

***Building Confidence,
Improving Lives,
Delivering Change.***

*Restoring confidence and improving the
quality of life for people with
intellectual disability in residential care*

ÁRAS ATTRACTA SWINFORD REVIEW GROUP (ÁASRG)
CONSULTATION PAPER

“Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world.”

Eleanor Roosevelt (“In Our Hands”, 1958 speech delivered on the tenth anniversary of the Universal Declaration of Human Rights)

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Foreword

Like many others the members of the Áras Attracta Swinford Review Group have been upset and angered by the reports highlighting the incidents of abuse and the undignified treatment of people with intellectual disability. In too many cases, people have been let down when they were vulnerable and most needed help. People with intellectual disability and their families have the right to receive high quality compassionate and safe services.

It was for this reason the Health Service Executive set up the independent Review Group to review and provide assurance that the standards of care meet the needs of the residents in the Áras Attracta Service, Swinford, Co Mayo. It was envisaged that the scope of the review would include submissions made from the wider Disability Community and relevant National and International Research. The paper we are publishing today for consultation draws on the body of evidence we have gathered over the past six months and we would like to thank everyone who has contributed to our work so far.

We know that there are some services providing excellent supports and services enabling people to live fulfilling lives and we need to learn from them to get dignified care and quality of life right for every person every time. All our services for people with intellectual disabilities should be beacons to the rest of the community, demonstrating how we are all richer when people with intellectual disability are respected and valued.

Delivering dignity will mean changing the way we design, pay for and monitor services that provide dignified care. Alongside the consistent application of good practice and the rooting out of poor care, we need a major cultural shift in the way everyone thinks about dignity to ensure that services are person-centred and not task-focused. This will require empowered and entrepreneurial leadership in residential services as well as in external management teams. It will mean changing the way we recruit and develop staff working for people with intellectual disability so they have the right values as well as the right skills.

We will have to do more to listen and respond to residents and their families so we can learn from their feed-back and continually improve care. A report based on this consultation that produces more noise than practical action is not what we want. It is very clear that we all need to work together to improve dignity in care and earn back public confidence. The Review Group is determined to drive change quickly and safely and we urge all those with an interest in the provision of services to people with an intellectual and people with an intellectual disability and their families to respond to this consultation and help make the changes that will make a real difference.

Dr Kevin McCoy, Chair, Áras Attracta Review Group
August 2015

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Introducing the Consultation

1.1 This consultation seeks to explore views on a range of questions and proposals developed in response to events at the Áras Attracta facility in Swinford, Co. Mayo.

1.2 These questions and proposals should be seen within a context of building upon a range of existing policies and plans, but particularly;

- National Disability Strategy, 2004
- Time to Move on from Congregated Settings, 2011
- Value for Money and Policy Review of Disability Services in Ireland, 2012
- New Directions, 2012
- National Strategy for Service User Involvement in the Irish Health Service 2008-2013
- HSE Social Care Division Operational Plan, 2015

1.3 The document sets out a range of ideas and options rather than definitive proposals for a specific package of measures. We are seeking your views on which of the actions suggested in this document would be likely to have most impact and/or if there are other measures that you believe would have greater impact.

1.4 The scope of the consultation primarily relates to:

Assessment and treatment of adults with an intellectual disability who reside in a residential setting;

Care and support, primarily for adults with an intellectual disability

1.5 Intellectual disability is defined in this document as a disability that includes the presence of:

- a significantly reduced ability to understand new or complex information and to learn new skills, with
- a reduced ability to cope independently; and
- which started before adulthood, with a lasting effect on development

Many persons with intellectual disability have other health or cognitive conditions and/or autism spectrum disorder as well.

1.6 We are, in particular, seeking views from:

- People with intellectual disability, their families and carers;

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- Individual health and social care bodies responsible for the planning, commissioning and provision of services for people with intellectual disability,
- Individual health and social care professionals;
- Representatives of local and national organisations for health and social care bodies or professionals; and
- Any other person or group with an interest in improving the rights, health and well-being of adults with an intellectual disability.

We need to hear from you about examples of best practice both here in Ireland and abroad and, in addressing the consultation questions, we would ask you to highlight these examples where they are relevant.

1.7 The consultation period will run from July 31st, 2015 to September 28th, 2015. The consultation questions are summarised at the end of this document in Appendix 2. An Easy Read version of this consultation is also available online and on request from the Review Group office (details below).

1.8 Respondents are welcome to make submissions in a format of their own choice but the preferred method is by making use of the response booklet. You can respond to the consultation in the following ways:

By completing the on-line response booklet that will include both the consultation questions and an opportunity to reference examples of good practice.

By email using the booklet to:

aasrg2015@gmail.com

In writing, using the booklet, to:

Consultations Coordinator, Áras Attracta Swinford Review Group, Lower Ground Floor, Sir Patrick Dun's Hospital, Grand Canal Street Lower, Dublin 2.

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2. What happened, what we are doing and what we hope to achieve

2.1 Áras Attracta, a residential and respite/day facility for 95 people, staffed and managed by the HSE, became the subject of an RTE Primetime undercover investigation in late 2014. Using undercover filming, the programme showed many serious areas and incidents of concern that are currently being investigated.

