

Outcome Measurement in evaluating the Quality of Disability Services

Discussion Document

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Executive Summary

This discussion paper explores the purpose, challenges and limitations of outcome measurement in disability services. It highlights the need to align outcome measurement with the development of person-centred disability services. Such services provide tailored support and opportunities to each individual with a disability. In this way, each person is in a position to strive for his/her goals and attain a good quality of life. The target audience for this paper includes policy makers, funders of services, regulatory bodies and service providers including the Department of Health, HSE and HIQA. This paper provides an overview of considerations regarding outcome measurement in disability services and the range of developments to enhance quality assurance in this regard. The paper is intended to assist the initiation of a discussion among the relevant stakeholders about how best to use outcome measurement in disability services so that it reinforces the delivery of appropriate supports and opportunities to individuals with disabilities so that they can strive to attain personal outcomes and a good quality of life.

There is a tension between particular outcomes measurement approaches and embedding a personal outcomes approach in disability services. The paper explores these tensions, highlighting the need for outcome measurement to support the building of robust person-centred disability services. Cook and Miller (2012) warn that reductionist and linear approaches to outcomes measurement can detract from a focus on quality conversations between staff and the persons they support.¹ Only by working with each individual can staff come to know each person's goals, priorities and strengths. They can then provide an individual with tailored support and opportunities so that he/she can strive for his/her goals. Good personal and professional relationships are central to person-centred services and the ultimate purpose of outcome measurement in disability services is to ensure that services learn to support each individual in a personalised way.

Traditionally, stakeholders monitored public services by measuring funding and staffing, programmes delivered and numbers of persons supported. Today, the drive is to place personal outcomes at the heart of monitoring and accountability frameworks. In Ireland, the 2012 'Value for Money and Policy Review of Disability Services' recommended outcome measurement at personal, organisational and programme levels to ensure progress in improving personal outcomes for persons with a disability.

¹ Cook, A. and Miller, E. (2012) Talking Points personal outcomes approach: Practical Guide, JIT: Edinburgh <https://personaloutcomes.files.wordpress.com/2014/03/talking-points-practical-guide>

Since 2012, the National Disability Authority (NDA) has supported the Department of Health and the HSE to deliver the recommendations of the 'Value for Money and Policy Review of Disability Services' through the implementation of the Transforming Lives Programme. Its purpose is to develop services so that they can deliver individualised and community supports so that each individual person with a disability attains a good quality of life in the community.

Significant NDA contributions to the Transforming Lives Programme include the development, with the HSE, of three aligned frameworks for disability services to help them support persons with disabilities more effectively. The three frameworks are:

- A Quality of Life Outcomes Domain Framework for Disability Services
- A National Framework for Person-Centred Planning in Services for Persons with a Disability
- A Quality Framework: supporting persons with disabilities to achieve personal outcomes

A Quality of Life Outcomes Domain Framework for Disability Services

In 2016, following research and consultation on outcomes, the NDA proposed nine quality of life outcome domains. The Department of Health and the HSE approved this outcomes framework for Irish Disability Services. The outcome domains align with the Health Information and Quality Authority (HIQA) Residential Standards, the Interim Standards for New Directions and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The outcome domains reflect widely recognised aspects of life important for all people, which constitute the various aspects of quality of life. The approved nine quality of life outcome domains framework for disability services are as follows:

Persons who use disability services:

- 1. Are living in their own home in the community**
- 2. Are exercising choice and control in their everyday lives**
- 3. Are participating in social and civic life**
- 4. Have meaningful personal relationships**
- 5. Have opportunities for personal development and fulfilment of aspirations**
- 6. Have a job or other valued social roles**
- 7. Are enjoying a good quality of life and well being**
- 8. Are achieving best possible health**
- 9. Are safe, secure and free from abuse**

For an individual person, his/her desired goals and vision for life fall under the various outcome domains: living where and with whom he/she wishes; having friends and good relationships with family and others in the local community; skills development, meaningful activities, a social life, etc.

A National Framework for Person-Centred Planning in Services for Persons with a Disability

This framework informs and guides the implementation of person-centred planning in services for persons with a disability. To commence the implementation of the framework, the HSE has agreed a Demonstration Project with five provider organizations in 2019. The five organizations participating in the implementation of the Person-Centred Planning Framework during 2019 will be evaluating their current model of Person-Centred Planning and its alignment with the Person-Centred Planning Framework. The experience learned through this demonstration project will inform the development of strategy and planning for the wider roll out of the framework throughout the adult disability service sector. Person-Centred Planning is central to embedding personal outcomes in practice and ensuring that staff work with each individual, and with his/her family where relevant, to identify the goals that are important to him/her. Staff then provide appropriate supports to help each person attain the desired goals in the various outcome domains in the way that they want.

A Quality Framework: supporting persons with disabilities to achieve personal outcomes (awaiting publication)

The interplay between individualised services and supports and the achievement of personal outcomes is extremely important and is the focus of this quality framework. The purpose of developing the framework was to identify the elements of services and supports that facilitate the achievement of outcomes by adults with disabilities. To do this, the NDA reviewed the literature on developing disability services and systems and on the predictors of outcomes for persons with disabilities. The quality framework identifies a range of outcome predictors, which are the elements of services and supports that facilitate the achievement of personal outcomes by adults with disabilities.

It is important that stakeholders and, in particular, funding and evaluating bodies, support the implementation of these interrelated frameworks until they are embedded in services so that personal outcomes for individuals with disabilities improve. “The next piece of the jigsaw” is outcome measurement. Stakeholders can use this paper to consider, discuss and plan how best to employ outcome measurement in disability services so that it reinforces the delivery of appropriate supports and opportunities to individuals with disabilities so that they can strive to attain personal outcomes and a good quality of life.

Using Outcome Measurement in Disability Services

Outcome measurement in services can evaluate individual progress towards goals set by the individual in the PCP process. It can assess the quality of life of individuals. It can attempt to determine what services have contributed to individual progress towards their goals. It can identify the presence or absence of outcome predictors in disability services. Outcome predictors are the supports and opportunities that enable persons with disabilities develop their capacities and attain goals in the quality of life outcome domains and include, for example, transport, person-centred planning and access to advocacy, etc. In order to evaluate whether services are supporting persons with disabilities to attain outcomes, one must answer the following related questions:

- Are persons with disabilities who use disability services making progress towards attaining personal outcomes and a good quality of life?
- What are disability services contributing to progress towards personal outcome attainment where the person himself/herself has defined the personal outcomes?
- Are outcome predictors evident in the disability services under evaluation?

In outcome measurement, different assumptions about the relationship between service provision and outcomes alter the way in which one measures outcomes. However, those using and measuring outcomes are rarely explicit about such differences. It is important to clarify assumptions about the relationship between services and outcomes and the implications of the relationships for measurement. It is important to explain ones' concept of 'outcome' and explicitly state individual personal outcomes, service provider outcomes and system-wide outcomes to highlight where there are conflicting goals. For example, if a service provider's outcome is to provide congregated residential care for persons with disabilities, this service provider cannot appropriately support a person whose desired outcome is to live independently in the community. Similarly, if a stated national outcome is that people with disabilities live independently in the community, funding a provider of congregated residential services cannot help attain this goal.²

While it is possible to identify broad categories of outcomes, as in the Quality of Life Outcomes Domains Framework, in practice, what is important to an individual varies from person to person and with the life-stage of the person, their age, health, and skills, etc. Consequently, a central feature of person-centred

² p.147, Report of Disability Policy Review prepared by Fiona Keogh PhD on behalf of the Expert Reference Group on Disability Policy December 2010 https://health.gov.ie/wp-content/uploads/2014/08/ERG_Disability_Policy_Review_Final.pdf

planning is that the person defines their goals. Thus, services need to work with each person, one by one, to determine the goals that are important to them and how they will achieve them. In this process, staff build on the individual's strengths and, where indicated, provide him or her with supports and opportunities. As set out in the framework for person-centred planning, there is a need for regular reviews of person-centred plans, with both formal and informal review encouraged. There should also be an overall system of evaluation in place across the service including the measurement of outcomes - the changes in a person's life resulting from person-centred planning. This approach distinguishes clearly between outcomes important to a person and outcomes experienced because of a disability service programme or intervention, which may or may not be what the person wants.³

In summary, the ultimate purpose of outcome measurement in disability services is to ensure that each person receives the supports and opportunities they need to strive for their goals and enjoy a good quality of life. Monitoring individual progress towards attaining personal goals in the various outcome domains should help to ensure this. The framework for person-centred planning advises that measuring outcomes should be part of an overall system of evaluation within a service. The best indication of the usefulness of outcome measurement, therefore, from the viewpoint of developing person centred disability services, is to use measurement to help services deliver appropriate and tailored supports and opportunities to the individuals that need support.⁴ Services should feed the results of outcome measurement into their quality improvement system to identify where and how they can improve on their delivery of supports and opportunities. One of the outcome predictors in the 'quality framework: supporting persons with disabilities to achieve personal outcomes' is that 'an organisation aligns services and supports and resource allocation with desired personal outcomes.'

While the ultimate purpose of outcome measurement is to ensure that each person attains a good quality of life, commensurate with that of their non-disabled peers, stakeholders measure outcomes in disability services at different levels, in different ways and for different purposes:

³ Cook, A (2017) Outcomes Based Approaches in Public Service Reform
<http://whatworksscotland.ac.uk/wp-content/uploads/2017/04/>

⁴ It is important to point out, for example, that many persons with an intellectual disability do not require supports. In 2011, a case study in two regions in Ireland showed that 72.7% of persons with ID in one region and 80.8% in the second region, did not require supports. This study used the National Intellectual Disability Database, a national service planning tool.
www.ucd.ie/psychology/pdfs/.../FINAL_MOVING_AHEAD_POLICY_REVIEW.pdf

- At the individual level, the purpose of outcome measurement is to identify whether each individual with a disability is making progress towards his/her desired goals in the quality of life outcome domains.** At this level, the outcomes of interest are those that are important to the person and defined by him/her. Measuring outcomes at this level should help services to remain focused on providing supports/opportunities that facilitate individuals to attain their goals. Staff must ascertain what each person's goals are, for example, employment, living in the community, engaging in meaningful activities, etc. They must create a learning and collaborative culture so that staff work creatively to provide individualised support that gives each person his/her best chance of working towards their goals. Results of outcome measurement at this level should indicate if services are person-centred and outcomes-focused. There are a number of tools available to assist in personal outcome measurement. For example, the Council on Quality and Leadership's Personal Outcomes Measure Tool, POMS, is a licensed individual outcomes tool for individualised outcome planning and measurement. Some service providers in the USA, Ireland, Canada and Australia use POMS. Small disability service providers that cannot afford costly tools may create their own planning/monitoring tools. Some services in Ireland, Australia and England use software packages, such as I-Planit, adapted for person-centred planning and outcome measurement at the individual and service level. Others use software packages such as Salesforce.
- At the service level, stakeholders' measure aggregated individual outcomes or use standardised outcome indicators to evaluate service quality and/or to benchmark services and assess value for money.** If using such outcome data to benchmark services, one must ensure that data is risk adjusted to account for differences in individual characteristics such as age, level of intellectual disability, mobility level, health status, mental illness and whether behavioural supports are needed to prevent destructive behaviour or self-injury. At the service level, stakeholders using standardised indicators are not investigating the outcomes important to each individual but using a set of agreed quality of life outcome indicators. These outcome indicators might include, for example, the proportion of persons in paid employment, who have attained a certain level of education, who have access to an independent advocate, who are living in their own home, etc.
- To support quality improvement systems in disability services, the purpose of outcome measurement is to identify what needs to change so that services and staff deliver the support that helps each person work towards quality of life outcomes.** Results/data from aggregated individual personal outcome measurement and from standardised outcome measurement at the service level should both feed into the disability

services quality improvement system in order to improve the provision of appropriate supports and opportunities.

- **The purpose of quality assurance is to ensure that services fulfil (in particular, any statutory) quality management requirements such as demonstrating sound governance structures, including financial procedures, implementing standards, and having complaints and incident reporting processes:** Quality assurance uses a standardised process for assessing service quality. Nowadays, this process should include an outcomes focus and, increasingly, quality assurance/inspection processes in disability services do include some element of outcome measurement. This is because, while compliance with policies, standards and regulations is essential, if the quality assurance processes do not deliver improved personal outcomes to individual persons, something is amiss. In the UK, the Initial Government Response to the Mid-Staffordshire NHS Foundation Trust Public Inquiry emphasised what goes wrong with quality assurance if the person and his/her personal outcomes are not the focus of assessment.⁵ A Kings Fund paper highlights that while regulatory bodies are often criticised when services are of poor quality, external regulation/quality assurance is only the third line of defence.⁶ First and second lines of defence are the attitudes, behaviours and practices of front-line staff and those of the management including managers and board members. To ensure that services deliver outcomes, quality assurance should include a focus on quality of life personal outcomes.

Challenges associated with Outcomes Measurement in Disability Services

There are challenges in measuring outcomes in meaningful and effective ways and Section 2.1 of this paper explores challenges, which include the following:

- Outcomes are multifaceted in nature (as are interventions that support persons attain their goals), which makes outcome measurement difficult.
- A literature review on outcome measurement highlighted that while there is agreement on the importance of individuals with disabilities attaining particular outcomes such as full societal participation and self-determination, it is challenging to develop tools that effectively measure such outcomes.⁷ This is

⁵ <https://www.gov.uk/government/publications/government-initial-response-to-the-mid-staffs-report>

⁶ Dixon, A., et al (2012) How to assure quality in the NHS: preparing for the Francis Report https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/preparing-for-the-francis-report-jul2012.pdf

⁷ Quilliam, C., Wilson, E. (2011) Literature Review Outcomes Measurement in Disability Services: a review of policy contexts, measurement approaches and selected measurement tools. Melbourne: Deakin University

because operationalising concepts such as ‘self-determination’, ‘societal participation’, ‘care’ and ‘support’ into outcome measures is difficult. Also designing measures of abstract and complex concepts that can take into account variations in individual capacity is challenging.

- A significant proportion of individuals with intellectual disabilities who live in congregated settings in Ireland have a severe or profound intellectual disability. Cognitive and verbal limitations can affect the ability of individuals to communicate their goals, express themselves and their satisfaction with the quality of supports, and evaluate the role that services play in supporting them attain their goals.
- Experts do not recommend using proxies to evaluate subjective quality of life in persons with a severe or profound intellectual disability and many consider the use of proxies invalid in assessing subjective quality of life. However, agencies continue to use proxies rather than exclude individuals from data collection, trying instead to improve how proxies assess outcomes and quality of life.⁸ In proxy triangulation, two familiar observers and a third unfamiliar observer attempt to determine subjective quality of life in persons with severe and profound intellectual disability: “While triangulation is seen to be good practice in quality of life, the role of proxies in assessing the quality of life of persons with profound intellectual and multiple disabilities needs further investigation”.⁹
- There is growing interest in the use of observation to evaluate quality of life even if time consuming and more difficult to standardise. However, this method may result in modifications in the behaviour of staff and persons with a disability. Disability services have an important role to play in finding new ways to develop effective communication and in researching how best to evaluate the quality of life of people with profound cognitive and verbal difficulties.
- Attaining outcomes are generally due to multiple interacting factors, some of which are unrelated to services, such as individual characteristics, motivation, health status, support from family and friends, and access to independent financial means. In addition, a person’s situation can change and a health condition can worsen or improve, etc., with an impact on outcomes attained that is independent of the quality of service provision. It is therefore more

⁸ Rand, S., Caiels, J (2015) reviewed the issues and challenges and made recommendations on using proxies to assess Quality of Life. <https://core.ac.uk/download/pdf/42411586.pdf>

⁹ p.1, Appolonia M. Nieuwenhuijse, Dick L. Willems, Johannes B. van Goudoever, Michael A. Echteld & Erik Olsman (2017): Quality of life of persons with profound intellectual and multiple disabilities: A narrative literature review of concepts, assessment methods and assessors, *Journal of Intellectual & Developmental Disability*,

realistic to assess contribution of disability services to outcome attainment rather than trying to attribute outcomes to disability services alone. All the outcomes of a person's life are unlikely ever to be attributable to the impact of one factor or service. That is why it is good when evaluating the quality of services to use various methods in addition to measuring personal outcomes. For example, methods might include observation of interactions between staff and the persons they support, the culture and climate of services, assessing satisfaction with services and assessing the presence of outcome predictors.

- While standardised outcome measurement has its role in assessing the quality of services and the quality of life of persons using services as compared to others, individual personal outcome measurement that evaluates progress towards or attainment of goals in the aspects of life important to the person is crucial. Standardised outcome measures cannot attend to the areas of life important to individuals and can miss important changes in outcomes at the individual level.

Developing Better Approaches to Outcomes Measurement

Internationally, ongoing efforts to develop better approaches to outcome measurement in disability services include developing approaches that capture what is important to the individual. These approaches include the following:

- Using observation to measure quality of life of people with severe and profound intellectual disabilities. External stakeholders increasingly use observation when evaluating quality of services and individual quality of life in people with severe and profound intellectual disability. Bigby et al (2014)¹⁰ continue to develop indicators, particularly around staff practices and engagement, from qualitative analysis of observations of people with severe and profound intellectual disabilities in group-homes. They proposed using observation indicators to assess quality of life of people with severe and profound intellectual disabilities.¹¹ Observation directly witnesses the experience of people, providing description that is unconstrained by predetermined concepts and categories, which is useful when describing

¹⁰ Bigby, C., Knox, M., Beadle-Brown, J., Bould, E (2014) Identifying Good Group Homes: Qualitative Indicators Using a Quality of Life Framework. *Intellectual and Developmental Disabilities*, 52 (5), 348-366.

¹¹ See Tables 4 and 5 in this report.

complexity.¹² While it may require more time and money than other methods, its benefits may outweigh any extra cost.¹³

- Checking in a random selection of personal interviews that the goals and outcomes set out in a person's PCP coincide with what the person expresses at interview. One can also assess at interview progress made towards outcomes and the contribution of services to that progress.
- Developing individualised person-driven outcomes approaches. Goal Attainment Scaling (GAS), created for programme evaluation, is an individualised outcome measurement system. It involves setting goals and developing descriptions of possible outcomes for each goal. By using a numerical rating scale for descriptions, evaluators can assess the level of attainment of goal. The person or a person working with them, such as a teacher, person-centred planner or support worker, can set the goals. Where possible, one can ensure that the person is the one who sets the goals and decides how to evaluate goals. Developed in 1968, education, mental health, medical, disability, autism, psychology and other professionals have used GAS. Stakeholders have used it to evaluate community initiatives. Another example of developing an individualised approach to outcome measurement is the effort of the National Committee for Quality Assurance (NCQA) in the USA. In 2016-2017, the NCQA carried out a pilot project in which individuals laid down their own goals. They chose standardised outcome measures or they designed individual measures to assess progress towards their goals. Findings suggested that setting and validly measuring person-determined outcomes was feasible and valuable. In addition, the persons who determined and designed their own measures attained better personal outcomes. The NCQA are conducting a three-year project (2018-2020) to evaluate how organizations can help individuals set and measure personalised goals.¹⁴

However, such individualised approaches may not work with persons with severe, profound and even moderate intellectual disability. Here, one must focus

¹² Mansell, Jim (2011) Structured observational research in services for people with learning disabilities. SSCR methods review, 10. NIHR School for Social Care Research, London, UK. at: <http://eprints.lse.ac.uk/43159/>

¹³ Many countries are using more observation. Georgia, in the USA, introduced an Individual Quality Outcomes Measures review tool ('Recognise, Refer and Act' evaluation method), which relied on support coordinators having developed effective observation skills. Support coordinators used the results of observation to work collaboratively with stakeholders. The method worked well in resolving issues and improving supports for those using services. <https://gadbhdd.policystat.com/policy/4479734/>

¹⁴ The National Committee for Quality Assurance is an independent non-profit organization in the United States that works to improve health care quality through the administration of evidence-based standards, measures, programs, and accreditation.

on evaluating through observation whether each person is receiving the assistance that enables him/her to participate in meaningful activities and social relationships at home and in the community. For example, Active Support enables people with severe intellectual disabilities to engage in meaningful activities and relationships. It devises structured activities on an individual basis by breaking down tasks/activities into steps in a predictable and manageable way. Staff develop the skills needed to provide opportunities for persons with profound intellectual disabilities to learn to “do” simple tasks and to be involved in activities. Research shows that Active Support has a positive impact on the quality of life of persons with intellectual disabilities. **The Quality Framework: Supporting Persons with Disabilities to Achieve Personal Outcomes** identifies the provision of active support, in line with a person’s needs and wishes, as an important outcome predictor. Observation, as mentioned earlier, is important in assessing quality of life where persons have severe or profound intellectual disability.

