

Annex 2 - Template for proposal of social module for the Quarterly National Household Survey

Government Department or Organisation proposing module

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Please give a brief outline of the proposal

This proposal is for a module on wellbeing, with a specific focus on living independently and being included in the community. An international trend towards measuring wellbeing is emerging as an aspect of health promotion, replacing ‘quality of life’ standards in determining the population’s potential for social and economic activity. The New Economics Forum has argued for the “integration of social, economic and ecological policies in order to ensure that maximising population well-being is viewed as complementary to and equal in importance to maximising economic growth.”¹ Many countries have developed national indicators for measuring wellbeing, using data collected to shape social and economic policy to ensure maximum productivity.

The focus of this proposed module will be on the level of choice open to individuals to live independently, and the supports to enable people to be included in their communities, as integral aspects of human wellbeing. These specific issues have been selected as they are important preconditions for economic and social activity. Living independently (particularly with regard to financial independence and housing options) is a vital step both towards social integration and economic participation, including access to the open labour market. There is increasing international recognition of the connection between social capital, the economy and wellbeing, and the subsequent impact which this relationship can have on the development of public policy.

There is a significant gap in national data in Ireland on these issues, especially as they relate to people with disabilities (including those with mental health difficulties), carers, children, families and older people. This approach will allow for the analysis of previously isolated cohorts and their combined experiences, using a lifecourse perspective. While these populations are the key target of this proposed module, the questions are sufficiently broad in scope to allow the general population to participate in this module, and the data collected can subsequently be disaggregated by disability status and other demographics to provide an overall picture of wellbeing and its impact on economic and social activity. This module on wellbeing aims to cover three discrete topics. The first two are based on the idea of living independently, and examine financial independence and options for independent housing barriers. The final topic focuses on social participation and being included in the community. Key outputs required (in the form of suggested questions) are described further below.

Please outline the compatibility of the proposal with the core QNHS

(The main purpose of the QNHS is the production of quarterly labour force estimates. The survey also includes a broad range of categorical variables including age, sex, region, employment status, Occupation, Economic activity, Hours worked, Educational attainment levels and Family composition)

This module would be compatible with the core QNHS as data on wellbeing (including information on financial independence and social participation) is of particular interest in analysing the make up of the labour force in Ireland, and assessing the potential and current contributions of those who might not currently be working in the open labour market. It would demonstrate whether social connectedness is linked to certain economic advantages, and show the social and economic consequences of diminishing social capital and wellbeing.

While the proposed module avoids duplication in terms of the questions already posed in the core QNHS and in previous social/ad-hoc modules, it also compliments the information already available, and the key outputs required can be posed as questions in a similar format to that currently used on the QNHS. The broad range of variables included in the core QNHS will also be useful for this proposed module, especially demographics on sex, age, and family composition.

¹ Barry, M., “Addressing the Determinants of Positive Mental Health: Concepts, Evidence and Practice” 11(3) *International Journal of Mental Health Promotion* (2009) 5.

What are the key outputs required?

(Please identify the key pieces of information required and the type of categorical analysis required. It may be useful to consider what the potential release tables might look like. For example in relation to Disability one of the key outputs might include: The number of persons with a Disability classified by age, sex, region etc.)

While there can be a temptation to use the ad-hoc module as an opportunity to cover all areas of a particular topic, our experience over the past several years shows that this does not work in the QNHS modules. Respondents will already have answered the lengthy core QNHS questionnaire and respondent fatigue becomes a considerable issue if modules are too long. Therefore we suggest a 'focussed' module identifying three to four areas of interest.

As stated above, the key outputs relate broadly to two focus areas: independent living (financial independence, choice in living arrangements) and social participation (being included in the community). A number of suggested outputs in each category are listed below.

A. Living independently – Financial independence

Financial literacy is an important determinant of economic activity. Marginalised cohorts such as people with disabilities, older people or carers may need support to achieve financial independence, which in turn facilitates economic activity. In particular, support with making major financial decisions e.g. whether to re-mortgage a property, can have a significant impact on other aspects of wellbeing. The key outputs suggested below aim to reflect the broad spectrum of financial decision-making and independence.

