need would at a minimum reflect the expected diversity of needs among persons of middle and older years in the general population. The Forum's report does not however provide any specific estimates or data on the potential number of former residents.

Information from the Commission of Investigation: The Working Group recognises that the Commission of Investigation (Mother and Baby Homes and certain related Matters) is seeking to collate and analyse diverse sources of information at a level never been possible before. The Commission has the necessary legal powers to access records and seek oral witness testimony from public and private bodies/individuals. It has retained the necessary expertise and developed bespoke systems to assist in this comprehensive analysis. The Minister for Children and Youth Affairs advised her cabinet colleagues that the Commission of Investigation will be the best source of reliable collated data based on its analysis of registrations in these institutions and related evidence.

The Commission has reported that when its cross-referencing of all records is complete it should provide as comprehensive an account of former residents in these institutions as is possible to establish. The level and depth of this account and any related data will only become available when the Commission submits its final report - expected in February 2020.

It is important to understand that the 14 named institutions which are being examined, and the representative sample of County Homes, were quite different institutions in terms of ethos and their respective accommodation and care arrangements for mothers and infants. Some institutions pre-existed the establishment of the Irish Free State in 1922 while others opened at various intervals and operated for varying lengths during the period under investigation, namely 1922 – 1998.

County Homes are known to have played an important role in relation to unmarried mothers but importantly they also provided services for a diverse range of health and social services, including: services to older persons; the chronically sick; those with mental health and intellectual disabilities and children with disabilities. In some cases these institutions effectively functioned as homeless shelters where individuals and entire families resided for varying periods. The Commission has confirmed that there were 29 County Homes located throughout the State in the year 1949/1950 all of which were in operation since the establishment of the State in 1922. These institutions continued to operate until the 1960s when the remainder were converted into homes for the aged. The availability of records was one of the major factors considered by the Commission when selecting the representative sample of County Homes chosen for the inquiry.

The Second Interim Report from the Commission of Investigation states that the scope of its investigation includes approximately 70,000 mothers and a larger number of children who were

resident in the 14 named homes and selected 4 county homes. This figure (>140,000) is a further useful guide in seeking to assess the potential numbers involved. The Commission plans to include detailed information on infant and maternal deaths in the institutions in its final report. We already know from various published sources that mortality rates for the children of unmarried mothers in general, and in particular in the case of some of the specific institutions under investigation, were exceptionally high during the first half of the twentieth century. It is possible therefore that this information may further illustrate where the present exercise (based on CSO average life expectancy data) potentially overestimates the numbers who might avail of services in 2019 and beyond.

Furthermore, the Commission has confirmed that the named homes it is investigating are unquestionably the main such homes which existed in the 20th Century. However, it has also indicated that its investigations have identified some additional but generally smaller institutions which could also be described as Mother and Baby Homes. It has provided no further details to date but its final report may identify other facilities, and by extension other persons, which it may consider as potentially comparable to those resident in the institutions being investigated.

The data approach adopted by the Working Group: The Working Group concluded that in the limited time available it was not feasible or desirable to attempt to duplicate the work of the statutory Commission in this regard. For these reasons the Working Group has concentrated its efforts on generating projections from existing (but incomplete) macro level data on the numbers of mothers and children who were resident for a time in these institutions. The emphasis in the Working Group's approach was to establish an estimate of the number of former residents who might need to be factored into Government deliberations on any package of any supports which might be introduced in 2020 and beyond. Appropriate caution must be exercised in interpreting this data in recognition of the limitations and underlying assumptions necessarily adopted in the exercise.

The Minister previously informed her Government colleagues that preliminary data suggested that approximately 46,000 mothers and children (on an approximately 50:50 basis) spent time in the main mother and baby institutions from 1950 onwards. This data did not include the smaller mother and baby institutions, the county homes or any persons resident in these institutions pre 1950.

As part of its input to the Working Group, the Department of Children and Youth Affairs sought to develop a fuller picture of potential demand. The results of further analysis indicate that approximately 190,000 individuals (unmarried mothers and children as defined in the Commission's terms of reference) may have resided at some time in one of the 14 named institutions or in one of the County Homes (29 separate institutions existed in 1949/1950). This data covers the entire period from 1922-1998 consistent with the Commission's remit. While the available data does differentiate between persons who were resident pre1950 and post 1950 it does not readily assist in building a definitive age profile of the cohort of mothers or children.

It is evident that there will be a substantial difference between the potential total population of residents and the number of persons who may come forward now. In an effort to generate a more realistic estimate of potential demand in 2019/2020 the Department utilised the extensive data on life expectancy available from the Central Statistics Office. The cumulative figures are presented in Table A below and the Group proceeded on the basis of a working assumption of 57,000 former residents who may be alive today.