In addition to capturing what is important to the individual, ongoing efforts to develop better approaches to measuring outcomes at service level include:

- Improve standardised outcome measurement tools. The National Core Indicators (NCI) survey tool is a widely used standardised outcomes indicators tool in the USA that is periodically refined (See Table 3 in Section 2.3.1.) Most USA states use the tool in conjunction with other measures to evaluate the quality of intellectual and developmental disability services. The federal government uses the NCI to benchmark quality of disability services across states.
- Another possibility to consider in terms of evaluating disability services is to assess the presence of outcome predictors as an indication of the quality of disability services or to use them as standardised outcome indicators. Research has identified supports and opportunities that predict that persons will attain personal outcomes. The presence of these predictors indicates that services are providing some of the supports and opportunities required for working towards particular quality of life outcomes. Confirming the presence of predictors can strengthen the case that outcomes found may be due, in part, to service provision of relevant supports and opportunities. Attributing outcomes to service intervention is inappropriate if services have not provided any of the supports necessary to attain those outcomes. For example, if a proportion of persons using services are working but services have not provided them with any training, work or employment opportunities, it is unlikely that disability services contributed to the achievement of their work-related goals. **The Quality Framework: Supporting Persons with Disabilities to Achieve Personal Outcomes** identifies 42 outcome predictors, which are the elements of services and supports which enable persons with disabilities to attain personal outcomes.

Table 4 in the Appendix shows examples of outcome predictors while Table 5 shows what outcome predictors might look like in service delivery.

- Consider developing tools for particular populations¹⁵ and dedicate time and energy to exploring how best to evaluate important but difficult-to-measure outcomes such as community integration.

Below is an example of different measurement approaches for the first two of the nine Quality of Life outcome domains approved for Irish Disability Services:

Outcome domain 1: Living in one's own home in the community

- Standardised indicator: Did you choose where you live? Do you choose whom you live with? Do you have a key to your accommodation? Are you happy with your accommodation?
- Observation: Assess if person has access to all areas in his/her home and garden and can come and go in home and garden as and when he/she appears to want to. Assess if home is adapted to his/her needs in terms of size, design, location, etc., and if person has his/her own possessions around the home.
- Outcome predictors: Does person have access to transport and to local community facilities and to personal assistants in the community?
- Open-ended interview questions: Do you want to move house? What are your goals? Have services supported you to attain these goals? How have they done this?

Outcome domain 2: Choice and control

- Standardised Indicator: Do you get up and go to bed at the time you want to? Can you eat your meals when you want to? Do you decide what activities you do during the week?
- Observation: Staff are supporting person to express preferences and make choices about day-to-day aspects of his/her lives which mean that a person's preferences guide what staff do. Staff use appropriate communication to support choice and to respect people's decisions

¹⁵ For example, QOMID is a recently piloted quality outcome measure in the UK for individuals with intellectual disabilities and dementia. QOMID is available to use free of charge. QOMID built on a self-assessment framework that measured outcomes for services across 15 standards as well as on the experience of the authors in working with people with Down's syndrome and dementia. See, Dodd, K., Bush, A., Livesey, A. (2015) "Developing and piloting the QOMID – quality outcome measure for individuals with intellectual disabilities and dementia", *Advances in Mental Health and Intellectual Disabilities*, 9 (6) pp. 298-311.

Specific outcome indicators are also crucial for persons with challenging behaviour.

- Outcome predictor: Staff are using Active Support. The person has access to opportunities and supports to maintain and develop valued social roles in the community, in line with his/her needs and wishes.
- Open-ended interview questions: What are your most important goals? What have services done to help you attain them?

Conclusion

Given the complexity of outcomes, the heterogeneity of populations, and the fact that each person is unique, a standardised outcome measurement tool that one can administer to all, and which accurately reflects individual quality of life and progress towards goals, is challenging to achieve. An individualised approach is essential. However, the use of standardised outcome measurement tools and assessing the presence of outcome predictors still form a useful part of assessing and improving the quality of disability services. However, it must never deflect attention from the provision of individualised and person-centred support or supplant some form of individual outcome measurement.

To maximise the potentially positive impact of outcome measurement, the NDA recommends the following:

- Each service develop a feedback or quality improvement approach that uses the results of individual outcome measurement, standardised outcome measurement and quality assurance processes to fuel continuous development of staff and service processes so that they deliver ever more tailored supports and opportunities to individuals.
- Each service establish individual outcome measurement processes that focus on the personal goals in outcome domains important to the individual. This is central to transforming disability services into person-centred ones and to the process of person-centred planning. (Remember that the outcomes experienced due to service activities may or may not be what an individual person wanted.)
- Use observation to measure quality of life of people with severe and profound intellectual disabilities. Conduct more research comparing the results of observation and its implications for developing services with the results of proxy use including proxy triangulation.
- Use standardised outcome indicator tools such as the NCI tool (USA) in conjunction with other outcome measurement approaches such as observation or assessing the quality of person-centred planning processes. This could include interviews with individuals where one compares what they say with what staff record in their PCP plan. One can also assess the understanding of staff of the values that underpin PCP and explore how they implement PCP.

- Assess the presence of outcome predictors to help evaluate whether services are providing opportunities and supports that research has shown are associated with attaining outcomes: e.g., transport, PCP and Active Support. The quality framework identifies 42 outcome predictors. (One would do this principally using observation).
- Continue to develop tailored outcome measurement in particular populations such as persons with challenging behaviour, dementia, etc. With people with challenging behaviour, for example, outcome indicators might include the following: making decisions themselves in daily things; doing things that they want to do; staff practices are in keeping with best practice evidence. One can also use a social validity survey with staff to identify if persons with challenging behaviour are, for example, making more use of the community than before, has more (or improved) relationships with others, are able to communicate needs more effectively, etc.
- Continue to work to develop nuanced indicators for crucial outcomes that are not so easy to measure such as understanding and achievement of meaningful friendships, self-determination, autonomy, community participation and integration.
- While currently a direct focus on personal outcomes is not a statutory requirement for HIQA, the NDA suggests that monitoring against standards and regulations is of limited benefit if compliance does not result in good outcomes for the individuals in the services in question. Therefore, NDA advises that it may be useful for HIQA's Disability inspection team, etc., to consider inclusion of a specific personal outcomes-focus in their inspections in addition to examining standards, regulations, etc. HIQA inspectors could use standardised observation approaches in addition to existing measures to evaluate outcomes, in particular, where persons have severe or profound intellectual disability. See, for example, Bigby's standardised observation indicators in Table 4 and 5 in this paper.
- Currently HIQA's Disability inspection team is legally responsible for the monitoring, inspection and registration of designated centres for adults and children with a disability. In the future, it is likely that HIQAs remit will extend to all disability services and not only designated centres. HIQA recognises new and emerging models of care in Ireland that do not meet the definition of a designated centre and that result in a significant number of service users who are outside the protections of a regulatory framework. HIQA intends to work with the Department of Health and other relevant stakeholders with a view to advancing reform in this area, including consideration of how one

might evaluate the achievement of personal outcomes in a regulatory context.¹⁶

- If the Department of Health/HSE signals that disability services acquire Quality Assurance Accreditation, it would be important that such accreditation processes have a specific focus on personal outcomes including some observation and interviews in evaluating personal outcomes. It would be beneficial if all agencies would incorporate some element of an outcomes focus into their quality assurance processes in order to orient services towards delivering personal outcomes. The NDA has carried out a review of five quality assurance systems currently used by disability services in Ireland, to examine the extent to which they address the outcome predictors in 'A Quality Framework: supporting persons with disabilities to achieve personal outcomes'.
- In terms of a periodic survey of residential disability services, the Department of Health/HSE or HIQA could usefully adopt some of the National Core Indicator (NCI) survey questions for each of the nine outcome domains approved for Irish Disability Services (See table 4 in the main report). They could combine this with some evaluation of an individual person's progress towards his/her goals by reviewing goals outlined in person-centred plans compared to goals stated in personal interviews, etc. In those with severe or profound intellectual disability who do not communicate verbally, one could evaluate subjective quality of life through observation.
- Within services, create a learning culture that embraces setting and attaining goals and measuring progress towards goals in the outcome domains. Start focusing on outcomes simultaneously with individuals with disabilities and staff. Allocate sufficient time and resources for this individualised goal setting; for recording goals and the supports implemented to support persons' attain their goals and for evaluating progress towards goals (Person-Centred Planning). This is essentially recommending good practice in person-centred planning as set out in the framework for person-centred planning.
- Personnel involved in monitoring progress at the individual level should record outcomes in a readily accessible format so that service providers can aggregate and use data at the service level to provider KPI data. Provide

¹⁶ HIQA's Disability inspection team is legally responsible for the monitoring, inspection and registration of designated centres for adults and children with a disability. In the future, it is likely that HIQA's remit will extend to all disability services and not only designated centres. HIQA recognises new and emerging models of care in Ireland that do not meet the definition of a designated centre and that result in a significant number of service users who are outside the protections of a regulatory framework. HIQA intends to work with the Department of Health and other relevant stakeholders with a view to advancing reform in this area.
<https://www.hiqa.ie/sites/default/files/2017-04/Regulation-overview-2016-web.pdf>

training in outcomes measurement and the use of individual tools. Have 'outcome measurement leaders' within organisations.

- All quality mechanisms in disability services should ultimately promote person-centred services that deliver quality of life to individual persons. Table I illustrates possible methods for outcome measurement for different purposes. Each still includes individual outcomes evaluation. In this way, outcome measurement always aligns with and promotes a person-centred culture and processes that deliver appropriately individualised supports and opportunities.

Table I: Outcome measurement for different purposes

Evaluating individual quality of life outcomes	Evaluating quality of disability services	Quality improvement systems	Quality Assurance
Evaluate quality of person centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview.	Evaluate quality of person centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview.	Evaluate quality of person centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview.	Evaluate quality of person centred plans and progress made towards personal goals by comparing written plans with desired goals expressed at interview.
+	+	+	+
Interviews (where possible)	Interviews (where possible)	Interviews (where possible)	Interviews (where possible)
+	+	+	+
Observation	Observation	Observation	Observation
+	+	+	+
The use of standardised outcome indicators	The use of standardised outcome indicators	The use of standardised outcome indicators	The use of standardised outcome indicators
	+	+	+
	Evaluate presence or absence of outcome predictors	Evaluate presence or absence of outcome predictors	Evaluate presence or absence of outcome predictors
		+	+
		Feedback from Quality Assurance Processes	Standardised Quality Assurance Tools (management responsibility, structures of management systems, etc.)
		+	
		Plan and implement changes to services based on findings	

I. Introduction

I.1. Outline of paper

The paper addresses outcome measurement in disability services: its' purpose; what it entails including the challenges of measurement and how to overcome them. The target audience includes policy makers, funders of services, regulatory bodies and service providers including the Department of Health, HSE and HIQA. Evaluating disability services necessitates assessing what outcomes persons with disabilities attain due to the services/supports accessed.

The structure of the paper is as follows:

- Executive Summary
- Section I outlines the content of the paper and overviews what outcome measurement entails and its place in promoting quality in disability services:
 - Outline of paper and its target audience.
 - Transforming public services through a focus on outcomes.
 - Quality regulation by balancing quality assurance with quality improvement.
 - The challenges of outcome measurement and its limitations
- Section 2 addresses approaches to outcome measurement.
- Section 3 discusses some of the issues in outcome measurement.

The appendix outlines some of the work the NDA has done with the HSE in the transforming lives programme, which seeks to develop person-centred services that deliver outcomes to individual persons with a disability so that they can access the supports and opportunities they need to attain their goals in the various outcome domains. These frameworks are inter-related. For example, the nine quality of life outcome domains are a useful reference point when supporting a person to set goals in the person-centred planning process and to evaluate progress towards these goals. Through the process of goal setting and monitoring progress towards goals, all experience how working towards goals leads to improved quality of life. The Quality Framework and the Person Centred Planning Framework guides staff practices including the provision of individualised supports and opportunities.

I.2. Transforming services through a focus on outcomes

Traditionally, funding bodies and service providers monitored public services by measuring inputs, such as funding and staffing, and outputs, such as programmes delivered and the number of persons supported. However, internationally, the

trend is to place outcomes at the centre of design and accountability frameworks for services. In line with this trend, services are developing person centred models and quality improvement processes that focus on achieving personal outcomes. In this transformation of disability services, there have been consultations with individual persons with disabilities regarding service design. Results of consultations internationally are similar with comparable findings emerging from distinct jurisdictions. In New South Wales, Australia, in 2011-2012, more than 4,000 persons with disabilities, carers and families took part in consultations on disability services. They proposed person-centred disability services that would:¹⁷

- Support individuals with disabilities to reach their potential and live as independently as possible, taking part in their communities and the economy.
- Assist individuals with disabilities to have choice and control in working out the support arrangements that best meet their needs.
- Be diverse, sustainable and offer individualised and effective person-centred support.
- Support families and carers.

Other consultations and reform processes internationally yielded similar findings to those cited above, confirming that persons with disabilities worldwide have the same aspirations as their non-disabled peers. They want to live in the community and access all the community facilities and mainstream services such as education, employment, health, transport and housing/accommodation.

In Ireland, the 2012 Working Group Report, 'New Directions Review of HSE Services and Implementation Plan 2012- 2016' was based on a programme of research, a census of day service provision and a national public consultation with more than 1,500 persons with disabilities, families, carers, service providers and members of the public:

The strong emphasis was on the need for community inclusion, with less segregation of services, more choice, more worthwhile and meaningful activities, and more flexible, individualised supports that fit with the person's life stage. As people strive for inclusion in the economic and social life of the community, they recognise that they need particular supports to attain various work-life goals and improve the quality of their lives. They want that

¹⁷ NSW Government (2012) Living life my way: putting people with disability at the centre of decision making - outcomes of state-wide consultations
https://www.adhc.nsw.gov.au/__data/assets/file/0018/262530/Stage_3_consult_report_Aug2012.

support to be appropriate to their needs and to focus on opportunities to enrich their personal and social lives and relationships.

The 2012 'Value for Money and Policy Review of Disability Services' involved consultation with persons with disabilities and recommended the measurement of outcomes at personal, organisational and programme levels to monitor progress in improving outcomes for person with disabilities and service quality. Since 2012, the Department of Health, the HSE, the National Disability Authority (NDA), the disability sector and persons with disabilities have worked to implement the Transforming Lives Programme and deliver the recommendations of the 'Value for Money and Policy Review of Disability Services'. The heart of the reform is to ensure that disability services deliver personalised supports so that individual persons with disabilities attain a good quality of life in the community. Reform includes de-congregation and providing community and individualised supports. It is important that stakeholders and, in particular, funding and evaluating bodies maintain the impetus to implement and embed these changes so that personal outcomes for persons with disabilities continue to improve.

1.3 Regulating Quality: balancing assurance with improvement

The function of regulation includes improving performance and quality, providing assurance that there are minimally acceptable standards in force and ensuring accountability for levels of performance and value for money. These functions play different roles and give rise to different information. It is important to recognise that each of them is important and to structure them in a coherent whole. For example, if the priority is to provide assurance only, minimal standards are set but this will not necessarily give rise to improvements in quality and performance. If the primary purpose is accountability, methods are required that enable regulators to compare performance in a meaningful way.¹⁸ Reliance on external regulation and measurement, particularly where disability services do not feed results into quality improvement processes, carries the risk that services focus on measurement for quality assurance purposes to the detriment of improving outcomes for persons with disabilities. Thus, there is a need to balance quality assurance processes with continuous quality improvement in disability services and to use outcome measurement for quality improvement as well as for quality assurance. To this end, it is important that quality assurance processes now include a focus on outcome attainment and quality improvement.

¹⁸ Report of Disability Policy Review prepared by Fiona Keogh PhD on behalf of the Expert Reference Group on Disability Policy December 2010 https://health.gov.ie/wp-content/uploads/2014/08/ERG_Disability_Policy_Review_Final.pdf

External quality regulation systems provide some assurance regarding the quality of services and the safety of the services environment. However, the scope of regulation is limited. It is a means of supplementing internal quality processes but not a replacement for such processes. One cannot rely exclusively on external regulatory systems to detect poor quality of care. In the UK, instances of poor quality and abuse in disability services had passed accreditation and regulation requirements and this highlighted the need for a culture of quality improvement in services as well as improving external quality assurance processes. The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry¹⁹ emphasised what can go wrong with quality assurance when the individual and his/her outcomes are not the focus of assessment. “The essential diagnosis is of a system that veered from humanitarian values and had its priorities wrong. Targets and performance management overwhelmed quality and compassion... Regulators, commissioners and others in the system focused on their own roles and, in some cases, lost sight of the persons they were there to serve”(p.21). In response to these serious instances of abuse of persons with a disability and the reviews, the Quality Care Commission in the UK changed its’ way of regulating and inspecting services The new approach included more observation and interviewing - listening carefully to what individuals with disabilities and their families said about services.

A Kings Fund paper pointed out that while regulatory bodies are criticised when services are of poor quality, external regulation is only the third line of defence.²⁰ The first line of defence is the attitudes, behaviours and practices of front-line staff. The second line of defence is the attitudes, behaviours and practices of management including service managers, board members and other stakeholders. The third line of defence is external quality assurance structures and systems that are responsible for assuring the public about the quality of care. These bodies take action when organisations fail to resolve issues and they can require organisations to account for their performance and actions. The Kings Fund paper proposed the four principles of person-centeredness, engaging staff, promoting good governance and effective leadership including clarity about organisations roles and responsibilities for a quality assurance system. Regarding roles and responsibilities, the paper states:

¹⁹ <https://www.gov.uk/government/publications/government-initial-response-to-the-mid-staffs-report>

²⁰ Dixon, A., Foot, C., Harrison, T (2012) How to assure quality in the NHS: preparing for the Francis Report
https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/preparing-for-the-francis-report-jul2012.pdf

A challenge is that the elements that make up quality assurance systems were not designed as part of a coherent whole... Interdependencies and connections between organisations within the quality assurance system need to be identified and agreements formed about how they will work together to avoid unnecessary duplication, e.g., data collection. There is some confusion about how different organisational and service quality standards relate to each other... The various components of the quality assurance system must have clearly defined roles, so that their activities do not overlap or interfere with each other.²¹

It is important for those working within a quality assurance system to understand their roles and responsibilities in the system. Managers are accountable for the performance of others and should advise people of their duties. Outcome measurement can never be a substitute for their responsibility and judgement. They must ensure that staff receive training to carry out their responsibilities and access the necessary resources for their work. It is not under-performance when individuals are unable to carry out tasks because they have not received the necessary guidance, training and resources.