1. Awareness of and access to bank account (this is a particularly pertinent question for people with disabilities and older people)
2. Managing money on a daily basis (e.g. do you manage your money to pay for groceries, utility bills, rent, etc. or does someone else do this for you?)
3. Making major financial decisions (e.g. have you made decisions about re-financing, taking out a loan, purchasing property)
4. Support for major financial decisions (e.g. did you seek support in making these decisions, e.g. from family members, carers, service providers, or state-operated supports e.g. the Money Advice and Budgeting Services)

B. Living independently – Housing and Accommodation

A key factor in living independently (particularly for people with disabilities and older people) is whether people can choose where and with whom to live. Barriers to making these choices need to be identified before these issues can be addressed by comprehensive public policy. Specifically, it will be important to determine whether these barriers relate to financial issues, accessibility of the built environment/transport, or lack of other types of support. While these questions have been asked in some other national surveys, they have not been framed in terms of barriers to independent living, and this is a key output sought from the proposed module. In addition, the existence or lack of opportunities for carers to live independently from those they support is a very important issue which has not been addressed in previous surveys. The inclusion of such a question in the proposed module may result in data which shows a pattern of service providers rationing supports on a theory that the carer is always available – thus substantially constricting the right to independent living for carers.

1. Choice of where and with whom to live
2. Barriers to choice (e.g. insurance constraints re freedom in dwelling, financial barriers to moving out of home, lack of accessible transport to home/work/community, distance from family/support network, unaware of alternatives)
3. Need for and availability of in home supports (e.g. aids/devices and personal assistance)

4. Who provides support (e.g. family, unpaid carer, paid support person, aids/adaptations provided through local authority grant or private service provider)

5. Reasons for not having support (e.g. financial barriers, lack of suitable person to provide support, unaware of the aids/adaptations needed or how to obtain them)

6. Opportunities for carers to live independent lives (e.g. whether they perceive themselves as living independently, what they view the barriers as, whether they feel that their social circles have become constricted, etc.)

C. Being included in the community – social connectedness

Social connection and inclusion in the community are key indicators of wellbeing and life satisfaction which can be linked to economic activity. Some of the key issues which need to be addressed here are the types of social activity which children and young people, carers, people with disabilities and older people are engaged in, and the levels of intergenerational activity in the community. Again, barriers to participation must be highlighted and interrogated, along with the perceived impact of participation or lack thereof. Specific issues of particular interest include loneliness and victimisation – and the impact which these have on social integration (including discouraging children from remaining in mainstream education, leading to the reinstitutionalisation of disabled people and older people and contributing to a decline in mental health and wellbeing in carers and others). In addition, it will be important to measure levels and types of political participation and civic engagement across the cohorts mentioned, and compare this with participation and involvement in the general population. Finally, this section includes a question on health insurance and life assurance, as key contributory elements to the notion of social participation. This question will determine whether appropriate access to insurance reflects the social purpose of insurance, and ensures that those who need the benefits which insurance affords are not removed from the insurance pools.

1. Types of social/community activities participated in (e.g. cultural activities, leisure, recreation, sport, political/lobbying, etc.)

2. Supports to facilitate participation in community (personal assistance, accessible transport, etc.)

3. Who provides support (e.g. family, unpaid carer, volunteer, paid support person, etc.)

4. Reasons for not having support (e.g. financial barriers, lack of suitable person to provide support, unaware of the support available or how to obtain it)

5. Reasons for not participating in community/social activities (lack of support, inaccessible facilities, inaccessible transport, no interest/desire to participate)

6. Impact of lack of social participation (e.g. loneliness, deterioration in health condition/general wellbeing, etc.)

7. Victimisation/bullying/harassment (e.g. in education linked to reasons for leaving mainstream education and re-entering special schools, in the community this is linked to deinstitutionalisation and re-institutionalisation)

8. Social networks and social connectedness (e.g. who do individuals turn to for support, do they feel connected to others in the community, are there levels of intergenerational interaction)

9. Political participation (e.g. proportion who voted in last election, participation in lobbying/campaigning)

10. Health insurance and life assurance (e.g. where increase in premium or refused insurance, do you think this is linked to one of the following issues: health status, age, sex, request for family history of

illness)

How well does the proposal sit within the context of the core survey?