Limitations of the data: It is essential to reiterate the inherent limitations of this exercise, in particular the margin of error introduced by the extrapolations based on a relatively small data

sample for County Homes. The underlying assumptions and weaknesses must be appreciated in interpreting and utilising this data.

Persons living outside the jurisdiction: Experience from State engagement with survivors of other types of institutions demonstrates that approximately one third of potentially eligible applicants were residing outside the State. A similar trend could be expected in relation to the former residents of the institutions in question. Living outside the jurisdiction presents obvious practical barriers for such persons in seeking to avail of any health supports provided directly through the Irish health and social care services. In view of these difficulties, it is notable that the Forum makes specific recommendations which it considers capable of potentially meeting the needs of persons currently residing outside the jurisdiction. For this reason, no reduction for those potentially outside the jurisdiction has been made in these estimates.

Table A

	Total Mothers	Total Children	Total Residents	Estimated number of residents deceased	Number of residents who left institution less those recorded/estimated as dead			
Totals for Mother and Baby Homes	55000	51390	106390	64829	41561			
Totals for 3 County Homes	4600	4600	9200	7495	1705			
Estimated numbers in 25 County Homes	38333	38333	76666	62458	14208			
Estimated Totals County Homes	42933	42933	85866	69953	15913			
Notional Total Possible Survivors	97933	94323	192256	8785	183471			
Combined Totals MBH and County Homes	97933	94323	192256	134782	57474			
Age Now	Age 60+ Mother and Baby Homes Mothers Only	Age 60+ County Homes Mothers Only	Age 70+ Mother and Baby Homes Mothers Only	Age 70+ County Homes Mothers Only		Age Now	Age 60+ All Institutions Mothers and Children Estimated Still alive	Age 70+ All Institutions Mothers and Children Estimated Still alive
60	3842	312				60	13011	
70	4624	1315	4624	1315		70	14762	14762
80	1858	1002	1858	1002		80	5690	5690
90	667	894	667	894		90	1841	1841
100	137	176	137	176		100	313	313
Total Mothers in these age Categories	11128	3700	7286	3388		Total Number Survivors	35617	22606
Total Number of Surviving Mothers	16807	4046	16807	4046				
60+	66%	91%				60+	62%	
70+			43%	84%		70+		39%

Age Profile: An analysis of the expected age profile of the survivors suggests that in the case of the 14 Mother and Baby Homes 66% of the surviving mothers are expected to be more than sixty years old, while 43% of mothers could be more than seventy years old. These figures increase to 91% and

84% respectively for mothers in the County Homes. Including all former residents (mothers and children) for all qualifying institutions it is estimated that 60% may be more than sixty years old, with 40% being more than seventy years old.

Opportunities to build a clearer profile of former residents: As outlined in section 7.1 above, the Working Group also considers that measures which provide a dedicated support gateway for former residents could assist further research efforts to develop a more accurate profile of service need and potential demand from this Group of citizens. Such additional information would assist in the development of service responses which seek to tailor or target health system responses to this Group of citizens.

Eligibility – how to define and related practical issues: On the basis of the above analysis the scale and complexity of the task involved in seeking to reliably quantify the number of former residents who might seek to access any package of supports is immediately evident. This difficulty could be compounded by the practical challenges of assessing eligibility for any public health and social care service which may be deemed to be of value to the general population.

Should a decision be taken to set proof of residency in a qualifying institution as the eligibility threshold, then documentary evidence would presumably be required to demonstrate an individual was resident in a qualifying institution for a period of time. The records of some but not all of the relevant institutions are in the possession of the Child and Family Agency, TUSLA. It is understood that many of these records have now been digitised by the Commission in the course of its work. The comprehensiveness of the records is unknown although the Commission has signalled that many records are incomplete while others appear to have been lost, or perhaps not handed over when the relevant institutions ceased operating, but in any event cannot be located at this time. However, it is clear that significant additional TUSLA capacity and expertise would be required to enhance the accessibility of available information. Additional Freedom of Information and subject access requests under GDPR to relevant departments and their agencies could also be expected.

The Working Group recognises that eligibility could be further defined by residency in an attempt to prioritise specific cohorts, or to achieve a phased approach to targeting supports even within the Group of former residents. For example, eligibility defined on the basis of those who are now aged over 60, or alternatively those who were resident in the institutions as mothers, might deliver a more equitable and prioritised focus on the cohort of former residents who are of advanced years.