A 2013 Workforce Guide for disability service providers lists themes to consider when developing the disability workforce:²²

- Communication underpins all the other strategies
- Organisation, culture, values²³ and expectations
- Recruitment
- Flexible, responsive and creative work
- Training mentoring and support

²¹ p.11-12, Dixon, A., Foot, C., Harrison, T (2012) How to assure quality in the NHS: preparing for the Francis Report
https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/preparing-for-the-francis-report-jul2012.pdf

²² These themes emerged from an analysis of 68 interviews with stakeholders in Australia, England, Sweden and Canada on workforce opportunities and challenges in the Disability Services environment and appear in Laragy, C., Ramcharan, P., Fisher, KR, McCraw, K., Williams, R (2013) Making it work; A workforce guide for disability service providers:
https://www.sprc.unsw.edu.au/media/SPRCFile/RMIT_Workforce_Guide_Making_it_work_FINAL_FINAL_12613.pdf

²³ “A community facilitator said that they look for the right values when they recruit staff. The values needed are to be patient, to see the person, to look past disability, not to judge, not to push the worker’s values on the person, not to be mothering and to be honest.” p.12, Laragy, C., Ramcharan, P., Fisher, KR, McCraw, K., Williams, R (2013) Making it work; A workforce guide for disability service providers as above.

- Recognition and incentives
- Career pathways

Disability Service Providers should agree which values are essential, communicate these to staff and provide them with the support and training required to put them into practice. The values and principles underpinning the service frameworks developed by the NDA and the HSE, include the following:

- Respect for the inherent dignity of the person
- Person-centeredness and individual autonomy/self-determination –the person is at the centre of all decisions affecting him/her and everyone takes the person’s right to make all his/her decisions seriously. It involves putting in place mechanisms that support autonomy and empowerment
- Outcome-oriented services and supports and accessibility (The UNCRPD defines accessibility as a general principle in Article 3 and a stand-alone right in Article 9. Dimensions of accessibility include physical accessibility, information and communication accessibility, institutional accessibility and economic accessibility)
- Accountability, clear leadership and management, planning and using resources effectively, partnership working and quality
- Equality; inherent equality of all regardless of difference, non-discrimination²⁴, respect for difference, equal rights, equality of opportunity, equality of men and women
- Inclusion and participation in society, active citizenship and solidarity, which requires society to sustain the freedom of each person with appropriate social supports
- Safety, freedom from abuse

Recommendations made by disability service providers with experience in using outcome measurement include the following recommendations on what they would do differently if they were starting out again to develop outcomes-focused disability services).²⁵

²⁴ The goal of the non-discrimination principle in the UNCRPD is to ensure that all existing rights are equally effective for persons with disabilities. Comparative law throughout the world adds the obligation of ‘reasonable accommodation’ in the context of disability. Most comparative law deems failure to achieve reasonable accommodation as discrimination. Quinn, G (2007) The UNCRPD <https://www.ihrec.ie/download/doc/gquinn.doc>

²⁵ Ken Baker, National Disability Services, Australia (2012) Measuring Outcomes for People with Disability www.nds.org.au/asset/view_document/979321223 - section on key lessons learned and what organisations would do differently

- Create a person-centred framework responsive to individual goals. Align service processes with delivering the supports needed to attain goals. To keep the focus on supporting individual persons to attain their goals, a person-centred culture is crucial. Disability service personnel need to understand and practise person-centred values and principles.
- Allocate time and resources for individualised goal setting (Person-Centred Planning) and record goals and the supports implemented to support persons attain their goals. Evaluate progress towards goals.
- Personnel involved in monitoring progress at the individual level should record outcomes in a readily accessible format so that the service providers can aggregate and use data at the service level to provider KPI data.
- Create a learning culture that embraces setting and attaining goals and measuring progress towards goals in the outcome domains. Start focusing on outcomes simultaneously with individuals with disabilities and staff.
- Embed outcome measurement in the service planning process.
- Provide training in outcomes measurement and the use of individual tools. Have 'outcome measurement leaders' within organisations.
- Dedicate the time needed to develop outcome indicator tools that are person-centred, achievable, meaningful, accessible and valid.

1.4 Overview of challenges and limitations of outcome measurement

Despite international interest in outcomes, the empirical evidence to underpin implementation is limited. Whilst there is literature on outcomes, most of it describes outcomes based approaches and there is a dearth of systematic research into the effectiveness or impact of specific approaches. The majority of challenges in the international evidence is associated with outcome measurement and attribution.²⁶

²⁶ Cook, A. (2017) Outcomes Based Approaches in Public Service Reform <http://whatworksscotland.ac.uk/wp-content/uploads/2017/04/>

Some challenges and limitations are summarised below^{27,28,29,30}

- Outcome tools/instruments may not be suited for all individuals. For example, tools designed to collect self-report data may not be suitable for some people with intellectual disabilities. Interviewer expectations and respondent acquiescence may play a greater influence in the responses of persons with intellectual disability than others (this has not been investigated).
- While there are specific quality of life instruments for people with intellectual/cognitive disabilities, these tools still require a level of cognitive ability that is beyond the capacity of some people with intellectual/cognitive disabilities, and supporting these persons to respond introduces additional complexities relating to agency and to the use of proxies. Some evaluators rely on information from proxies when assessing subjective quality of life but this is now widely held to be invalid. International consensus reached by expert members of the Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities advise that proxies' responses are not valid as an indication of another person's perception of his/her quality of life. The group recommends observation as a preferable approach to proxy use.
- It may not be clear what level of achievement of an outcome is acceptable/desirable.
- Peoples' perspectives about whether a person has achieved an outcome and the extent to which the person has achieved the outcome can differ.
- Measurement of outcomes before sufficient time has elapsed for observers or tools to identify change may lead to inaccurate conclusions.
- In some cases, desired outcomes can take years to materialise.
- Outcome measurement is about the past while decision-making is about the future, where environments and other influencing factors may be changing.

²⁷ Ken Baker, National Disability Services, Australia (2012) Measuring Outcomes for People With Disability www.nds.org.au/asset/view_document/979321223

²⁸ Compassion Capital Fund National Resource Center (administered by the U.S. Department of Health and Human Services (2010) Measuring outcomes <http://strengtheningnonprofits.org/resources/guidebooks/MeasuringOutcomes.pdf>

²⁹ Quilliam, C and Wilson, E. (2011) Literature Review Outcomes Measurement in Disability Services: a review of policy contexts, measurement approaches and selected measurement tools. Melbourne: Deakin University

³⁰ Malley, Juliette and Fernández, José-Luis (2010) Measuring quality in social care services: theory and practice. *Annals of public and cooperative economics*, 81, 4, 559-582.

- Outcome measurement is not in and of itself a meaningful activity. It is a means to help services collect information in support of continuous improvement of services and to provide funders with a means of comparing the performance of different services.
- Approaches to outcome measurement are often not comprehensive or accurate. There can be a tendency to focus on easy to measure outcomes at the expense of crucial outcomes. For example, “soft outcomes” such as building relationships within communities are important but hard to measure. Outcome measures can be unsatisfactory when they are poor substitutes for important soft outcomes or when people ignore soft outcomes because of the difficulties in measuring them.
- The issue of attribution limits the usefulness of various outcome measures when making conclusions about the effectiveness of disability services. While donors and funders may wish to get evidence of attribution, there are many evaluators and practitioners who favour using contribution as the model for understanding causation as it better reflects the complexity of the real world. Where one delivers an intervention in a closed system, it may be appropriate to seek to attribute an outcome to an activity. For example, at an individual level, one can attribute immunity to measles to having had the MMR vaccine; if an individual has received the MMR vaccine, there is a high probability that they will be immune from measles infection. However, direct attribution is not possible in complex systems where other factors that one cannot predict or control for with certainty, influence the outcomes.³¹ This is the case in human services such as disability services and social care services.
- Running across different conceptualisations of outcomes are different assumptions about the relationship between the outcome and activity. Within the outcomes literature there are two broad positions in relation to this:³²
 - The relationship between activity and outcome is linear and it is possible to identify a cause and effect relationship between the two. One attributes outcomes to the intervention.
 - Outcomes are particular to the person/organisation and co-created and it is not possible to identify a linear cause and effect relationship. Instead, one can try to understand the contribution of the intervention to outcomes.

³¹ Cook, A. (2017) Outcomes Based Approaches in Public Service Reform
<http://whatworksscotland.ac.uk/wp-content/uploads/2017/04/OutcomeBasedApproachesinPublicServiceReform>

³² Cook, A. (2017) Outcomes Based Approaches in Public Service Reform as above

- These different assumptions about the relationship between cause and effect relate to two different sets of assumptions about the context in which interventions are being delivered.³³
 - The system in which one delivers the intervention is closed and external factors do not influence it or influence it in predictable ways.
 - The intervention one delivers is into a complex, adaptive system, in which internal and external factors influence it in unpredictable ways.
- Many outcome measurement tools do not directly evaluate the contribution of service provision to outcome attainment. For example, one generally uses easy-to-collect data as a proxy for outcome information. This means that outcomes measured differ from how people experience the effect of services. In order to discern the links between outcomes and interventions one needs to engage with the complexity of peoples' lives.³⁴ However, genuine research into outcomes is resource-intensive and, therefore, expensive. If organisations were to measure the impact of interventions accurately, it would possibly cost more to evaluate interventions than to deliver them. Each person has a unique perspective on what desired outcomes should look like and, therefore, to understand the impact of an intervention, one would need to be very familiar with peoples' lives. The usual approach of employing easy to collect data as a proxy for outcome information relies on simplification and abstraction in outcome measurement and attribution in order to fit the complexities of life into neat measurement tools. The problem with this approach is that managers and practitioners can develop tactics to produce data that “prove” outcome attainment.³⁵
- Capturing outcomes is a complex process and the purpose of outcome measurement influences which tools one will use and the way one develops and implements outcome measurement. Table 2 demonstrates differences in indicator tools when measuring outcomes for quality improvement as opposed to measuring outcomes in order to judge the performance of disability services.

³³ Cook, A. (2017) Outcomes Based Approaches in Public Service Reform as above

³⁴ Lowe, T (2013). The paradox of outcomes – the more we measure, the less we understand. *Public Money and Management*, 33 (3), 213-216.

³⁵ Lowe, T, Wilson R. (2017) Playing the game of Outcomes-Based Performance Management. Is gamesmanship (competitiveness) inevitable? *Evidence from theory and practice*, 51(7), 981-1001

Table 2: Characteristics of indicators used for judgement and improvement

Judgement on performance	Quality Improvement
Data for public use	Data for internal use
Used for judgement, punishment/reward	Used for learning and improving practice
Good data quality	Poor data quality tolerable
Good risk adjustment required	Partial risk-adjustment tolerable
Unambiguous interpretation	Variable interpretation possible
Unambiguous attribution	Ambiguity tolerable
Definitive marker of quality	Screening tool
Statistical reliability necessary	Statistical reliability is preferred
Stand-alone	Allowance for context possible
Risk of unintended consequences	Lower risk of unintended consequences
Cross-sectional	Time trends

Source: Adapted from Raleigh V, Foot C. Getting the Measure of Quality. The King's Fund, 2010.

- Measurement can never take the place of judgment. Managers still need to have and apply critical thinking skills to the information gathered in the process of outcome measurement and make decisions. Stakeholders involved in capturing outcomes include persons with disabilities, their families and carers, direct service providers, service senior management, allied health professionals, community members, government officials, and quality assurance personnel.
- Each outcome measurement tool has strengths and limitations that those using them may not appreciate. Outcome domains captured by quality of life tools should reflect the purpose of the service, as different types of services, for example, accommodation versus advocacy services, vary in the outcomes they facilitate.
- The introduction of an outcomes focus including outcomes measurement requires a significant organisational culture shift within services and requires knowledge and training about outcome measurements. A study exploring barriers to outcome measurement in learning (intellectual) disability challenging behaviour services in the North of England identified barriers at various levels. Barriers at the individual level included lack of time, lack of knowledge/skills, attitudes, differences in practice and team dynamics. Barriers at the level of direct interaction with 'service users' included the differences in outcomes prioritised, complexity of working with 'service users and joint-working with private and other service providers. At the organisational level, barriers included lack of funds/resources, pressure for turnover, service

design issues and changing priorities. At the government and wider field level, barriers included a lack of evidence for individual outcome measures, the complexity of the field and lack of priority or interest.³⁶

The following examples illustrate the difficulty of implementing effective outcome measurement systems in human services. Some outcomes such as specific clinical outcomes in health services may be easier to identify and measure than outcomes in disability services. In the UK, Scotland has undertaken large patient outcomes surveys but does not have a national system for routine outcome measurement. Wales and Scotland have developed outcomes frameworks to measure the impact of policies on the mental health of the whole population such as the average scores of the Warwick-Edinburgh Mental Well-being Scale. Northern Ireland emphasises measuring mental health recovery but without agreement of how to do this. England has implemented various attempts to measure outcomes, but of the three dimensions of outcomes - health status change, context and intervention - necessary for meaningful feedback, usable data on the latter are almost absent in most UK services.³⁷

In mental health settings, routine outcome measurement to assess the quality and effectiveness of services and to guide decision-making and intervention planning has been emphasised in the last decades. In 2015, the International Review of Psychiatry published articles on the state of play of routine outcome measurement in mental health services in various jurisdictions. The German mental healthcare system had not integrated any outcome measurement initiative into routine mental health care on a nationwide or trans-sectoral level. Barriers in their mental health service system include fragmentation and a lack of coordinated national or state-level service planning.³⁸ Norway, a country that generally produces policy accompanied with detailed implementation plans, has struggled to implement routine outcome measurement in mental health:

Fifteen years after the decision by the national health authorities to make rating of the Global Assessment of Functioning scale (GAF) mandatory, at admission, and discharge of each treatment episode, in adult mental health services, this is not fully implemented. Well-established electronic patient

³⁶ Birrell, J., Dagnan, D. (2011) Measuring outcomes in learning disability challenging behaviour services: Exploring barriers to outcome measurement in northern challenging behaviour teams. *Cumbria Partnership Journal of Research Practice and Learning*, 1(1), 5-8.
https://cdn.cumbriapartnership.nhs.uk/uploads/cpft-journal/CPJRPL_1_1_Spring_2011_p05_Measuring_Outcomes.pdf

³⁷ MacDonald, A.J.D., Fugard, A.J.B (2015) Routine mental health outcome measurement in the UK *International Review of Psychiatry*, August 2015; 27(4): 306–319

³⁸ Puschner, B., Becker, T., Bauer, S (2015) Routine outcome measures in Germany, *International Review of Psychiatry*, 27(4): 329–337

records in the mental health services and established procedures for reporting routine data to the National Patient Register should make it possible to collect and use routine outcome data... The regional health authorities have a role in establishing electronic systems that make outcome measurements available, in a seamless way, and contributing to a culture where quality and outcomes are valued and prioritised.³⁹

Australia alone has implemented routine outcome measurement as part of service delivery in its specialized public sector mental health services. It uses clinician-rated and consumer-rated measures administered at set times during inpatient, ambulatory and community residential episodes of care. Policy-makers and planners use the data on outcomes to inform decisions about system-wide reforms. Service managers use data to monitor quality. Clinicians use data to guide clinical decision-making. Consumers, carers and the general community can use the data to ensure that services are accountable for the care they deliver.⁴⁰

A Scottish review of the implementation of outcomes based approaches highlights the tension between reductionist approaches to measuring and attributing outcomes and the complex nature of public service delivery. The review shows the negative unintended consequences of outcomes based approaches that arise when organisations seek to attribute outcomes in complex systems where there is limited control over interventions. Performance management systems that drive programmes/initiatives, and simplify their work to fit into pre-existing conceptual frameworks, exacerbates the tension. This tension reflects broader tensions in public services between the New Public Management approach that tries to improve effectiveness through management, targets and incentives and the New Public Governance approach that promotes co-production and collaboration. These tensions exist in the Scottish National Performance Framework, which seeks to foster an open relationship of transparency and accountability and drive collaboration through a performance management system based on measures and numerical indicators, despite an explicit recognition that public service partners can only contribute to outcomes.⁴¹ This review found that while there is evidence of efforts by both local and national government to links population, programme and personal level outcomes based approaches, further progress is required. For example, stakeholders use the National Health and Wellbeing Outcomes to evaluate performance of Health and

³⁹ Ruud, T (2015) Routine outcome measures in Norway: Only partly implemented, *International Review of Psychiatry*, 27(4): 338–344

⁴⁰ Burgess, P., Pirkis, J., Coombs, T (2015) Routine outcome measurement in Australia *International Review of Psychiatry*, August 2015; 27(4): 264–275

⁴¹ Cook, A. (2017) Outcomes Based Approaches in Public Service Reform <http://whatworksscotland.ac.uk/wp-content/uploads/2017/04/OutcomeBasedApproachesinPublicServiceReform>

Social Care Partnerships and research into personal outcomes informs this. Guidance to support implementation includes patient and staff stories to illustrate the difference that achievement of outcomes makes to people. The performance framework, however, is composed of quantitative indicators. Some indicators measure aspects of patient experience and outcomes such as the percentage of adults supported at home who agree that the health and social care services they use are well co-ordinated. However, there is no capture of personal outcomes per se.⁴²

2 Approaches to outcome measurement

2.1. Introduction

The use of outcome measurement to assess the quality and effectiveness of disability services attempts to identify to what degree services support persons with disabilities to set and attain personal goals in the various outcome domains. It is through support that many persons with disabilities reach their full potential in self-determination, social and civic participation, education, training, employment, etc. Outcome measurement attempts to

- Quantify the effectiveness of services in delivering personal outcomes.
- Identify effective practices by, for example, identifying the presence of outcome predictors.
- Identify which practices need improvement if they are to lead to outcomes.
- Prove the quality of services.
- Bring clarity and consensus around the purpose of services.

As set out in the introduction, measuring outcomes to monitor quality of disability services involves answering the following related questions:⁴³

⁴² *ibid*

⁴³ Another question, not addressed in this paper, is the following: How do persons with disabilities compare to persons without disabilities in terms of achieving the outcomes that constitute a good quality of life? When comparing outcomes for persons with and without disabilities, whether or not they receive disability services, one uses some kind of population based measure or secondary data analysis of national population datasets including census surveys as benchmarking tools. The Danish Institute for Human Rights identified 10 gold statistical outcome indicators to measure the progress of the implementation of the UNCRPD in Denmark. The Gold Indicators are a set of 10 statistical outcome indicators that compare the

- Are outcomes and quality of life improving for persons with disabilities who are using disability services?
- What are services contributing to attaining outcomes and quality of life?
- Are the characteristics of services that predict good outcomes present in the services under evaluation?