(The QNHS survey interviews take place in a face-to-face environment with laptops (electronic questionnaires are used). Respondents are often answering questions while other household members are present (including children) or at their front door. Therefore, the sensitivity of the proposed topic is an important factor to consider. The types of questions that work best are those where the answer is obvious to the respondent (questions that require access to household documentation to enable responses do not work in the QNHS)).

The sensitivity of questions asked is a key consideration in any social module for the QNHS. However, questions on the proposed topics outlined above can be framed in a sensitive manner and still produce the key outputs required. None of these questions or topics address more sensitive areas than those which have been the focus of previous social modules (e.g. equality module questions on discrimination, health service module questions on health levels, etc.) In addition, the answer to the vast majority of the questions proposed will be obvious to the respondent and do not require access to household documentation (with the possible exception of questions on insurance).

What are the key policy implications?

These focus areas would stitch together a number of previously isolated cohorts across the lifecourse (children and young people, families, people with disabilities and older people) and data gathered could lead to the development of more coherent policies, building on the experience of all these groups. For example, separate approaches to independent living have been taken in relation to people with disabilities and older people, and there is a clear need for joined-up thinking in this area. Another example exists in relation to social participation, as a lack of social connectedness is often anecdotally linked to onset of mental health difficulties and increased vulnerability to exploitation and abuse, but no coherent policy approach has been introduced to address this, as there is no accurate national data to demonstrate the link.

The potential impact of such a module on key public and social policy documents is significant. Some of the key policies which could be adapted or reframed in light of this information are the National Disability Strategy, the National Children's Strategy, the National Positive Ageing Strategy (currently in its consultation phase), National Carers Strategy (unpublished), A Vision for Change: Report of the Expert Group on Mental Policy, Towards 2016: The Ten-Year Framework Social Partnership Agreement, etc. Ultimately, it is hoped that this kind of data-collection could facilitate the adoption of lifecourse public policies based on population wellbeing, to replace the current approach of separate policies for various cohorts, operating in isolation.

Are there any alternative sources and if so what is the rationale for the inclusion of a module in the QNHS?

Although some alternative sources touch on the topics identified in the key outputs above, none addresses the issues raised in a comprehensive way, gathering data from a number of target groups across the lifecourse (children, families, carers, older people and people with disabilities). The existing data sources are also inadequate in terms of the level of detail obtained from the questions asked. For example, there are several sources on employment status, but few which explore reasons for failure to take up employment or barriers to entering the open labour market from the perspective of people with disabilities. Also, although some of the key outputs listed are similar to questions which were asked in the National Disability Survey it is unlikely that this survey will be repeated, and the inclusion of a module in the QNHS is the only way to ensure comparable data is obtained. Finally, the QNHS represents an opportunity to take a holistic sample from private households, and obtain information which can be periodically updated in future cycles of similar social modules. This opportunity is not available with any of the existing data sets. The full list of sources currently available, limitations of existing data and ways in which the proposed module could address these gaps is given below in the section on reference documentation.

Please identify the target group?

(Note: The survey only interviews persons aged 15 and over)

The target group for this module would be young people aged 15-18, persons with disabilities aged 15+, carers and family members aged 15+ and older people aged over 65. Although the core QNHS does not cover people aged 65+ certain social modules have included older people in their target group e.g. the module on carers in 2009. If these groups (15-18 and 65+) were to be excluded from the module the key outputs obtained would be less relevant in terms of potential impact on policy. In addition, although the QNHS focuses only on private households, and does not cover nursing homes, hospices, hospitals and other institutions it should be noted that many people with disabilities live in congregated settings and for those individuals, although they may not have chosen to live there, this setting may well be their home/household. It would be important not to exclude those in congregated settings from future cycles of the QNHS and additional social modules.

Please outline (where available) reference documentation including survey work previously undertaken on this subject (whether nationally or internationally)? In addition, please outline how this module will add to the body of research already in existence?

A number of sources exist in Ireland which contain data similar to that sought in the key outputs section above. Some of the most relevant national sources on the specific focus areas are listed here.