Below the paper lays out a number of tools that evaluate outcomes at different levels and discuss how they work, and where relevant one can map these tools against the nine outcome domains approved for Irish disability services to show the applicability of any tool in an Irish context.

2.2. Measuring individual outcomes

An individualised approach is fundamental to person-centred and outcomes-focused services. In order to assess whether outcomes and quality of life are improving for persons accessing disability services, one must investigate whether there is an individualised approach to outcome setting and measurement in the service. To track and evaluate a person's progress towards goals in the various quality of life outcome domains, one has to use some form of individual outcomes planning and periodic measurement. To evaluate what services contribute to outcomes and quality of life, one needs to relate findings on outcomes and quality of life to the services received, while allowing for participant characteristics and other risk factors. How much of the progress made towards goals can one attribute to services? One method used to investigate the links between service provision and outcomes is assessing whether a person's goals as set out in the person-centred plan actually corresponds to the goals of the person and if there is progress towards those goals. Progress towards goals might include the provision of relevant individualised supports, skills attained, goals reached, etc. Increasingly, in quality assurance processes, there is some comparison of the goals set out in person-centred plans with the desired goals as expressed in personal interviews with people with disabilities and some assessment of progress towards goals as set out in person-centred planning. While it is possible to aggregate the findings from individual planning tools up to the service/organisation level, this exercise is time-consuming and costly. Thus to study outcome attainment at the service level or to compare outcome attainment across services in an organisation, or across organisations, a standardised outcomes indicator instrument is generally used.

situation of persons with and without disabilities in relation to 10 key thematic areas of the UN Convention on the Rights of Persons with Disabilities (CRPD).

2.2.1. Bespoke individual outcome planning and assessment tools

Many small disability service providers, that cannot afford licensed planning and evaluation tools, which are often expensive, create their own tools and systems. Some disability services, including in Ireland, Australia and England, use software packages such as I-Planit (Aspirico) for person centred planning and outcome evaluation. This software is adapted to the service and to the preferences of individuals with disabilities, staff and other stakeholders. There are other software packages in use in disability services for individualised outcomes planning such as Salesforce. Other Irish services use the Outcome Framework with its nine outcome domains approved for disability services in Ireland to create their own planning and evaluation tool.

2.2.2. POMS individual outcome planning and assessment tool

The Council on Quality and Leadership's Personal Outcomes Measure Tool (POMS) is an individual outcomes planning and monitoring tool. First used in 1977, it measures outcomes and supports and services use it to identify a person's goals and guide Person-Centred Planning and individualised supports. It is a licensed instrument and part of the Council of Quality and Leadership accreditation process. Some service providers in the USA, Ireland, Canada and some organisations in Australia use the POMS tool. A POMS Trial in Victoria demonstrated that the tool was an effective way to verify the quality of disability support provision and to reorient disability services. However, the cost, unless subsidised, restricts its use.⁴⁴

The POMS measure explores a person's quality of life and supports from an individualised perspective. As it is an individualised planning tool, POMS assesses quality of life as defined by the individual and assesses whether the supports provided to individual persons by service providers align with the personal goals as defined by the individual. POM measures are self-defined and the goal of interviews with clients is to build on the priorities/interests of clients.⁴⁵ With this tool, outcomes have no norms and each person is a sample of one. Each person defines friendship, health, etc., uniquely. "Thus, the meaning and definition of personal outcome indicators will vary from person to person. As a result, an organisation can only design and provide the needed supports after it figures out how the person defines his or her outcomes."⁴⁶ Since personal definitions of outcomes vary, supports are individualised. Supports that facilitate a particular outcome for one person may not do so for another. Because individual outcomes

⁴⁴ Ken Baker, National Disability Services, Australia (2012) Measuring Outcomes for People with Disability www.nds.org.au/asset/view_document/979321223

⁴⁵ *ibid*

⁴⁶ p.9 in <https://www.c-q-l.org/files/2017Documents/2017-CQL-POMs-Manual-Adults.pdf>

assume a different level of importance for each person, the person must rank or weight them. All measures are of equal importance until the person prioritises them. Specific outcomes may be more important for some people at particular times in their lives. People determine changes for themselves by sharing information about their personal situations. Organisations use POMS to understand, measure, and improve personal quality of life of those using their services.⁴⁷ There are three steps in the use of this tool:

- Identify each individual's definition of his or her personal outcomes
- Define whether the outcomes as defined by the person are present
- Talk with person, family, staff and volunteers to identify whether the specific individualised services and supports are aligned with outcomes as defined by the person

Principles of POMS include:

- Each person defines the meaning of the personal outcomes
- No standard definition of any outcome applies to a group of people
- It is unlikely that any two people will define an outcome in the same manner
- People define their own outcomes based on their own experiences
- The person defines personal outcomes from his/her perspective
- Personal outcomes reinforce difference and diversity

There was a revalidation of the POMS tool was in 2017, which used a principal components factor analysis. Based on this exercise, CQL reformatted the POMS tool into the following factors:

- My Human Security - non-negotiable human and civil rights
- My Community - access to be in, a part of, and included in the community
- My Relationships - social support, familiarity, intimacy, and belonging
- My Choices - decisions about one's life and community
- My Goals - dreams and aspirations for the future

2.2.3. Goal Attainment Scaling (GAS)

Goal attainment scaling is a tool or process for quantifying progress on personal goals. Participation of the person in the goal setting process enhances goal

⁴⁷ ibid

relevance and commitment. The person is central to the process of setting the goals and this necessitates dialogue in services between the person and staff. The person providing support must get to know what is important to the person and discuss with the person how to evaluate the goals. The person centred plan should reflect the goals as articulated by the person. The basic GAS approach is as follows:⁴⁸

- Define a goal
- Choose a behaviour or outcome that reflects the degree of goal attainment
- Define the person's starting point with respect to the goal
- Define expected goal attainment levels, e.g., ranging from a no change to a much better than expected outcome (A five point ordinal scale can range from -2 as the initial baseline level, -1 progression towards goal without goal attainment, 0 is the expected and most likely level with some goal attainment, +1 represents a better outcome than expected and +2 is the best possible outcome that could have been expected for this goal)
- Set a time interval for evaluation
- Evaluate after the defined time interval
- Calculate the attainment score

Designed in 1968, practitioners in physiotherapy, rehabilitation medicine, psychiatry, geriatrics and special education have used GAS. Stakeholders have also used it in community initiatives,⁴⁹ psychosocial interventions in autism in community settings,⁵⁰ and, for example, evaluating an inclusion program in early childhood learning in Australia.⁵¹ Professionals have often used it where precise goals are a fundamental part of planning but anyone can use it. Establishing the criteria for outcome measurement in advance of measuring the outcome should help to reduce potential bias.⁵²

⁴⁸ Krasny-Pacini, A., Hiebel, J., Godon, S., Chevignard, M (2013) Goal Attainment Scaling in rehabilitation: a literature based update, *Annals Physical Rehabilitation Medicine*, 56 (3), 212- 230

⁴⁹ For example, Kloseck, M. (2007). The use of Goal Attainment Scaling in a community health promotion initiative with seniors. *BMC geriatrics*, 7, 16. doi:10.1186/1471-2318-7-16

⁵⁰ For example, Ruble, L., McGrew, JH., Toland, MD (2012). Goal Attainment Scaling as an Outcome Measure in Randomised Controlled Trials of psychosocial interventions in autism. *Journal Autism Development Disorder*, 42, 1974-1983

⁵¹ E. Manning, K. Williams, G. O'Brien, M. Sutherland (2016) "Use of Goal Attainment Scaling in the evaluation of the Kids Together inclusion program in early childhood learning environments", Melbourne Convention Centre Melbourne, September 2016

⁵² Chapman, M., Burton, M., Hunt, V., Reeves, D. (2006) Implementation of Goal Attainment Scaling in Community Intellectual Disability Services, *Journal of Policy and Practice in Intellectual Disabilities*, 3 (2), p. 119-128

2.3. Standardised outcomes indicators tools to assess services

One uses standardised outcomes indicators tool to assess links between services and outcomes. A variety of tools are currently in use and set out below are examples of tools that have been used in the Irish context as well as in the USA, England, Australia and the Netherlands. The tools chosen are validated tools and are in use for some time (e.g., NCI) or are attempts to use new approaches to overcome the limitations of standard outcome measurement tools.

2.3.1. The National Core Indicators (NCI) Instrument

An example of a standardised outcomes indicators tool, using surveys, and employed at service/organisation level and at State and Federal Levels in the USA, in conjunction with other forms of assessment and quality assurance, is the National Core Indicators (NCI) tool. Most USA states now use this tool, together with other measures, to evaluate disability services for persons with intellectual disabilities and, at the Federal level, to benchmark the quality of services within states against each other.

In the USA, the National Core Indicators (NCI) project/program started in 1997 to provide systems-level information for quality management. It is possibly the largest worldwide effort to systematically collect and use standardised Key Performance Indicators to inform quality management in intellectual and developmental disabilities (IDD) services.⁵³ The NCI is a partnership and collaborative effort in the USA between the Human Services Research Institute (HSRI) in Cambridge Massachusetts and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in the USA. It started as a voluntary effort by these public developmental disabilities agencies to establish and review indicators to measure the performance of ID/DD services and supports in and across states. It ranks results for each state by question and living arrangement. Individual state scores are ranked “significantly above the national average,” “at the average,” or “significantly below the national average.”⁵⁴ The federal government now supports states financially to use the NCI tool and, in 2016-2017, 46 states used NCI data to assess quality in disability services. Authorities are now also using the NCI tool with older people and with other people with disabilities through the NCI-AD.

The NCI data used with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service

⁵³ In the USA, IDD, refers to people with co-occurring intellectual and developmental disabilities

⁵⁴ NCI (NASDDDS & HSRI), 2013, Using National Core Indicators ‘NCI’ Data for quality improvement initiatives

http://www.nasddds.org/uploads/documents/How_to_Use_NCI_Data_doc.pdf

coordination level. To understand the implications of the data, people from varying perspectives are often included in the review groups because they may have different perspectives and reflections on the meaning of what the data appears to suggest. Other data sources may provide a further explanation of the findings and the review group can study the various sources together. For instance, if the numbers of individuals who say that they do not feel safe in their homes is increasing from one year to the next or is significantly higher than the national norm, then the group may also want to review the patterns in incident management data.⁵⁵

NCI data is risk adjusted to account for differences in individual characteristics including age, level of intellectual disability, verbal/non-verbal, mobility level, health status, mental illness and whether behavioural supports are needed to prevent self-injury or disruptive/ destructive behaviour. NCI measures have the advantage of consultation and development over 20 years, with testing of their validity, etc. Increasingly states are trying to maximise the use of the data they collect to improve services. In 2015 and 2016 a pilot study in Virginia tested the feasibility of linking three databases together (the NCI Adult Survey, the Supports Intensity Scale (SIS) on support needs and Medicaid Expenditures Data) in order to examine links between outcomes, support needs and costs in Virginia.⁵⁶

The NCI performance indicators come from several data sources including an adult consumer survey, family surveys, a provider survey, and system data such as mortality rates from state administrative records. Through these KPI indicators for consumers (persons with disabilities), family, system, and health and safety features, one assesses outcomes for persons with disabilities, system performance, staff stability and competence as follows:

- Individual outcomes – self-determination, choice and decision-making; work; relationships; community inclusion and personal satisfaction.
- Health, welfare and rights outcomes – safety, health, wellness, medications, restraints, respect/rights.
- Staff stability and competence outcomes.
- System performance outcomes.

The Adult Consumer Survey is a face-to-face survey that collects data on approximately one-half (70) of the NCI outcome indicators. In the yearly survey,

⁵⁵ NCI (NASDDDS & HSRI), 2013, Using National Core Indicators ‘NCI’ Data for quality improvement initiatives
http://www.nasddds.org/uploads/documents/How_to_Use_NCI_Data_doc.pdf

⁵⁶ National Indicators at a glance Report. Selected Findings from the 2015-16 surveys
https://www.nationalcoreindicators.org/upload/core-indicators/2015-16_At_a_Glance.pdf

trained staff collect data in face-to-face interviews from persons with disabilities in participating states. Every state or service area draws a random sample of at least 400 individuals who are receiving services. Sample selection is randomized so that every person in the state or service area that meets the criteria for selection has an equal opportunity to participate. Samples are usually limited to individuals who are age 18 years or older and who receive at least one service besides case management.⁵⁷

Section I of the Survey includes questions that can only be answered by the individual him or herself since it includes questions that require subjective judgments and personal experiences. Section II of the Survey allows for the use of “proxy” or other respondents who know the individual receiving services very well (such as a family member or friend). It consists of questions about objective facts regarding the individual’s circumstances. States employ a variety of interviewers to conduct the face-to-face conversations with the major requirement being that they have no personal connection with the individual (such as a service provider, relative, personal case manager, etc.). Within this constraint, states have used university students, state staff, private contractors, advocacy organizations, and individuals with disabilities and their families to conduct the conversations. NCI provides standardized training to ensure uniform application of the survey.

Table 3 applies some of the NCI questions used in the NCI Adult Consumer Survey to the nine agreed outcome for Irish Disability Services to show how one could use elements of the NCI to measure outcomes in an Irish context.

⁵⁷ A sample size of at least 400 – this is based on the minimum number needed to yield a valid sample that meets the standard of +/-5% margin of error and a 95% confidence level. This strategy is consistent with agreed upon statistical methods.

Table 3: NCI Indicators as KPIs for the personal outcome domains in Irish Disability Services

	Outcome Domain	NCI domain indicator – proportion of people who	NCI Questions for indicator
1	Living in the Community	have choice in where they live have choice in whom they live with are satisfied with where they live ...	Did you choose where you live? Did you choose who you live with? In general, do you like where you are living right now? What don't you like about where you live? Would you prefer to live somewhere else? Where would you prefer to live?
2	Choice and control	feel in control of their lives make decisions about their everyday lives	Do you feel in control of your life? Do you get up and go to bed at the time you want to? Can you eat your meals when you want to? Are you able to decide how to furnish and decorate your room/house? Are you able to choose who you live with?
3	Social and civic participation	shopped in last month – did errands – went out for entertainment – went out to eat – went to a religious or spiritual service – went on vacation in past year...	Did you go shopping in the last month? Did you do errands in the last month? Did you go out for entertainment in the last month? Did you go out to eat in the last month? Did you go to religious or spiritual services in the last month? Did you go on vacation in the past year?
4	Personal relationships	have best friend see their friends when they want are lonely	Do you have a best friend? Can you see your friends when you want to? Do you ever feel lonely?
5	Education and personal development	have access to self-advocacy know who to call with a question, concern or complaint about their services	Have you gone to a self-advocacy meeting? If you have a complaint about the services you are getting right now, do you know whom to call
6	Employment and valued social roles	have employment like where they work job pays at least the minimum wage would like a job have had job search assistance volunteer	Do you have a paid job in your community? Do you like where you work? Would you like a job? Has someone talked to you about job options? Do you do any volunteer work?
7	Quality of life	are satisfied with what they do during the day are satisfied with the staff who work with them	Do you like how you usually spend your time during the day? Do the people who are paid to help you do things the way you want them done? Do the people who are paid to help you change too often?
8	Health and well-being	Exercise have access to healthy foods	Did you go out to exercise in the last month? Do you have access to healthy foods like fruits and vegetables when you want them?

	Outcome Domain	NCI domain indicator – proportion of people who	NCI Questions for indicator
		have ever had to cut back on food because of money can get an appointment to the doctor when they need to have poor health (self-reported) receive the services that they need	Do you ever have to skip a meal due to financial worries? Can you get an appointment to see your GP when you need to? How would you describe your overall health (excellent/v. good/good/fair/poor/very poor)? Do the services you receive meet your needs and goals? If no, what additional services might help you?
9	Safe and secure and free from abuse	feel safe at home feel safe in neighbourhood feel safe around their caregiver/staff feel safe at work or in their daily activities are treated well by staff in public services basic rights are respected by others feel that their belongings are safe	Do you feel safe in your home? Do you feel safe in your neighbourhood? Do you feel safe around the people who are paid to help you? Do you feel safe at your work and day activity? Does your case manager ask what you want? Does your case manager call you back right away when you call? Do your staff at work treat you with respect? Does your case manager help get what you need? Do people ask your permission before coming into your home? Do you have enough privacy at home? Are you ever worried for the security of your personal belongings? Has anyone used or taken your money without your permission

2.3.2. Using observation to assess outcomes and outcome predictors

The use of observation to assess outcomes is an important addition to outcome measurement in disability services. This is particularly relevant for people with profound intellectual disability.

Ethnographic method of research have long used observations, which can be particularly helpful when researchers are interested in the daily routines and interpersonal communications of residents and staff. As noted by Luff et al. “while self-report scales and questionnaires are traditionally ‘quick and easy’ forms of data collection, this may not be the case when working with people living in care homes” (p.25), owing to the high levels of physical and cognitive frailty. Furthermore, there is evidence that it is inappropriate to rely solely on the self-report information collected through surveys/questionnaires when making judgements about the quality of a service.⁵⁸

Bigby et al (2014) proposed observation of qualitative indicators to assess the quality of life of people with severe and profound intellectual disabilities. They developed indicators from qualitative analysis of observations over 9-12 months in homes for people with severe and profound levels of intellectual disability. Table 4 shows these observational indicators⁵⁹. Bigby et al consider that auditors, community visitors, funders, advocates and family members could use the tool, shown in Table 4, to guide/standardise observation. Table 5 shows these observational indicators applied to the nine outcome domains approved for Irish Disability Services.

The strength of direct observation is that it measures aspects of the lives of people as they live them, in situations where people are unable to answer interviews or questionnaires about their experience. No other method provides such direct evidence of the reality of people’s lives in situations where they cannot speak for themselves. This method has focused attention on how staff provide help to the people they support as a more important predictor than many other aspects of services. Observational research has shown that not everyone experiences the benefits of new service models to the same extent and

⁵⁸ Luff R, Ferreira Z, Meyer J. Care Homes: Methods Review 8. London: NIHR School for Social Care Research; 2011 as cited by Towers et al (2015) Adapting the adult social care outcomes toolkit (ASCOT) for use in care home quality monitoring: conceptual development and testing. BMC Health Services Research, 15, 304

⁵⁹ Bigby, C., Knox, M., Beadle-Brown, J, Bould, E (2014). Identifying good group homes: Qualitative indicators using a quality of life framework. Journal of Intellectual and developmental disabilities, 52, 5, 348-366

one cannot assume that new models will invariably provide a better life for the people they serve.⁶⁰

Establishing the outcome predictors that are present in disability services can form part of assessing whether services are providing supports to persons with disabilities that help them attain outcomes and a good quality of life. How relevant are the predictors for people with profound/severe/ ID? Outcome predictors are the characteristics of services that predict good outcomes. A body of international research has identified these elements of services that are associated with persons with disabilities attaining outcomes in the various quality of life domains. One can investigate outcome predictors and outcomes using observation as well as using questionnaires, interviews and checking personal plans against what persons say in interviews, etc.

Using observation is essential in the case of persons with severe and profound intellectual disabilities. In these cases, assessors, e.g., HIQA, or some other assessor independent from the service provider, can use an observation methodology rather than proxies to assess subjective quality of life as well as the presence/ absence of outcomes and outcome predictors. Observation might focus on the following with regards persons with severe and profound intellectual disabilities:

- How well do staff listen to people? Do they treat them with respect and as individuals (shown to have intrinsic as well as instrumental value)?⁶¹
- Are staff using staff-support practices⁶² such as Active Support⁶³? Active Support is a person-centred way of enabling people with severe or profound intellectual disabilities to engage in meaningful activity and relationships.⁶⁴ It

⁶⁰ Mansell, Jim (2011) Structured observational research in services for people with learning disabilities. SSCR methods review, 10. NIHR School for Social Care Research, London, UK. http://eprints.lse.ac.uk/43159/1/SSCR_Methods_review_10_%28Isero%29.pdf

⁶¹ Barrie, K., Miller, E (2015) Measuring Personal Outcomes in Service Settings: Collected Briefings from the Meaningful and Measurable https://meaningfulandmeasurable.files.wordpress.com/2015/04/mm_projectreport_measuringpersonaloutcomesinservicesettings.pdf

⁶² Felce, D., Perry, J. (2007). Living with support in the community: factors associated with quality-of-life outcome. In: Handbook of Developmental Disabilities (eds S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher), pp. 410–428. Guilford Press, New York.

⁶³ Mansell J., Beadle-Brown J. & Bigby C. (2013) Implementation of active support in Victoria, Australia: an exploratory study. *Journal of Intellectual and Developmental Disabilities* 38, 48–58.

⁶⁴ Mansell, J., Beadle-Brown, J (2012) Active support: Enabling and empowering people with intellectual disabilities. London, England: Jessica Kingsley Publishers Ltd. Mansell and Beadle Brown reviewed research using structured, direct observation, which demonstrated that staff practices crucial in attaining outcomes for people with severe intellectual disability.

devises structured activities on an individual basis by breaking down each task, activity, etc., into manageable units, that is, into a series of steps in a structured and predictable way. Active Support involves staff developing the skill to provide opportunities for persons with profound intellectual disabilities to learn to “do” simple tasks (to be involved in activities/tasks in some way). There are reviews of the positive impact of Active Support on the quality of life of people with intellectual disabilities.⁶⁵ As well as being a good predictor of outcomes for people with severe or profound intellectual disability and complex needs, it is a robust indicator of the presence of skilled support.⁶⁶ Active Support is a cost-effective intervention because it yields better outcomes by using existing staff more effectively (not by increasing staffing).⁶⁷ Research indicates that Active Support should be a component in the support of people with challenging behaviour.⁶⁸

- Are the following present/absent (they were present in higher performing group accommodation for people with severe intellectual disability:⁶⁹
 - Staff doing things with people rather than for them and open to change and ideas
 - Do staff regard the people they support as the same as other citizens (‘like us’)?

⁶⁵ In Australia, for example, Stancliffe, R.J., Jones, E., Mansell, J (2008) Research in Active Support, *Journal of Intellectual and Developmental Disability*, 33, 194-195 and in the UK, for example, Mansell, J., Beadle-Brown, J (2012) *Active Support: Enabling and Empowering People with Intellectual Disabilities*. Jessica Kingsley, London.

⁶⁶ Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., Bradshaw, J (2016) Quality of Life and Quality of Support for people with severe intellectual disability and complex needs, *Journal of Applied Research in Intellectual Disabilities*, 29, 409-421

⁶⁷ Stancliffe, R.J., Harman, A.D., Toogood, S., McVilly, K.R. (2005) *Australian implementation and evaluation of Active Support*. Sydney: Centre for Developmental Disability Studies www.adhc.nsw.gov.au/__data/assets/file/0008/228176/2_AustralianImplementationandEvaluationofActiveSuppo.pdf

⁶⁸ McGill, P and Toogood, S (1994) Organizing community placements, in *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services*, ed. Emerson, E, McGill, P and Mansell, J. London: Chapman & Hall and Jones, E., Lowe, K., Brown, S., Albert, L., Saunders, C., Haake, N., Leigh, H (2013) Active Support as a primary prevention strategy for challenging behaviour. *BILD, International Journal of Positive Behavioural Support*, 3 (1), 16-30 cited by Ockenden, J et al (2014) Positive Behaviour Support and Active Support: Essential elements for achieving real change in services for people whose behaviour is described as challenging

⁶⁹ Bigby, C., Knox, M., Beadle-Brown, Julie., Clement, T (2015) ‘We Just Call Them People’: Positive Regard as a Dimension of Culture in Group Homes for People with Severe Intellectual Disability *Journal of Applied Research in Intellectual Disabilities*, 28 (4), 283–295

Table 4: Using observation: Qualitative indicators using a quality of life framework (Bigby et al, 2014, Journal of Intellectual and developmental disabilities, 52, 5, 348-366)

Quality of Life Domain	Indicators
Emotional Well-Being	People appear content with their environment, their activities, and their support; they smile and/or take part relatively willingly in a range of activities (including interactions) when given the right support to do so
	People appear at ease with staff presence and support
	People appear comfortable in their environment , including with the level of arousal
	People appear pleased when they succeed in activities, do something new, or experience interaction with new people in their environment
	People do not show challenging behaviour or spend long periods in self-stimulatory behaviour
Inter-personal Relations	Staff are proactive and people are supported to have positive contact with their family on a regular basis; family can visit whenever they want to
	People experience positive and respectful interactions with staff and others in their social network including co-residents
	People are positively regarded by staff, they are seen as essentially human "like us" and differences related to impairment or health are attended to from a value neutral perspective
	People have members in their social network other than paid staff and immediate family and are supported to meet new people with similar interests, both with and without disabilities, and to make and maintain friendships with people outside of their home as well as those within their home
	From most of these contacts, people experience affection and warmth.
Material Well-Being	People have a home to live in that is adapted to their needs in terms of location, design, size and decor within the constraints of what is culturally and economically appropriate
	People have their own possessions around their home
	People have enough money to afford the essentials and at least some non-essentials (e.g. holiday, participation in preferred activities in the community)
	People are supported to manage their financial situation so they can access their funds and use them in accordance with their preferences (preferences are sought and included in decisions about holidays, furniture, or the household budget)

Quality of Life Domain	Indicators
	People have access to some form of transport in order to access the community
Personal Development	People are supported to engage in a range of meaningful activities and social interactions that span a range of areas of life (e.g., full occupation or employment, household, gardening, leisure, education, social)
	People are supported to try new things and have new experiences with just enough assistance and support to experience success and, thus, to develop their skills
	People are supported to demonstrate what they can do (their competence) and experience self-esteem
Physical Well-Being	People are supported to be safe and well in their own home and in the community (without staff being risk averse)
	Personalised and respectful support with personal care is provided well and promptly - all aspects of personal care reflect individual preferences as well as specific needs in respect of things such as swallowing are provided
	The environment is safe and healthy (e.g., environment not too warm or cold, no uneven or dangerous floors); people can move around their environment safely)
	People are supported to live healthy lifestyles at least most of the time - good diet, some exercise, etc.,
	Pain or illness is recognised and responded to quickly
Self-Determination	People are offered and supported to express preferences and make choices about day-to-day aspects of their lives, which mean people’s own agendas, and preferences guide what staff do rather than those of staff
	Staff use appropriate communication to support choice and respect people’s decisions
	People are supported to understand and predict what their day will be like, based on their own preferences and agendas
	People are supported to be part of Person-Centred Planning and other decision making processes as much as possible and to have someone who knows them and who can help others to understand their desires and wishes, such as an advocate or members of circle of support
	People lead individualised lives rather than being regarded as part of a group of residents
	People live in an ordinary house in an ordinary street in which other people without disabilities live

Quality of Life Domain	Indicators
Social Inclusion	People are supported to have a presence in the local community - access community facilities (shops, swimming pool, pub, and cafe) and are recognised, acknowledged, or known by their name to some community members
	People are supported to take part in activities in the community and not just with other persons with disabilities; for example, they actually do part of the shopping
	People are supported to have a valued role, to be known or accepted in the community - membership of clubs, taking collection in church, are viewed respectfully by people in the community (e.g. shopkeeper/bus driver/neighbours makes eye contact with them and call them by name), people are helped to be well presented in public, staff speak about people respectfully and introduce people by their name
Rights	People are treated with dignity and respect in all their interactions and have privacy
	People have access to all communal areas in their own home and garden, and are supported to come and go from their own home and garden, and are supported to come and go from their home as and when they appear to want to
	People have someone external to the service system who can advocate for their interests
	People can physically access transport and community facilities that they would like to or need to access
	People are supported to take part in activities of civic responsibility - e.g., voting, representing persons with disabilities on forums, telling their story as part of lobbying for change
	People and staff are aware of and respect the arrangements in place for substitute decision making about finances or other life areas (guardianship, administration)

Table 5 shows the qualitative indicators of outcomes evaluated through observation as formulated by Bigby et al (2014)⁷⁰ applied to evaluate outcome domains and staff practices in Irish Disability Services.

⁷⁰ Bigby, C., Knox, M., Beadle-Brown, J, Bould, E (2014). Identifying good group homes: Qualitative indicators using a quality of life framework.

Table 5: Using observation to assess outcome domains applied to the nine outcome domains approved for Irish Disability Services [These are the same observational indicators as in Table 2 from Bigby et al (2014) but laid out under the nine outcome domains approved for Irish disability services]	
Nine Outcomes	Indicators
Living in own home in the community	People live in an ordinary house in an ordinary street in which other people without disabilities live
	People are supported to be safe and well in their home and community (without staff being risk averse)
	People have access to all communal areas in their own home and garden, and are supported to come and go from their own home and garden, and are supported to come and go from their home as and when they appear to want to
	People have a home to live in that is adapted to their needs in terms of location, design, size and decor within the constraints of what is culturally and economically appropriate
	People have their own possessions around their home
Exercising choice and control in their everyday lives	People are offered and supported to express preferences and make choices about day-to-day aspects of their lives, which mean people's own agendas, and preferences guide what staff do rather than those of staff
	Staff use appropriate communication to support choice and respect people's decisions
	People are supported to understand and predict what their day will be like, based on their own preferences and agendas
	People are supported to be part of Person-Centred Planning and other decision making processes as much as possible and to have someone who knows them and who can help others to understand their desires and wishes, such as an advocate or members of circle of support
	People lead individualised lives rather than being regarded as part of a group of residents
Participating in social and civic life	People are supported to have a presence in the local community - access community facilities (shops, swimming pool, pub, and cafe) and are recognised, acknowledged, or known by their name to some community members
	People are supported to take part in activities in the community and not just with other persons with disabilities; for example, they actually do part of the shopping
	People are supported to have a valued role, to be known or accepted in the community - membership of clubs, taking collection in church, are viewed respectfully by people in the community (e.g. shopkeeper/bus driver/neighbours makes eye contact with them and call them by name), people are helped to be well presented in public, staff speak about people respectfully and introduce people by their name

Table 5: Using observation to assess outcome domains applied to the nine outcome domains approved for Irish Disability Services [These are the same observational indicators as in Table 2 from Bigby et al (2014) but laid out under the nine outcome domains approved for Irish disability services]	
Nine Outcomes	Indicators
Meaningful relationships	People are supported to engage in a range of meaningful activities and social interactions
Have opportunities for personal development and fulfilment of aspirations	People are supported to engage in a range of meaningful activities and social interactions that span a range of areas of life (e.g., full occupation or employment, household, gardening, leisure, education, social)
	People are supported to try new things and have new experiences with just enough help and support to experience success and, thus, to develop their skills
	People are supported to demonstrate what they can do (their competence) and experience self-esteem
Have job or social role	<i>Note: These observational indicators were developed with persons with severe/profound intellectual disability who did not have jobs or social roles but hopefully supports/opportunities to such roles will be developed</i>
Enjoying a good quality of life and well being	People have enough money to afford the essentials and at least some non-essentials (e.g. holiday, participation in preferred activities in the community)
	People are supported to manage their financial situation so they can access their funds and use them in accordance with their preferences (preferences are sought and included in decisions about holidays, furniture, or the household budget)
	People have access to some form of transport in order to access the community
Achieving best possible health	Personalised and respectful support with personal care is provided well and promptly - all aspects of personal care reflect individual preferences as well as specific needs in respect of things such as swallowing are provided
	The environment is safe and healthy (e.g., environment not too warm or cold, no uneven or dangerous floors); people can move around their environment safely)
	People are supported to live healthy lifestyles at least most of the time - good diet, some exercise, etc.,
	Pain or illness is recognised and responded to quickly

	Table 5: Using observation to assess outcome domains applied to the nine outcome domains approved for Irish Disability Services [These are the same observational indicators as in Table 2 from Bigby et al (2014) but laid out under the nine outcome domains approved for Irish disability services]
Nine Outcomes	Indicators
	People are supported to access healthcare promptly when ill and preventative care such as regular health checks appropriate to age and severity of disability - are not over/under-weight - specific health issues are managed
Safe, secure and free from abuse	People are treated with dignity and respect in all their interactions and have privacy
	People have someone external to the service system who can advocate for their interests
	People can physically access transport and community facilities that they would like to or need to access
	People are supported to take part in activities of civic responsibility - e.g., voting, representing persons with disabilities on forums, telling their story as part of lobbying for change
	People and staff are aware of and respect the arrangements in place for substitute decision making about finances or other life areas (guardianship, administration)

2.3.3. Generic patient-reported outcome measures (PROMS)

There is widespread use of general patient-reported outcome measures (PROMs) to ask persons to evaluate aspects of their health, quality of life and functioning. Generic PROMs are questionnaires that measure multiple dimensions of health and quality of life. They are generic, that is, they do not target specific age groups, disease groups, etc. Widely used generic, multi-dimensional PROMs include the following:

- Short Form-36 (SF-36) is a 36-item, person-reported survey of person health.
- Short Form-12 (SF-12) is a multipurpose short form survey with 12 questions taken from the SF- 36 survey. It was developed to provide a shorter, yet valid alternative to the SF-36, which has been seen by many researchers as too long to administer to studies with large samples.
- WHOQOL-Bref – The four WHOQOL-Bref domains are physical health, psychological, social relationships and environment. The psychological domain, for example, explores bodily image and appearance; negative and positive feelings; self-esteem; spirituality; thinking, learning, memory and concentration. The environment domain explores financial resources; freedom; physical safety and security; health and social care (accessibility and quality); home environment; opportunities for acquiring new information and skills; participation in and opportunities for recreation /leisure activities; physical environment (pollution /noise /traffic /climate); transport.
- EQ-5D measures a person's health across the five domains of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression

A new generic, multidimensional PROM is PROMIS Global Health-10 short form (Patient-Reported Outcomes Measurement Information System). The PROMIS Global Health assessment tool is publically available. It measures symptoms, functioning, and healthcare-related quality of life for chronic diseases/conditions. The PROMIS Global-10 short form consists of 10 items that assess health and functioning including physical, mental and social health and pain, fatigue and overall perceived quality of life. The 10 questions of the Global-10 have been adapted from other measures such as the SF-36 and EQ-ED but with modifications in order to create an instrument that is more sensitive and precise.⁷¹ Stakeholders use this data to evaluate how health and social care interventions affect a person's life.

⁷¹ <https://www.codetechnology.com/promis-global-10/>

2.3.4. ASCOT Social Care Related Quality of Life Toolkit (UK)

The Department of Health and HM Treasury in the UK funded the development of the Adult Social Care Outcomes Toolkit (ASCOT) in the UK to measure the outcomes of social care for individuals in a variety of care settings. They wished to use data collected during the annual Adult Social Care Survey (ASCS) to generate a measure that reflected the impact of social care support on service users' quality of life. The ASCOT toolkit has been in use since 2011/2012 to capture information about a person's social care related quality of life (SCRQoL).

Social care related quality of life (SCRQoL) refers to the aspects of people's quality of life that are the focus of social care interventions. "The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible. In identifying and defining the domains, the aim is to ensure that the measure is sensitive to outcomes of social care activities".⁷²

The annual Adult Social Care Survey (ASCS) includes the ASCOT toolkit measure of SCRQoL, which is one of the indicators in the Adult Social Care Outcomes Framework (ASCOF).

The ASCOT toolkit supports outcomes measurement in the following ways:⁷³

- Compare current SCRQOL in a pre- and post-intervention study design
- Estimate SCRQOL gain by comparing the difference between current and expected SCRQOL in the absence of the intervention
- Outcomes of prevention and enablement interventions, expected to reduce or prevent the need for support, can be measured by looking at changes in expected SCRQOL in the absence of services (expected needs) before and after interventions

The ASCOT toolkit addresses functioning and capability. Capability refers to the opportunities an individual has to be or do a range of things that is of value. This contrasts to functioning, which refers to states of being, for example, being safe or doing activities such as shopping. The ASCOT measure tries to capture functioning and capability as "for some aspects of SCRQoL, it could be argued

⁷² PI Netten, A., Forder, J., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., Towers, AM., Trukeschitz, B., Welch, E., Windle, K (2011) Adult Social Care Outcomes Toolkit v2.1: Main Guidance, PSSRU Discussion Paper No. 2716/3, Personal Social Services Research Unit, University of Kent, Canterbury.

⁷³ Netten, A., Forder, J., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., Towers, AM., Trukeschitz, B., Welch, E., Windle, K (2011) Adult Social Care Outcomes Toolkit v2.1: Main Guidance, PSSRU Discussion Paper No. 2716/3, Personal Social Services Research Unit, University of Kent, Canterbury.

that a low level of functioning is indicative of need, whether a person recognises that need or otherwise”.

A series of studies derived eight domains of Social Care Related QoL that form the basis of the Adult Social Care Outcome Toolkit (ASCOT)⁷⁴ and these appear in all of the ASCOT versions.

Table 6 outlines the domains with their definitions.

Table 6 The Social Care Related QoL ASCOT measure with its eight domains

Domain	Definition
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities
Personal cleanliness and comfort	The service user feels he/she is personally clean and comfortable and looks presentable or, at best, is dressed and groomed in a way that reflects his/ her personal preferences
Food and drink	The service user feels he/she has a nutritious, varied and culturally appropriate diet with enough food and drink he/she enjoys at regular and timely intervals
Personal safety	The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm
Social participation and involvement	The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends, family and feeling involved or part of a community should this be important to the service user
Occupation	The service user is sufficiently occupied in a range of meaningful activities whether it be formal employment, unpaid work, caring for others or leisure activities
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable
Dignity	The negative and positive psychological impact of support and care on the service user’s personal sense of significance

Four domains of the ASCOT tool are ‘basic’ aspects of quality of life. Three domains are higher order domains – social participation, occupation and control. The eighth ASCOT domain is ‘dignity’ –the domain that is specific to care and

⁷⁴ Netten, A., Forder, J., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., Towers, AM., Trukeschitz, B., Welch, E., Windle, K (2011) Adult Social Care Outcomes Toolkit v2.1: Main Guidance, PSSRU Discussion Paper No. 2716/3, Personal Social Services Research Unit, University of Kent, Canterbury.

relates to the aspect of the process that would not be expected to be reflected in other domains– that is, the impact on a person’s self-esteem of the way that care and support are provided.