The National Disability Survey

http://www.cso.ie/releasespublications/documents/other_releases/nationaldisabilityvol2/NDS2006Publication.pdf

This survey (volume 2 in particular) contains data on accessibility (of buildings and transport), caring and help from other persons, and social participation. However, the questions on accessibility do not consider the specific issue of independent living and the questions on caring do not include the perspectives of carers. Questions on social participation contained in the survey are well-framed and could form the basis for similar questions in the proposed module, with a view to obtaining comparable data.

Study of Young Carers in the Irish Population

http://childandfamilyresearch.ie/sites/www.childandfamilyresearch.ie/files/studyofyoungcarers-main_report.pdf

This study focused on carers under 18 who provide, or help to provide care to another person. It included questions on supports, impact of caring, reasons why help needed, etc., and produced valuable information on the experiences of young carers. However, it will be important to compare this data to the experiences of carers across the lifecourse and to the experiences of those cared for, and the proposed module can achieve these aims.

European Disability and Social Integration Module

http://circa.europa.eu/Public/irc/dsis/health/library?l=/reports/disability/edsim/edsim_final_2008pdf/E_N_1.0_&a=d

This module contains questions on access to and use of Internet, access to learning opportunities, employment, economic life, mobility, transport, community life and leisure pursuits, accessibility to buildings, social contact and negative attitudes and behaviour. While the proposed module is anxious not to duplicate the questions in EDSIM, it recognises that there are gaps in the data collected by

EUROSTAT, which could be usefully supplemented by the questions proposed in the key outputs section above.

Health Research Board databases (National Intellectual Disability Database and National Physical and Sensory Disability Database)

<http://www.hrb.ie/health-information-in-house-research/disability/npsdd/>
<http://www.hrb.ie/health-information-in-house-research/disability/nidd/>

These databases provide records of those receiving or applying for disability services – but are not comprehensive and only record service requirements. In terms of limitations in the data, the databases do not record the service needs of people with mental health difficulties there is no equivalent source of information regarding people with mental illness. Secondly, the NPSDD is not comprehensive both because it excludes people over 65 and because of the voluntary nature of responses recorded on the database.² Thirdly, the databases only relate to the provision and shortfall of the services provided by the State. The proposed module would add significantly to the information available in these databases.

Academic Network of European Disability experts, The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report

<http://www.disability-europe.net/content/pdf/ANED-Task%205%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf>

This report focuses on independent living for disabled people and collects data from across Europe, specifically on choice of where and with whom to live, and the availability of supports to live and be included in the community. The data focuses on policy approaches towards independent living and barriers to achieving independent living. However, it does not contain data on individuals' experiences of independent living or inclusion in the community, a valuable insight which the proposed module could provide.

Survey of Lifestyle, Attitudes and Nutrition in Ireland: Mental Health and Social Well-being Report 2007

http://www.slan06.ie/Slan2007_Mental_Health_Report_9.3_MB.pdf

This report contains key findings on mental health and wellbeing, and social wellbeing, including questions on loneliness, community involvement and social supports which could be used as models for the key outputs sought from the proposed module. Its conclusions are also framed in terms of policy implications, which is a useful example of how such findings can be presented. However, the sample here used participants who were aged 18 years and over, and the proposed module could compliment this data by including young people aged 15 to 18.

Health Behaviours in School Age Children Ireland

<http://www.nuigalway.ie/hbsc/2010survey.html>

This study provides a useful model for framing questions on health and wellbeing for children and young people. However, it does not address broader issues of social participation and independent living which are included in the proposed module. Although data from the 2010 survey has not yet been released the proposed module would be very useful in providing comparative data.

The Irish Longitudinal Study on Ageing

<http://www.tcd.ie/tilda/assets/pdf/DesignReport2010.pdf>

This study contains a wealth of information on ageing in Ireland, including economic information and data on social participation, and even contains a specific supplement on intellectual disability but the sample only includes people aged 50 and over. Therefore, the proposed module would add value to the data currently being gathered in TILDA and provide a useful basis for comparative analysis.

² Information is collected from people with a physical and/or sensory disability who are receiving or who need a specialised health or personal social service currently or within the next five years and who have a persistent physical or sensory disability arising from disease, disorder or trauma; in the case of dual disability, have a predominant disability that is physical or sensory; are under 66 years of age; are receiving, or require, a specialised health or personal social service which is related to their disability; and have consented to being included on the Database.