There are four options in the ASCOT toolkit:⁷⁵

- **SCT4:** A four-level self-completion tool is for use with people who live in community settings. It has nine questions to measure current QoL. Some domains reflect capabilities at the high quality of life end of the spectrum (social participation, occupation and control over daily life) while others reflect basic functioning (personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, and feeling safe). An Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT) for self-report by people with intellectual disabilities (SC4 ER version) was developed. “Findings suggest that the ASCOT-ER has made it easier for people with learning disabilities to interpret and answer the questions. In this way, the research contributes to the aim of improving the engagement of groups of people that are under-represented in the evidence and in the Adult Social Care Survey.”⁷⁶
- **INT4:** The four-level interview tool is for persons who live in community settings. It has 23 questions from which current SCRQoL and one can calculate expected SCRQoL.
- **SCT3:** The three-level self-completion tool is for use with people who live in community settings. It has 18 questions that calculate current SCRQoL and can generate predicted SCRQoL gain from indirect indicators based on previous research in a day care setting. These indicators may not be appropriate for all settings.
- **CH3:** ASCOT includes this tool for use in residential settings such as care homes. It uses a multi-method approach of observation (CHOBS3) and individual interviews with residents, relatives and staff (CHINT3) to score SCRQoL. The multi-method approach overcomes some of the challenges of gathering self-report information from care home residents. Around two-thirds of care home residents in the UK have dementia and engaging people with cognitive impairment through surveys poses many challenges. The CH3

⁷⁵ Netten, A., Forder, J., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., Towers, AM., Trukeschitz, B., Welch, E., Windle, K (2011) Adult Social Care Outcomes Toolkit v2.1: Main Guidance, PSSRU Discussion Paper No. 2716/3, Personal Social Services Research Unit, University of Kent, Canterbury.

⁷⁶ p.7, Turnpenny et al (2015) Discussion paper 2891: Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT) <https://www.pssru.ac.uk/pub/4907.pdf>

has three response options per item worded in the language of ‘functioning’ (no needs, some needs and high needs). No needs indicates that the person has no unmet needs in that area of their life; some needs means that they have some unmet needs and it is having a negative effect on their quality of life and high needs are distinguished from some needs by being severe or numerous enough to have physical or mental health implications. For example, in the case of food and drink, people who do not have meals at times they would like or choice over what to eat would have some needs; those who were getting an inadequate diet or insufficient liquids would have high needs.⁷⁷

Below are two of the four level questions of the ASCOT SCRQoL that one can administer to people living in the community as self-completion (SCT4) or by interview (INT4)

Q1. Which of the following statements best describes how much control you have over your daily life. By ‘control over daily life’, we mean having the choice to do things or have things done for you as you like and when you want.

Please tick () one box

- I have as much control over my daily life as I want
- I have adequate control over my daily life
- I have some control over my daily life but not enough
- I have no control over my daily life

Q9. Which of these statements best describes how the way you are helped and treated makes you think and feel about yourself.

Please tick () one box

- The way I am helped and treated makes me think and feel better about myself
- The way I am helped and treated does not affect the way I think or feel about myself
- The way I am helped and treated sometimes undermines the way I think and feel about myself
- The way I am helped and treated completely undermines the way I think and feel about myself

⁷⁷ It takes approximately one day to collect CH3 data for every five care home residents which is very resource-intensive, especially in large homes. Beadle-Brown J, Towers A, Netten A, Smith N, Trukeschitz B, Welch E. Adult Social Care Outcomes Toolkit: Additional Care Home Guidance v2.1. Canterbury: Personal Social Services Research Unit, University of Kent; 2011.

2.3.5. QOLIS tool used to evaluate training and rehabilitation

The Quality of Life Impact of Services tool (QOLIS)⁷⁸ uses the quality of life framework proposed by Schalock⁷⁹, that is, three structural dimensions, elaborated into eight variables. The tool integrates the structural dimensions of personal development, social inclusion and wellbeing into eight variables:

- Personal development – inter-personal relations and self-determination
- Social inclusion – employability, citizenship and rights
- Wellbeing – emotional, physical and material

The QOLIS questionnaire was initially developed in Portugal, a European group (17 rehabilitation professionals/managers and quality professionals from 7 countries and 10 different service provider organisations) further developed the tool and manual. The techniques, methods and materials have been piloted, evaluated and revised a number of times to improve the compatibility of the approach with different models of delivery of vocational rehabilitation services and different national contexts. The approach includes four elements:

- Develop Logic Models for participating Vocational Rehabilitation Programmes - a logical modelling procedure provides an overview of the programme theory underpinning a vocational rehabilitation programme and links the intended outcomes and impact to programme inputs and processes
- Administer QOLIS to participants who have completed each programme (random sample or all beneficiaries) - a Quality Of Life Impact of Services (QOLIS) questionnaire measures the extent to which the beneficiaries of vocational rehabilitation services attribute changes in their quality of life to the service they have received
- Enter responses into the QOLIS Scoring Book which produces programme outcome profiles - this Scoring Tool processes the responses of beneficiaries to provide a profile of the perceived QOL impact of the service – in addition to the results and comments of the QOLIS questionnaire, the scoring book records “hard” indicators including:

⁷⁸ European Platform for Rehabilitation (2012) Benchmarking the Quality of Life impact of vocational rehabilitation services: the EPR bench-learning tool for vocational education, training and rehabilitation services.
<http://www.epr.eu/images/EPR/documents/miscellaneous%202012/New%20website/Manual%20for%20administration%20-%20final%20version.pdf>

⁷⁹ Schalock RL (1996) Reconsidering the conceptualization and measurement of quality of life. In Schalock RL (ed.) Quality of Life. Volume I: Conceptualization and Measurement. Washington: American Association on Mental Retardation, pp. 123–139.

- Number of placements to open employment, supported employment, self-employment and sheltered employment
- Number progressing to other positive activities
- Progression to further education or training
- Progression to an internship or to work placement in open employment
- Progression to voluntary work
- Time spent on programme
- Educational learning outcomes
- Number gaining a full nationally recognised qualification
- Number gaining partial certification or a minor accredited certificate 6.
- Number inactive after completing programme
- Dropout rate

The QOLIS questionnaire is part of an approach to developing and evaluating vocational education, training and rehabilitation services.

The full version of the QOLIS is most suitable for people with an independent level of literacy and abstract understanding. It consists of 55 self-completion items. The QOLIS tool measures the outcomes of the education, training or rehabilitation services at an individual level.

The outcome measurement aims to relate the achievements of individuals, in terms of their quality of life, to the programmes and services they have received from the service provider. It comprises a process of gathering and analysing information that allows the extraction of knowledge about the effects of multilevel interventions.

The measurement explores each individual person's perceptions with a set of specific questions for each variable that allows one to infer the impact of the services on the individual's quality of life.

Shown below are some of the questions used in the areas of self-determination and employability:

Self-determination: My participation in the activities performed in the centre

Contributed to me feeling more capable in taking decisions

Enabled me to be more independent in my day-to-day life

Enabled me to better define my personal objectives

Enabled me to understand the consequences of my actions before doing it

Enabled me to actively engage in my education and learn new things

Employability: My participation in the activities performed in the centre

Improved my chances of getting a job

Enabled me to learn how to look for a job

Made me more capable of handling the demands of work

Have improved my confidence that I will get a job

Will help me to keep a job when I get one

Made me more aware of my strengths and needs in getting a job

Have increased my motivation to get a job

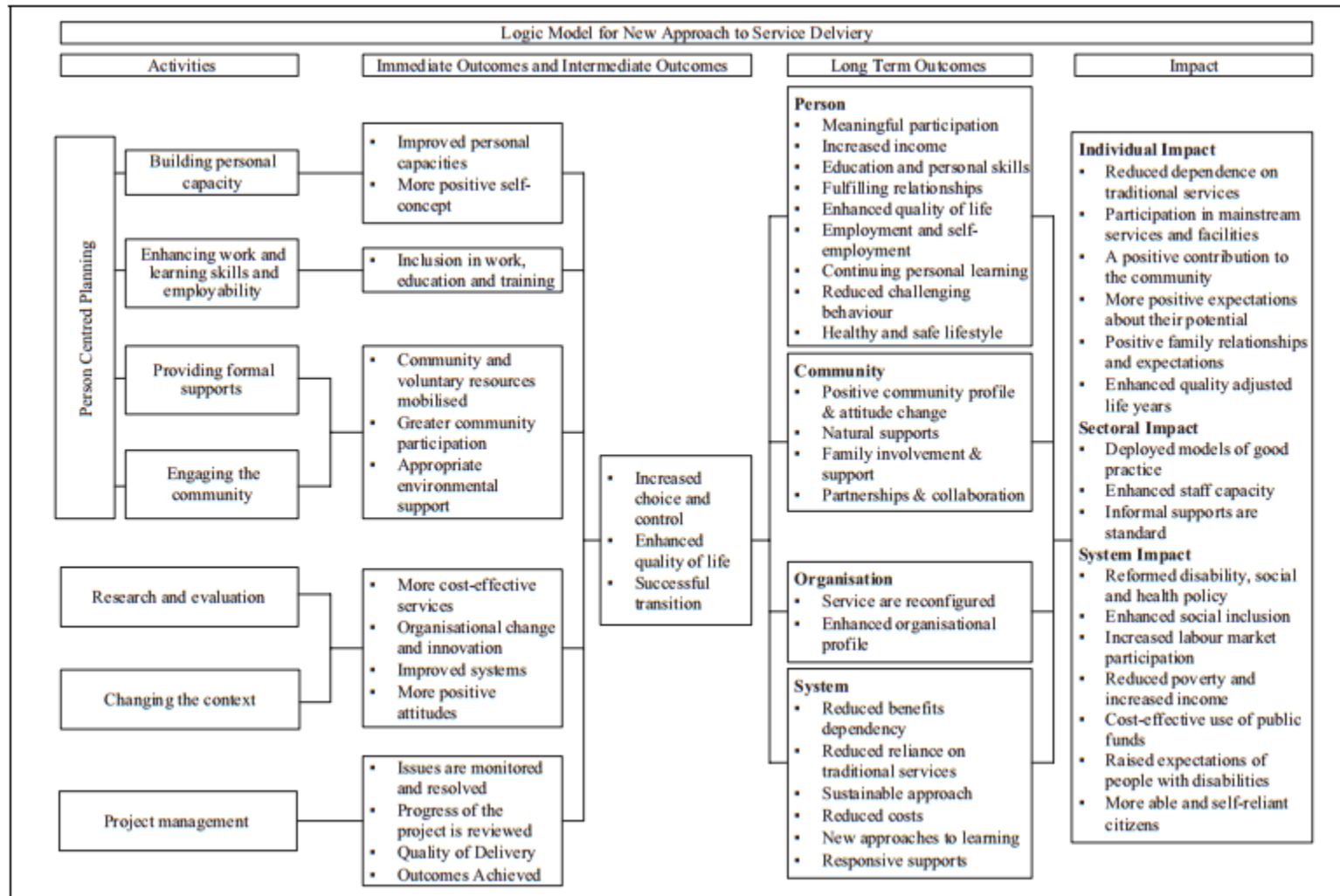
Have increased my sense of responsibility

Results are analysed using MANOVA to produce 95% confidence intervals for each dimension and element. One can benchmark each programme against the results for all programmes. The approach seeks to address challenges in programme evaluation that include:

- Finding a way to attribute effects which are identifiable in people who have participated in the programme to the actual programme itself rather than to changes in the environment or the person
- Attributing effects to specific elements - processes and activities - of the programme. Many approaches to comparison tend to give priority to statistical analysis and as a result lead to randomised controlled trials and other experimental techniques. The drawback in these approaches is that they can indicate that one programme is superior to another on whatever measures have been used but cannot explain why this is the case. Where there are no differences between programmes, these approaches cannot provide an explanation. One way to overcome this 'explanatory deficit' is to specify a programme theory for each of the programmes under consideration. Then it is possible to explore whether the differences in programme theories can explain differences in effects.

Genio, an Irish organisation, Genio, used the QOLIS instrument in Ireland in the evaluation of the activities and perceived outcomes of 15 projects supporting alternative ways of meeting the work, education, training and recreation needs of school-leavers through community-based services. Figure 1 shows how Genio used this model. Are they the only ones who have used it? Maybe just lead with the model itself, and then indicate Genio are one organisation who have used it?

Figure I Model of innovative disability projects evaluated with QOLIS (McAnaney and Wynne, 2016)



2.4. Quality Improvement – Buntinx Quality ‘Qube’

Buntinx attempted to develop a valid and reliable method for assessing perceptions of the support provided by services - perceptions are subjective measure of quality⁸⁰ by developing Quality Qube. Quality Qube examines three Quality dimensions and three Service perspectives has three levels of reporting - team, division and organisation. Buntinx bases his approach on the following suppositions. Support and care are services not products. Good support from disability services is pivotal to the wellbeing and outcome attainment of persons with disabilities. The support encounter is a partnership between persons with disabilities, their families and staff. The perception of persons with disabilities about the quality of the support they receive is important and a strategic element for the quality improvement of services. Support and care are interactive processes between persons with disabilities, staff and families and quality assessment should involve all three participants in a dialogue about support.

The Quality Qube produces an overview of the strengths and weaknesses of a service. Persons with disabilities and family committees can select the indicators for assessment. Management can add indicators they consider important. National agencies can add indicators they consider important for benchmarking. The Quality Qube examines three dimensions of the quality of supports:

- Outcomes (outcome related activities aimed at enhancing quality of life in the various outcome domains)
- Facilitators (conditions and activities necessary for delivering supports – individual support plan, information, staff availability, team work, staff competencies, continuity, security, management)
- Relationships between persons with disabilities and staff (responsiveness, trust, communication, commitment and empathy are the five dimensions of SERVQUAL which asks: How would you rate this service’s performance with respect to responsiveness, that is, how well and how fast does staff respond to the person’s demands? Is staff reliable and trustworthy? Is staff committed? Do they care about persons with

⁸⁰ Buntinx, WHE (2017), Overview of Quality Assessment in Support Services for persons with (Intellectual) Disabilities Quality Qube, Presentation at MAPS Annual Consultations May 30 & 31, and June 1. Toronto, Canada
http://buntinx.org/yahoo_site_admin/assets/docs/Quality_Qube_Overview_Torontoppt.25103017.pdf

Buninx, WHE., Herps, MA., Tan, J., Kuppens, S., Curfs, L (2015) Content analysis of Support service quality experiences, Presentation at AAIDD annual congress, Louisville, Kentucky, USA
<https://aaidd.org/docs/default-source/pp/content-analysis-of-service-quality-experience.pdf>

disabilities, family and their own work? Does staff understand the needs of persons with disabilities?)

Surveys can be restricted to participation of one or two stakeholders (persons with disabilities and/or family and/or staff). A minimum survey would include two open questions and one satisfaction rating and take 10 minutes. The Quality Qube uses quantitative (surveys) and qualitative data (open questions and focus groups) from persons with disabilities, families and staff. This allows comparisons, for example, between the satisfaction of persons with disabilities, staff and families about facilitators. Interviewers (independent) ask two open questions from persons with disabilities about their experiences of support received over the past 6 months and expressed in their own words and they gather the perceptions of family and staff in an internet or paper-based survey:

- What do you appreciate most in the support practices of this team? (What are you satisfied with? What is this team doing well? What are they good at?)
- What can be done to improve this team's support to the client? (What are you dissatisfied with? What are they not doing well? What do they need to improve?)

Evaluators ask staff about their perceptions: How would you agree with the statement that this organization is offering choices to the client in leisure activities? [Disagree completely/Disagree/Unsure/Agree/ Agree completely]
Evaluators ask persons with disabilities questions such as:

- How well does staff support you in making choices?
- Are you satisfied with the meals?
- Have you opportunities for participating in community activities?
- How satisfied are you with your involvement in your Individual Support Plan (ISP)?
- Is the plan in clear and understandable words?
- How prompt does staff respond to your needs and questions?

The evaluators code each individual answer in terms of outcomes, facilitators and relationships and summarise feedback on positive and negative issues from family, persons with disabilities and staff in 'Quality Improvement Cards', which can be used in discussions between two or the three parties. The cards present what aspects of supports are ok and what needs to be improved. At the individual level, one can use the data in the individual planning process to improve support effectiveness. One can use, at the team level, responses of each group and category to improve teamwork. One can use the profiles of strengths and weaknesses at the organisation level to improve policy and practice. One can use

the profiles of strengths and weaknesses to compare different organisations and over time within the same organisation. Knowledge of these profiles may be useful for marketing and communication purposes.

One can chart the improvement process for the different teams: goals based on the Quality Qube data, planned actions; actions carried out and improvements realised. The Quality Qube method has proven to be a reliable instrument. It allows for adding standard indicators for national survey purposes without losing efficiency with respect to local return on investment. Involving persons with disabilities, family and staff results in richer data and enhances joint improvement actions.⁸¹

2.5. Comparing an individualised tool with a standardised tool

Comparing and contrasting the POMS individualised outcomes planning and evaluating tool with the standardised NCI Indicators tool illustrates how the purpose of outcomes measurement will determine the tools used. The POMS tool and the NCI Indicators tool both have proven reliability and validity. They both assess personal outcomes attained by persons with intellectual/other disabilities in receipt of services/supports. While the principles of outcome measurement and quality of life are at the heart of both these tools, their approaches are different in practice and purpose and illustrate different characteristics that are a consequence of the different purposes of the tools.⁸²

The POM entails an exploration of a person's quality of life and supports from an individual perspective. POM measures are self-defined and the goal of the interviews is to have conversations that build on the priorities and interests of the persons with a disability. The individual defines quality of life and the instrument records the individualised supports that the person receives from services.

In contrast, the NCI tool is a system level measurement of the attainment of outcomes by people receiving services and supports based on participants answers to a number of questions. The NCI tool measures standard indicators using survey questions where there is a presumption that the questions are

⁸¹ Buntinx, WHE (2017), Overview of Quality Assessment in Support Services for persons with (Intellectual) Disabilities Quality Qube, Presentation at MAPS Annual Consultations May 30 & 31, and June 1. Toronto, Canada
http://buntinx.org/yahoo_site_admin/assets/docs/Quality_Qube_Overview_Torontoppt.25103017.pdf

⁸² Taub, S., Martin, D The National Core Indicators Consumer Survey and The Council on Quality and Leadership's Personal Outcome Measures: A comparison and analysis of compatibility

relevant to everyone. With the NCI, for example, if a person says he/she does not go shopping, the coded response is “no”. With the POM, however, if a person does not participate in community activities but expresses that this is his/her choice, the person codes the outcome as being present.⁸³ The NCI data shows, for example: what proportion had choice in where to live; what proportion work; what proportion expressed interest in working and, of these, what proportion had the goal of working actually stated in their person-centred plan. Table 7 illustrates the difference between POM and NCI in exploring community participation.

Table 7: Comparing some POM and NCI questions on community participation

POM My Self	NCI
OUTCOME: People participate in the life of the community	OUTCOME INDICATOR: Proportion of people who participate in integrated activities in their communities, including: shopping, using public services, attending arts/entertainment events, dining out, attending religious services/events, or attending clubs/community meetings.
Questions (for person):	Questions (for person or proxy):
<ol style="list-style-type: none"> 1. What kind of things do you do in the community (shopping, banking, church, synagogue, mosque, school, hair care)? How often? 2. What kind of recreational or fun things do you do in the community (movies, sports, restaurants, special events)? How often? 3. How do you know what there is to do? 4. Who decides where and with whom you go? 5. Is there anything you would like to do in the community that you do not do now? What do you need to do to makes this happen? 6. What supports do you need to participate, as often as you would like, in community activities? 	<ol style="list-style-type: none"> 1. Do you (this person) go shopping? 2. Do you (this person) go out on errands or appointments? 3. Do you (this person) go out for entertainment? 4. Do you (this person) always eat at home or do you, sometimes, go out to eat? 5. Do you (this person) go to religious services? 6. Do you (this person) go to other meetings in the community?

⁸³ Taub, S., Martin, D (2010) The National Core Indicators Consumer Survey and The Council on Quality and Leadership’s Personal Outcome Measures: A comparison and analysis of compatibility <https://ltssconsumerqualityadvisorycommittee.files.wordpress.com/2014/03/nci-and-cql-outcome-measures-comparison.pdf>

3. Discussion

The discussion paper outlined the purpose of outcome measurement in disability services and explored challenges associated with incorporating outcome measurement into service practice and into quality assurance and improvement systems. Fundamental outcome measurement issues are the need to measure outcomes that are important to the individual and to evaluate what services contribute to progress made towards outcome goals. As each person is unique, what is important to the person varies widely from person to person and so some form of individualised personal outcome assessment is essential.

The ultimate purpose of outcome measurement in disability services is to ensure that each person receives the supports and opportunities they need to strive for their goals and enjoy a good quality of life. Monitoring progress towards attaining personal goals in the various quality of life outcome domains should help to ensure this. The best indication of the usefulness of outcome measurement is that it supports the development and delivery of ever more appropriate and tailored supports and opportunities to individuals needing support. Efforts to ensure that disability services are person-centred and deliver personal outcomes include the following:

- Embed person-centred planning including periodic evaluation of individual progress towards his/her outcome goals into service delivery.
- Use standardised observation rather than proxies for persons with profound or severe intellectual disability to assess quality of life outcomes. Bigby et al (2014) developed indicators from qualitative analysis of observations in homes with people with severe/profound intellectual disability over 9-12 months. They proposed the use of these observation indicators to assess the quality of life of people with severe or profound intellectual disabilities.⁸⁴ Others increasingly use observation in their routine support coordination to improve provision of supports and opportunities.⁸⁵
- In quality assurance processes, include some element of individual quality of life assessment through observation, interview or comparison of interview to person-centred plan. Evaluate whether services are tracking individual

⁸⁴ See Tables 2 and 3 in this report.

⁸⁵ For example, in the USA, states use support coordination to ensure quality disability services for persons with intellectual/developmental disabilities. The Georgia Department of Behavioural Health and Developmental Disabilities use an Individual Quality Outcomes Measures review tool and update it. The tool includes observation and is part of a Recognise, Refer and Act evaluation method that appears to be effective. <https://dbhdd.georgia.gov/blog/2018-01-11/revision-individual-quality-outcome-measures-review>

progress towards goals in the quality of life outcome domains in the person-centred planning process. Check that services are operating a robust quality improvement system. Evaluate whether services are providing appropriate supports and opportunities by evaluating the presence/absence of predictors. International research has identified outcome predictors that are associated with an increased probability that persons will attain outcome goals in various outcome domains. Examples of outcome predictors include Active Support⁸⁶, access to transport and good person-centred planning. Establishing whether outcome predictors are present in services can form part of assessing whether services are providing appropriate supports to persons with disabilities. One can investigate whether outcome predictors are present through observation as well as with interviews. Another advantage of outcome predictors is that their presence strengthens the case that positive outcomes found are a result of supports provided by services.

- Improve standardised outcome measures, which are generic indicators of quality of life used to assess quality of services and to benchmark services. Given the complexity of outcomes and outcome measurement, the heterogeneity of populations, and the uniqueness of each person, developing standardised outcome measures for disability services is challenging. Some standardised outcome tools are too narrow in scope, too lengthy or too complex. Some tools developed may have robust psychometric properties but may not measure outcomes of interest to the individual or to governments and services in terms of, for example, achieving full societal participation in the light of the UNCRPD requirements. The process of building and developing a bespoke outcome measurement tool is challenging and time consuming but has its advantages. It builds commitment and collaboration. It compels stakeholders including disability service providers to clarify their purpose and to grapple with whether service structures and systems are delivering outcomes. It necessitates a collaborative effort to identify meaningful and measurable outcomes in particular disability services.

Given the report findings, the NDA recommends the following:

- Quality assurance and quality improvement systems should include some element of individual assessment of quality of life outcomes. While compliance with policies, standards and regulations are essential, if they do not lead to

⁸⁶ Active Support is a person-centred way of enabling people with severe/profound intellectual disabilities to engage in meaningful activity and relationships. It devises structured activities on an individual basis by breaking down each task, activity, etc., into a series of steps in a structured and predictable way that is manageable. Staff develop the skills needed to provide opportunities for persons with profound intellectual disabilities to learn to “do” simple tasks and to be involved in activities/tasks in some way. There are reviews of the positive impact of Active Support on the quality of life of persons with intellectual disabilities.

delivering personal outcomes and a good quality of life something is amiss. To ensure that services deliver outcomes, quality assurance and improvement processes should align with and include an outcome focus. HIQA's Disability inspection team could include, in their quality assurance processes, a specific outcomes-focus in addition to a focus on standards and regulations. While a direct focus on outcomes is not currently a statutory requirement for HIQA, it is vital to show alignment between regulations, standards and outcomes and to confirm that compliance with regulations and standards result in better outcomes. Using standardised observation, HIQA inspectors could evaluate outcome indicators and predictors in the outcome domains approved by the Department of Health/HSE for disability services.

- If the Department of Health/HSE hope to recommend Quality Assurance Accreditation for disability services, it would be helpful if accreditation processes included an outcomes focus. Outcomes measurement could include assessing personal outcomes at the individual level as well as measuring outcome indicators at the service level. In terms of standardised outcome measurement, the Department of Health/HSE could use:
 - Outcome indicator measurement at service level such as two or three standardised indicators per each of the nine outcome domains. The Department of Health/HSE or HIQA could usefully adopt some of the National Core Indicator survey questions for each of the nine outcome domains approved for Irish Disability Services (Table 3). For the nine quality of life outcome domains, some of the NCI questions are as follows:
 - **Outcome domain 1 - Living in the community:** Did you choose where you live? Did you choose whom you live with? Do you like where you are living?
 - **Outcome domain 2 – Choice and control:** Do you feel in control of your life? Do you get up and go to bed when you want to? Are you able to decide how to decorate and furnish your room and house?
 - **Outcome domain 3 – Social and civic participation:** Did you go out for entertainment in the last month? Did you go out to eat in the last month? Did you go on vacation in the past year?
 - **Outcome domain 4 – Personal relationships:** Do you have a best friend? Can you see friends when you want to? Do you ever feel lonely?
 - **Outcome domain 5 – Personal development/education:** Have you gone to a self-advocacy meeting? If you have a complaint about the services you are getting right now, do you know whom to call
 - **Outcome domain 6 – Employment and valued social roles:** Do you do any volunteer work? Would you like a job? Has someone talked to you

about job options? Do you have a paid job in your community? Do you like where you work?

- **Outcome domain 7 and 8 – Health, wellbeing and quality of life:** How would you describe your overall health? Did you go out to exercise in the last month? Do you have access to healthy foods like fruits and vegetables when you want them? Do you like how you usually spend your time during the day? Do the people, paid to help you, do things the way you want them done? Do the services you receive meet your needs and goals? If no, what additional services might help you?
- **Outcome domain 9 –Safe, secure and free from abuse:** Do you feel safe in your home? Do people ask permission before coming into your home? Do you have enough privacy at home? Has anyone used or taken your money without your permission? Do you feel safe around the people paid to help you? Do staff ask what you want? Do staff help you get what you need? Do staff treat you with respect?
- In addition to the use of standardised outcome tools, one could carry out some direct assessment of individual quality of life such as interviews or observation as well as assessment of outcome predictors:
 - Use observation, in particular, where persons have profound cognitive and verbal difficulties. Outcome assessments using observation provide direct evidence of the reality of people’s lives, which is important where persons cannot easily express or speak for themselves. Inspectors could also include a more specific outcomes focus in their interviews, surveys, etc.
 - Do random checks with a number of individuals on whether their person centred plans (PCP) correspond to their quality of life outcome goals? For example, from a random selection of person with disabilities in congregated settings, one could compare goals as set out in person centred plans with the supports delivered. Are the goals in the plan the same as the person expresses at interview? What individualised supports did service provide to the person to attain the goals set out in the various outcomes domains in his/her plan? Which goals did the persons attain in part or in full and in which outcome domains? How are the person-centred plans progressed? What supports are in place by services to supports persons make progress towards their desired outcomes?
 - Check that disability services operate a quality improvement system that fuels the ongoing development of supports and opportunities to better support persons with disabilities attain quality of life outcomes.
 - Assess the presence/absence of outcome predictors.
 - Establish whether services have a quality improvement process and are using it to improve the delivery of supports/ opportunities that facilitate attaining personal outcomes.

Appendix: Implementing the ‘Value for Money and Policy Review of Disability Services’: person-centred and outcomes-focused services

1.0. Overview

In Ireland, the 2012 ‘Value for Money and Policy Review of Disability Services’, which involved consultation with persons with disabilities recommended the measurement of outcomes at personal, organisational and programme levels to monitor progress in improving outcomes for person with disabilities through improving the quality of disability services. The Working Group Report, ‘New Directions Review of HSE Services and Implementation Plan 2012- 2016’, published in 2012, was based on a programme of research, a census of current day service provision and a national public consultation with more than 1,500 people with disabilities, families, carers, service providers and members of the general public. “The strong emphasis was on the need for community inclusion, with less segregation of services, more choice, more worthwhile and meaningful activities, and more flexible, individualised supports that fit with the person’s life stage. As people strive for inclusion in the economic and social life of the community, they recognise that they need particular supports to attain various work-life goals and improve the quality of their lives. They want that support to be appropriate to their needs and to focus on opportunities to enrich their personal and social lives and relationships.

Since 2012, the Department of Health, the HSE, the National Disability Authority (NDA), the disability sector and persons with disabilities have collaborated to implement the Transforming Lives Programme and deliver the recommendations of the ‘Value for Money and Policy Review of Disability Services’. The reform involves de-congregation and providing community and individualised supports for persons with disabilities. The heart of the reform is to ensure that disability services deliver personalised supports so that persons with disabilities attain a good quality of life in the community. Evaluating disability services in this context necessitates assessing what outcomes persons with disabilities attain due to the services and supports accessed. Key reports for the HSE Transforming Lives Programme include ‘Time to Move on from Congregated Settings’ (residential centres), New Directions programme (to improve day services) and Progressing Disability Services for Children and Young People (to improve therapy services for children).

The work of the NDA with Department of Health and the HSE in the Transforming Lives Programme has included inputs into the work of most of the Transforming Lives working groups. This work includes significant contributions to the development of a number of integrated and aligned Disability Service

frameworks so that services support persons with disabilities more effectively to make progress towards their goals in the quality of life outcome domains:

- The Person-Centred Planning Framework for Disability Services (HSE piloting this currently, 2019, in disability day services) focuses on supporting individual persons to attain their goals. This requires a person-centred organisational culture where personnel, at the individual, organisational and systems levels, practise person-centred values and principles. Person-centred planning enables a person to make informed choices about how they want to live their life, now and in the future. Supports must be responsive to the persons that need them and focus on the outcomes they want to achieve.
- The Quality of Life Outcomes Framework for Disability Services: Following research and consultation by the National Disability Authority outcome measurement and experiences from other jurisdictions on developing services and focusing on outcomes,⁸⁷ the Department of Health and the HSE approved nine outcome domains for Irish disability services for adults. Some Disability Services are using these outcome domains to improve personal planning processes with persons with disabilities and provide individualised supports so that persons progress towards their goals in the quality of life outcome domains.
- The Quality Framework for Disability Services (waiting implementation): This identifies the elements of services and supports that facilitate the achievement of outcomes by adults with disabilities.

All three frameworks are inter-related. The primary purpose of using the frameworks is to support the development of outcomes focused disability services so that persons with disabilities receive the individualised supports they need in order to attain the goals they set themselves in various quality of life outcome domains. These frameworks all require the following elements in services:

- Leadership to create shared values, goals and a culture of continuous improvement in services on providing appropriate individualised supports to persons with disabilities.
- Education and training so that everyone develops a vision for outcomes-focused services and collaborates in creating person-centred and outcomes-focused learning environments.

⁸⁷ The NDA paper on Outcomes for Disability Services can be accessed on the NDA website – <http://nda.ie/Publications/Disability-Supports/NDA-paper-on-outcomes-for-disability-services.html>

- Use the Person-Centred Planning Framework to implement the values and principles that underpin person-centred services and which establish and maintain a person-centred culture.
- Use of the Quality of Life outcome domains framework to support person-centred planning and the provision of appropriate individualised supports.
- Use the Quality Framework for Disability Services to identify and address each of the elements of services/supports needed to ensure the achievement of outcomes by adults with disabilities.

2.0. The Person-Centred Planning Framework

Person-centred planning is a way of discovering how a person wants to live his/her life and what is required to make that possible. The development of a plan is a means to ensure that person with disabilities take positive steps towards achieving their goals in various quality of life outcome domains. The NDA contributed to a body of work on person-centred planning and the development of a Person-Centred Planning Framework. In 2016, the first phase, to inform the development of the person-centred planning framework, included a literature review since the publication of the NDA Guidelines on Person Centred Planning in 2005, an analysis of 50 HIQA reports and, thirdly, an evaluation of current person-centred planning practice through interviewing key informants and conducting case studies of good practice. The second phase involved developing the framework itself. The purpose of a person centred planning framework is to support disability services to consistently achieve good practice in person-centred planning, resulting in positive outcomes for people who use services. The framework sets out key elements and principles of good practice in person-centred planning. It lays out the core beliefs, foundations and key elements in person-centred planning. The framework addresses organisational culture, structures and processes and the evaluation of person-centred planning.

3.0. The Quality of Life Outcomes Domain Framework

The quality of life outcome domains provides a framework for discussing individualised supports. A good quality of life is experienced when a person's basic needs are met and when he/she can access the opportunities and develop the capabilities that enrich life in the usual life activity settings.⁸⁸ If persons cannot access the supports they need to develop as persons, they will not enjoy a quality

⁸⁸ Verdugo MA, Navas PA, Gomez LE, Schalock RL. (2012) The concept of quality of life and its role in enhancing human rights in the field of intellectual disability. *Journal of Intellectual Disability Research*, 56(11), 1036-45.

of life of the same scope as other members of society. Amartya Sen,⁸⁹ and others, underline the importance of access to opportunities to develop capabilities, etc. According to Sen, real poverty is not only deprivation of income but also deprivation of capability through lack of access to the opportunities that a person needs to develop his/her capabilities.⁹⁰ This explains why disability services need to provide individualised supports and access to opportunities so that persons can develop. The interplay between environmental factors and personal characteristics is unique for each person and this requires staff to tailor support strategies to each person. The work of supporting the actualisation of individual possibilities is person-centred. This involves uncertainty and the dignity of risk⁹¹ and working with persons one by one and not as a group.

In 2016, following research and consultation on outcomes,⁹² the NDA proposed nine quality of life outcome domains for adult Irish Disability Services, which the Department of Health and the HSE approved for Irish Disability Services.⁹³ The nine outcome domains reflect widely recognised aspects of life that are important for all people and include, for example, having autonomy, meaningful activities,⁹⁴ education and training and good relationships including with family, friends and

⁸⁹ Sen, AK (2004) Capabilities, lists and public reason: Continuing the conversation. *Feminist Economics*, 32, 269-294 and Sen AK (1985) *Commodities and capabilities*, Amsterdam, The Netherlands: North-Holland.

⁹⁰ Sen, AK (1999) *Development as Freedom*, Oxford University Press, New York

⁹¹ Reinders, Hans S., Schalock, RL. (2014) How Organisations Can Enhance the Quality of Life of Their Clients and Assess Their Results: The Concept of QOL Enhancement, *American Journal on Intellectual and Developmental Disabilities*, 119 (4), 291-302.

⁹² The NDA researched and developed a set of outcomes for Irish Disability Services based on an examination of the literature on outcomes, outcome domains and quality of life, outcome measurement, and the experience of using outcomes in other jurisdictions. The NDA consulted with persons with disabilities and services providers on the draft set of outcomes. Persons across different levels of impairment, including persons who were non-verbal, different age groups, genders, and living arrangements/type of service. There were five focus groups and six interview with people with a disability. There was a focus group with service provider representatives, which included persons with disabilities, and a focus group with service providers. There were meetings between the NDA and service providers to cross map worked on outcomes.

⁹³ Further detail is set out in the NDA paper on Outcomes for Disability Services – <http://nda.ie/Publications/Disability-Supports/NDA-paper-on-outcomes-for-disability-services.html>

⁹⁴ Meaningful activities are the activities desired and chosen by all people. They include purposeful and meaningful work; skills development; educational activities and community inclusion activities. For an individual person, meaningful activities should directly link to his/her vision, goals, and desired outcomes.

community. The nine quality of life outcome domains framework for disability services are as follows:

The persons who use disability services:

- 1. Are living in their own home in the community**
- 2. Are exercising choice and control in their everyday lives**
- 3. Are participating in social and civic life**
- 4. Have meaningful personal relationships**
- 5. Have opportunities for personal development and fulfilment of aspirations**
- 6. Have a job or other valued social roles**
- 7. Are enjoying a good quality of life and well being**
- 8. Are achieving best possible health**
- 9. Are safe, secure and free from abuse**

The outcome domains align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Health Information and Quality Authority (HIQA) Residential Standards and the Interim Standards for New Directions.

There is consensus that quality of life (QOL) is the same for all and that it is multi-dimensional. Each outcome domain have objective and subjective aspects. Examples of “objective” data include mortality data, employment status, educational attainment and type of accommodation. Examples of “subjective” data include quality of life and wellbeing measures, satisfaction with services and evaluation of progress towards goals set in person-centred planning. The use of proxies for assessing subjective indicators is invalid. Subjective aspects of QOL refer to personal perceptions of the quality of various aspects of life and is an essential part of evaluating QOL. For example, self-reported health (SRH) is a subjective QOL measure that asks people to rate their health. SRH has proven to be a statistically powerful predictor of morbidity and mortality in all populations. It predicts mortality above more ‘objective’ health measures.⁹⁵ The association between SRH status and future health outcomes suggests a close relation between SRH status and more ‘objective’ measures of health status.⁹⁶ SRH status

⁹⁵ Idler, EL., Benyamini, Y. (1997) Self-rated health and mortality: A review of twenty-seven community studies, *Journal of Health and Social Behaviour*, 38, 21–37 and Lucas, RE., Diener, E. (2008) Personality and subjective wellbeing. In O. P. John, R. W Robins, & L. A. Pervin (Eds.), *Handbook of personality: Theory and research*, 3rd edn. (pp. 795–814). New York: The Guilford Press.