Other QNHS Social Modules (e.g. carers, equality, disability and employment, union membership, housing, voting, crime and victimisation, educational attainment, lifelong learning, ICT, childcare, pensions, etc.)

http://www.cso.ie/qnhs/spe_mod_qnhs.htm

The CSO has run several social modules which are relevant to the proposed module. In developing the proposed module, care has been taken to avoid duplication in the key outputs, while adding value to data currently available on similar issues.

For example, previous social modules have mentioned insurance generally, including the Equality module (2010) which asked: “In the past two years, have you personally felt discriminated against using services of banks, insurance companies or other financial institutions?”, and “why?”. This question did not differentiate insurance from banks or other financial institutions and did not ask specific questions on health insurance or life assurance. The Health Status and Health Service Utilisation module (2008) simply established what type of cover an individual has (for example, medical card, private health insurance).

The proposed module adds a new element in relation to insurance (in the context of independent living and inclusion in the community), focusing specifically on health insurance and life assurance, and the impact upon financial independence. In addition, the proposed module asks if there was an increase in the insurance premium/ or a refusal of insurance coverage, and if so, does an individual think this was linked to health status, age, sex, request for family history of illness/ disease. The issue of “request for family history of illness/ disease” has not been asked before across any of the social modules.

Finally, in terms of international research on wellbeing, the World Health Organisation has produced a number of reports, specifically relating to mental health and wellbeing, which identify indicators of wellbeing, and the impact of wellbeing and life satisfaction on social and economic activity.³ Helliwell has also conducted international research on social capital, the economy and well-being which could help to frame the methodology of the proposed module.⁴

Please outline your assessment of the potential burden on respondents?

Although some of the questions posed are of a sensitive nature the answers being sought can be made clear (e.g. through the use of examples as demonstrated above in the section on key outputs) and this should minimise the potential burden on respondents. In addition since the proposed module focuses on three specific areas it is relatively concise and should not pose a significant additional burden for respondents who have already answered the core QNHS questions.

Please provide an assessment of the complexity of the module proposed from a respondent’s perspective?

The key outputs sought on this module involve relatively straightforward questions about daily activities, choices and experiences which are not overly complex for respondents to answer.

Are there any other users/organisations who would be interested in this module?

(It is policy to set up liaison groups to discuss the details of a module that has been selected for inclusion in the QNHS. The names of individuals/organisations that you provide here will be used for that purpose).

³ See for example, World Health Organization, *Mental Health Action Plan for Europe: Facing the Challenges, Building Solutions* (Geneva, Switzerland: World Health Organization, 2005) and WHO Commission on the Social Determinants of Health, *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health – Final Report of the Commission on the Social Determinants of Health* (Geneva, Switzerland: World Health Organization, 2008).

⁴ Helliwell, J. F., “Social Capital, the Economy and Well-being” in Sharpe, A., St-Hilare, F. and Banting, K., *The Review of Economic Performance and Social Progress 2001: The Longest Decade: Canada in the 1990s* (Ottawa: Centre for the Study of Living Standards & The Institute for Research on Public Policy, 2001) and Helliwell, J. F., “Well-being, Social Capital and Public Policy: What’s New?” 116 *The Economic Journal* (2006) C34-45.

This proposal is being put forward by the Lifecourse Institute at the National University of Ireland Galway, which is made up of three distinct research centres: the Centre for Disability Law and Policy, the Centre for Child and Family Research and the Irish Centre for Social Gerontology. Many of the organisations and research bodies which work closely with these individual centres would have an interest in the key outputs proposed in the module, including the National Disability Authority, Ageing Well Network, Age and Opportunity and Age Action Older and Bolder, the Irish Senior Citizens Parliament, the National Disability Strategy Stakeholders Monitoring Group, Inclusion Ireland, the National Federation of Voluntary Bodies, Barnardos, the Children's Act Advisory Board, Saint Vincent de Paul, Foróige, Dáil na nÓg, Youthwork Ireland, the National Youth Council, Headstrong, etc.