⁹⁶ Jylhä, M. (2009). What is self-rated health and why does it predict mortality? Towards a unified conceptual model, *Social Science & Medicine*, 69(3), 307–16.

is stable across cultures, communities and age groups.⁹⁷ The subjective and objective aspects of QOL are important and together can provide a reasonable estimate of a person's quality of life. Research shows that the objective and subjective facets of QOL seem to operate independently. Some quality of life tools attempt to work around this issue of low correlation between objective and subjective measures by having individuals rate the importance of each of the quality of life domains for them.

Nieuwenhuijse et al (2017) assessed methods of evaluating the quality of life of persons with profound intellectual and multiple disabilities. They found five questionnaires and one instrument that used observations and interviews. All of the instruments used proxies.⁹⁸

Conner (2016) carried out a systematic review of quality of life assessment tools for adults with intellectual and developmental disabilities.⁹⁹ The aim of the research was to review QOL assessment tools for adults with all levels of I/DD that disability service systems could use to examine the individual, agency, and system levels of QOL outcomes. Following inclusion and exclusion criteria, 35 articles from 1990-2014 were included in the review. Of 25 QOL assessment tools for adults with I/DD identified through the systematic review, the authors retained 13 tools for comparison, shown in Table 2 and based on the following criteria:

- An English language version is available
- The tool demonstrates theoretically based QOL factors

⁹⁷ For example, Hirve, S., Oud, J.L., Sambhudas, S., Juvekar, S., Blomstedt, Y., Tollman, S., et al. (2014) Unpacking Self Rated Health and Quality of Life in Older Adults and Elderly in India: A Structural Equation Modelling Approach. *Soc Indic Res.* 117,1, p.105–19. 2) Craigs, CL., Twiddy, M., Parker, SG., West. RM. (2014) Understanding causal associations between self-rated health and personal relationships in older adults: A review of evidence from longitudinal studies, *Archives of gerontology and geriatrics*, 59,2,211–26 3) Eriksson, I., Undén, A-L., Elofsson, S. (2001) Self-rated health. Comparisons between three different measures: results from a population study, *International journal of epidemiology*, 30,2, 326–33 4) Vingilis ER, Wade TJ, Seeley JS (2002) Predictors of Adolescent Self-rated Health: Analysis of the National Population Health Survey, *Canadian Journal of Public Health / Revue Canadienne de Sante'e Publique*, 93, 3,193–7

⁹⁸ Appolonia M. Nieuwenhuijse, Dick L. Willems, Johannes B. van Goudoever, Michael A. Echteld & Erik Olsman (2017) Quality of life of persons with profound intellectual and multiple disabilities: A narrative literature review of concepts, assessment methods and assessors, *Journal of Intellectual & Developmental Disability* DOI: 10.3109/13668250.2017.1388913

⁹⁹ Conner, Brianne Leigh (2016) A systematic review of quality of life assessment tools for adults with intellectual and developmental disabilities. http://digitalrepository.unm.edu/padm_etds/

- The tool is not limited to a specific residential setting.

Table 1 QOL Tools identified for comparison (Conner, 2016)

QOL Tool	Author(s)
Comprehensive Quality of Life Scale-ID (ComQol-ID)	Cummins, 1997
Evaluation of Quality of Life Instrument (EQLI)	Nota & Soresi, 2002
INTEGRAL Quality of Life Scale	Verdugo, Gomez, & Arias, 2007
Life Situation Survey	Chubon, 1987
Lifestyle Satisfaction Scale	Heal & Chadsey-Rusch, 1986
Maryland Ask Me! Project	Bonham, et al., 2004
Personal Outcome Measures	Gardner, Nudler, & Chapman, 1997
Personal Outcomes Scale	Claes, et al., 2009
Personal Wellbeing Index-ID (PWI-ID)	International Wellbeing Group, 2006
Quality of Life Questionnaire (QOL-Q)	Shalock & Keith, 1993
Questionnaire on Quality of Life (short form)	Craig & Harrison, 1986
San Martin Scale	Verdugo, et al., 2013
WHOQOL-DIS	WHOQOL-Dis Group, 2010

The author compared these 13 tools in the following categories:

- Theoretical basis and purpose
- Tool properties
- Psychometric characteristics
- Intended or demonstrated use of results.

The purpose of the comparison was to provide information on how to use a variety of tools. Only one tool, the QOL-Q, met the recommendations of the review but this was primarily due to a lack of available psychometric data for many of the other QOL assessment tools.

A 2012 systematic review of QOL measures for people with intellectual disabilities and challenging behaviour by Townsend-White et al found that six of 24 QOL instruments were psychometrically sound. The authors assessed these tools against 24 criteria developed from the outcome measurement literature and concluded that there are a limited number of psychometrically sound QOL measures that are potentially suitable for measurement of QOL among people with ID. However, the study found no universally gold standard instrument to assess QOL of adults with ID who exhibit challenging behaviour.¹⁰⁰

The NDS in Australia (Baker, 2012) identified over 800 tools for measuring quality of life in disability services (including some developed for people with

¹⁰⁰ Townsend-White, C., Pham, ANT., Vassos, MV. (2012) A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviour. *Journal of Intellectual Disability Research*, 56 (3),270-284

intellectual or other cognitive disability and some for use by families). Most of the measures incorporate features of wellbeing, social involvement and opportunities to achieve personal potential.¹⁰¹ An older review of quality of life instruments undertaken for the Victorian Department of Human Services, Australia, in 2002¹⁰² identified 35 possible instruments for systematic and regular measurement of quality of life of people in the disability service system that could support assessing service outcomes, service monitoring and planning, client planning and evaluation. The study concluded no one tool was available to meet all the desired applications. Table 2 shows the tools identified in this study as best for different purposes.

Table 2 Summary of proposed best available resources (2002)¹⁰³

Potential Assessment Purpose	Tools
Whole system outcomes performance monitoring	National Core Indicators Project (NCI)
Benchmarking client quality of life to whole population norms	Comprehensive quality of life scale (Cummins) refined as the Personal Wellbeing Index
Client outcome focused accreditation	Personal Outcome Measure (POMS)
Individual quality of life monitoring by disability services/ person-centred planning aid/service quality improvement	University of Toronto Quality of Life Profile for People with Developmental Disability

4.0. A Quality Framework to support persons achieve outcomes

The aim of the quality framework is to support disability service providers to focus services and supports on achieving meaningful quality of life outcomes for persons with disabilities and to ensure that the quality assurance and quality improvement systems employed in disability services focus on the achievement of outcomes for the persons who use services. The Quality Framework is relevant

¹⁰¹ Ken Baker, National Disability Services, Australia (2012) Measuring Outcomes for People With Disability www.nds.org.au/asset/view_document/979321223

¹⁰² Victorian Government, Department of Human Services. Quality of Life Assessment for People with a Disability 2002 Performance, Planning and Research, Disability Services Division, Victorian Government Department of Human Services, Melbourne, Victoria

¹⁰³ Victorian Government, Department of Human Services. Quality of Life Assessment for People with a Disability 2002 Performance, Planning and Research, Disability Services Division, Victorian Government Department of Human Services, Melbourne, Victoria

for services for adults with a disability, including day, residential, home and community services.

To develop the quality framework, the National Disability Authority carried out a review of the literature on developing disability services. The review focused on disability-system and service-level research and on the predictors of outcomes for persons with disabilities. The learning from this research, including efforts in disability services to improve quality, transform services, measure outcomes, and identify the predictors of outcomes, informed the development of a draft Quality Framework to support disability service providers to focus services and supports on achieving personal outcomes.

Outcome predictors are the supports and opportunities that predict the attainment of outcomes. An expanding body of international research on predictors have identified elements of services and supports that are associated with persons with disabilities attaining their life goals. This interplay between individualised services and supports and achieving personal outcomes is the focus of the quality framework. The Quality Framework identifies elements of services and supports that facilitate the achievement of outcomes by adults with disabilities. The predictors identified in the quality framework should guide continuous quality improvement and the provision of outcomes-focussed services and supports. In the research literature, outcome predictors for persons with disabilities accessing supports and services included the following:

- Person-centred planning.¹⁰⁴
- Opportunities for development including education and training; volunteering, work experience and employment.
- Access to transport.
- Self-advocacy, self-determination (choice and control), control over the environment, social integration and engagement in meaningful activities.
- Staff practices such as practice leadership, active support and positive behavioural support.

¹⁰⁴ Person-centred planning predicts that persons with disabilities will attain the outcomes important to them when it reflects the person's life goals and when staff support the person to implement the plan. However, NCI data for 2015 -2016 in Michigan, USA showed that of the 42% of people who wanted a paid job in the community only 26% had employment as a goal in their plan. Similarly, in other states, some individuals who wanted to work as a major life goal did not have employment in their person centred plan.

- Community-based living arrangements and greater opportunities to make choices were associated and both of these factors are, in turn, associated with greater quality of life.
- Active Support for persons with significant cognitive, physical and behavioural challenges who will not attain outcomes without active support from others.
- A Total Communication approach that values and uses all forms of communication so that persons with disabilities can communicate and express themselves.
- It is also likely that in-school predictors for post-school success, such as networks and work experience, etc., will also facilitate progress in independent living, employment, etc., for adults with a disability. Predictors for post-school success in education, employment and independent living include formal agency-based networks and informal networks involving friends, family and community members; participation in work experience that resembles adult environments; and self-determination, self-care and independent living skills.

Table 3 shows the outcome predictors plotted against the nine outcome domains agreed for Irish Disability Services. The NDA drew on the research on outcome predictors to guide on formulating the practices that provide person centred supports and personal outcomes in its formulation of a draft quality framework for disability services. The Quality Framework describes the outcome predictors at the individual and organisational levels. Many outcome predictors at the individual level refer to having access to supports and opportunities, ‘in line with my needs and wishes’ to reflect that the persons who use services and supports are diverse, and that services and supports should be person-centred and individualised. In the Quality Framework, outcome predictors are set out under four themes at the individual level and written from the person’s point of view, as the focus of these outcomes predictors is on the individual. The four themes at the individual level are as follows:

- Individualised and Effective Service and Supports
- Safe Services and Supports
- Health
- Development

At the organisational level, the quality framework outlines what is required at the organisational and systems level to enable persons with disabilities to attain the goals that are important to them under the following four themes at the organisational level:

- Strategic and Practice-based Leadership

- Governance, Management and Use of Resources
- Responsive Workforce
- Outcome Measurement

Table 3: Outcome predictors across the outcome domains agreed for Irish Disability Services

Outcome Predictors	NINE OUTCOME DOMAINS								
	1.Live in own home in community	2.Exercise choice and control	3.Participate in social and civic life	4.Meaningful personal relationships	5.Personal development and fulfilment	6.Have a job/other valued social roles	7.Quality of life and wellbeing	8.Achieve best possible health	9.Safe, secure and free from abuse
Person-centred thinking including Person-Centred Planning	√	√	√	√	√	√	√		√
Leadership & appropriately-trained staff with positive attitudes		√	√	√	√	√	√	√	√
Access IT/electronic		√	√		√	√	√		√
Small community based living arrangements		√	√				√		√
Advocacy/supported decision making	√	√			√	√			√
Self-advocacy		√							
Access Transport		√	√		√	√	√		
Access Assistive technology devices and augmented communication systems		√	√	√					

	NINE OUTCOME DOMAINS								
Outcome Predictors	1.Live in own home in community	2.Exercise choice and control	3.Participate in social and civic life	4.Meaningful personal relationships	5.Personal development and fulfilment	6.Have a job/other valued social roles	7.Quality of life and wellbeing	8.Achieve best possible health	9.Safe, secure and free from abuse
Individual characteristics – self-care skills						√	√		
Active support				√	√		√		
Self-care supports					√	√	√		
Legal and human rights									√
Family involvement			√	√			√		
Social support, social networks, circle of friends			√		√	√	√		
Stable predictable environments		√	√				√		
Personal possessions							√		
Opportunities - post-secondary & continuing adult education		√	√		√				
Opportunities - job training, work experience, volunteering			√	√	√	√			
Opportunities – vocational services			√		√	√	√		

	NINE OUTCOME DOMAINS								
Outcome Predictors	1.Live in own home in community	2.Exercise choice and control	3.Participate in social and civic life	4.Meaningful personal relationships	5.Personal development and fulfilment	6.Have a job/other valued social roles	7.Quality of life and wellbeing	8.Achieve best possible health	9.Safe, secure and free from abuse
Opportunities - Independent Living programmes			√						

Figure 1: Structure of the Quality Framework: Supporting Persons with Disabilities to achieve Personal Outcome

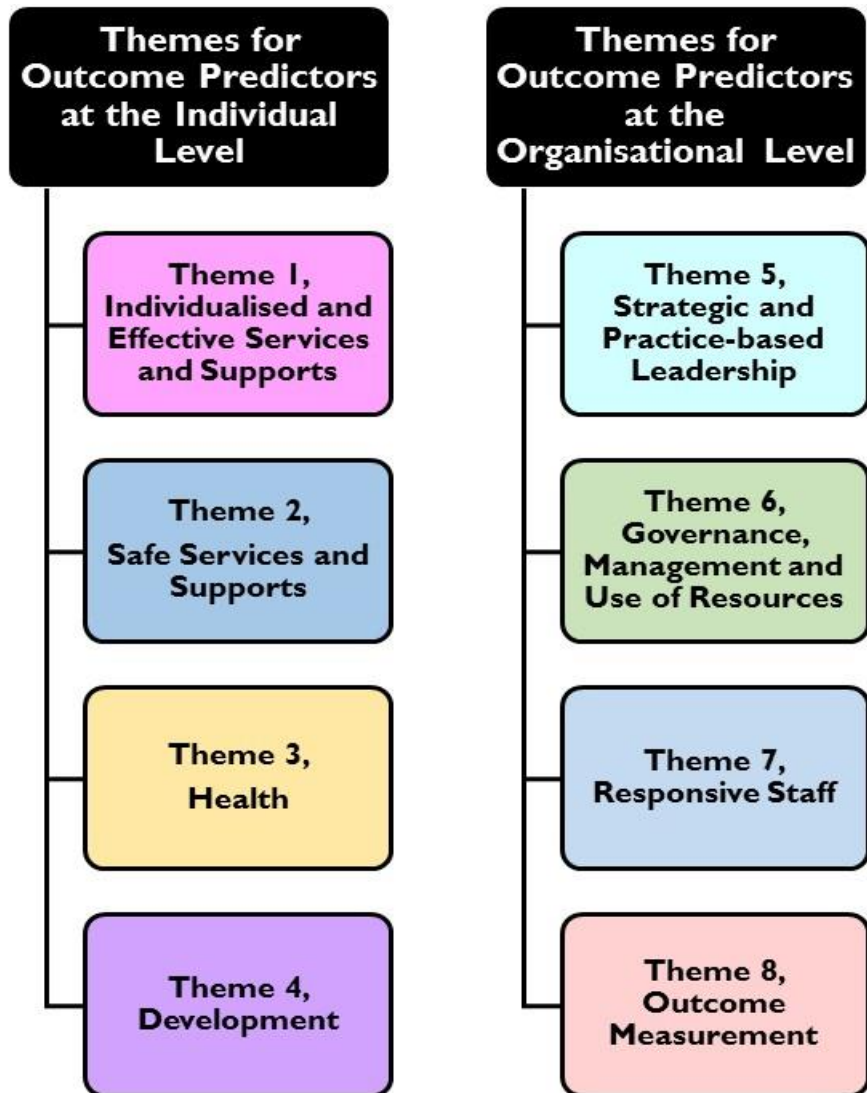


Table 4 Quality Framework – the outcome predictors at the individual level mapped against the 9 outcome domains for Irish Disability Services	1. Living in my own home in the community	2. Exercising choice and control in my everyday life	3. Participating in social and civic life	4. Meaningful personal relationships	5. Opportunities for personal development and fulfilment of aspirations	6. Having a job or other valued social roles	7. Enjoying a good quality of life and well-being	8. Achieving best possible health	9. Safe, secure and free from abuse
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Theme 1, Individualised and Effective Services and Supports

1	I am treated with dignity and respect.	●	●	●	●	●	●	●		●
2	My rights are respected and I have opportunities and supports to understand and exercise my rights and responsibilities, in line with my needs and wishes.	●	●	●	●	●	●	●		●
3	My privacy is promoted and respected	●	●	●	●	●	●	●		●
4	I have access to information that is accessible to me, in line with my needs and wishes.		●	●		●	●		●	●
5	I have access to supports and opportunities to advocate for myself, in line with my needs and wishes		●			●		●		●
6	My autonomy is respected, and I have access to supports and opportunities to make informed decisions and choices, in line with my needs and wishes.	●	●	●	●	●	●	●	●	●
7	I have access to support and opportunities to maintain and develop meaningful relationships with my family, in line with my needs and wishes.	●	●	●	●	●	●	●	●	●
8	I have access to support and opportunities to maintain and develop meaningful relationships and social networks, in line with my needs and wishes.	●	●	●	●	●	●	●	●	●
9	I have access to person-centred, individualised and flexible services and supports	●	●	●		●	●	●		●

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	that respond to my needs, wishes and goals.									
10	Through the person-centred planning process, I am supported to achieve goals that are important to me, in line with my needs and wishes	●	●	●	●	●	●	●	●	●
11	I have access to transport, in line with my needs and wishes.	●	●	●	●	●	●	●	●	
12	I have access to aids and appliances, assistive technology and information and communications technology, in line with my needs and wishes.	●	●	●	●	●	●	●		●
13	I have access to physically accessible services and supports			●				●	●	
14	I have access to advocacy services, including an independent advocate of my choice, in line with my needs and wishes.	●	●			●	●			●
15	I have access to person-centred home and community-based supports that promote my autonomy and self-determination and my participation in community activities, in line with my needs and wishes.	●	●			●	●	●	●	

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16	I have meaningful choice over where to live, and who to live with, in line with my needs and wishes. This includes access to small, community-based living arrangements or living on my own.	●	●	●	●	●		●		●
17	I am supported by people who know me well, and understand how I communicate.	●	●			●		●		●
18	I have access to Active Support, in line with my needs and wishes.				●	●		●		
Theme 2, Safe Services and Supports										
19	I am protected from abuse.				●			●		●
20	My environment is secure, safe and predictable, in line with my needs and wishes.		●	●				●		●
21	I enjoy consistency in the services and supports that I use, in line with my needs and wishes.									●
Theme 3, Health										
22	I have access to information and support to maintain and improve my health, in line with my needs and wishes.					●		●	●	
23	I have access to supports and opportunities to make					●		●	●	

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	informed decisions and choices about my health and well-being and to manage any long-term conditions that I have, in line with my needs and wishes.									
24	I have access to support to become emotionally resilient and to have a strong sense of my identity and well-being, in line with my needs and wishes.						●	●		
Theme 4, Development										
25	I have access to opportunities and supports for education, training and employment, in line with my need and wishes.		●	●	●	●	●	●		
26	I have access to local community facilities, in line with my needs and wishes.	●	●	●	●		●	●	●	
27	I have access to opportunities and supports to maintain and develop valued social roles in the community, in line with my needs and wishes.	●	●	●	●	●	●	●		●
28	I have access to supports and opportunities to maximise my independence, in line with my needs and wishes.	●		●		●	●	●		