2.2 There had already been concerns raised about the standards of care in Aras Attracta, for example, Francis Loughney's death in November 2012 led the Coroner for South Mayo to express concerns about the quality of care there and, as a result, the Health Information and Quality Authority carried out a number of inspections in early 2014.

2.3 By May, 2014, it was believed by HIQA and the HSE that specific care practices in Aras Attracta had significantly improved and that an effective management system was in place.

2.4 The RTE programme broadcast on December 9th, 2014 showed that this was not the case. In response to widespread public concerns, the Chief Executive of the HSE announced a number of immediate actions including the establishment of a Review Group led by Dr Kevin McCoy.

2.5 The purpose of this Review is as follows;

- Review the programme of work already underway at the centre on foot of reports from HIQA, HSE Audits and reports to establish their implementation and effectiveness, identify any gaps and make recommendations for further improvements.
- Identify any immediate concerns and advise on the care and safety of the residents to the Commissioner.
- Identify any key causal factors that may have occurred.
- Identify any contributory factors that caused the key causal factors.
- Recommend actions that will address the contributory factors so that the risk of future harm arising from these factors is eliminated or if this is not possible, then reduced as far as is reasonably practicable.
- Ensure that any learning from the review group is reflected and promoted throughout the system

2.6 This consultation document seeks to reflect learning and use knowledge from national and international research to stimulate feedback from a range of sources so that the final Review report can address the terms of reference set for the Review.

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2.7 The current situation calls for transformational change involving leaders at all levels. There needs to be an emphasis on staff development and the creation and maintenance of a collaborative, accountable and positive culture aimed at helping staff solve problems and difficulties more creatively rather than a blame culture which seeks to find scapegoats.

2.8 The Review Group cannot hope to achieve its purpose without significant input from a range of interested individuals and groups in the form of written and verbal feedback. It is for this reason that this consultation paper is being issued and a period of formal consultation entered into.

2.9 At the end of this period and before the end of 2015, the Review Group will publish its final report. The Review Group is determined to assist in bringing about real change and to ensure that the final report arising from this consultation will lead to fundamental, achievable and unstoppable changes to service improvement in the provision of care for people with an intellectual disability in Ireland.

2.10 The membership of the Review Group is set out in Appendix One.

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3. Law, policy and planning

The Legal Framework

3.1 Services for people with an intellectual disability are founded on the constitution and law of the country, the protection afforded by the United Nations relating to human rights and disability and the policies and plans of the Government of the day that flow from this legislation as reflected by its various agents.

3.2 The following legislative framework, while not exhaustive, is relevant in the Irish context;

- The Constitution - Bunreacht na hÉireann 1937
- United Nations Universal Declaration of Human Rights 1948
- Equality Act, 2004
- Education for Persons with Special Educational Needs Act 2004
- Disability Act 2005
- Citizens Information Act 2007
- Health Act 2007
- United Nations Convention on the Rights of Persons with Disabilities 2008

3.3 People with disabilities have the same rights as any other Irish citizen under the Constitution. While the constitution does not give any specific rights to people with disabilities, the 1998 Education Act enacted in law the right to education for all children including those with special educational needs and those with autism. Subsequent endorsements of the position of the United Nations have helped to promote equality.

3.4 The Citizens Information Act (2007) has still not been fully implemented, in particular the need to place the provision of advocacy services on a statutory basis. It has been suggested to the Review Group that the Health Act (2007) has created definitional difficulties for providers of "designated centres".

3.5 Although Ireland has signed the 2008 UN Convention, it cannot yet be ratified as Article 12.2 on consent requires States to ensure that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. This would be resolved by enacting the Capacity Bill (2013) but this has yet to happen. This is a very significant impediment.

3.6 It has also been suggested to the Review Group that there is a need to repeal and/or replace existing laws on sexual offences and the capacity to consent as recommended by the Law Reform Commission.

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Consultation Question One: How can the current legislative framework for adults with an intellectual disability be improved?

Consultation Question Two: What needs to be done to ensure any legislative changes are implemented?

The Policy and Planning Framework

3.7 The main policy documents relevant to this review are;

Time to Move on from Congregated Settings, 2011

National Housing Strategy for People with Disability 2011-2016

Value for Money and Policy Review of Disability Services in Ireland, 2012

New Directions, 2012

Care and Support of Residents in Designated Centres for Persons with Disabilities

Regulations 2013

HSE Social Care Division Operational Plan, 2015

Both the Housing Strategy and the Value For Money Review have associated implementation plans.

3.8 This policy and planning framework sets out a positive set of values for people with an intellectual disability, a vision for the regulation and future development of care, a plan for ensuring the right level of service in the right location and timescales and targets for achieving some of the key elements of required change.

3.9 The Value For Money Review sets out a long term vision for the development of services “where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being”.

3.10 During the course of this Review, a number of views have been highlighted to the Review Group and they are set out below;

- the need for sufficient community resources to avoid unnecessary admissions to institutional care (for example Challenging Behaviour Support Teams)
- the lack of a statutory requirement for government agencies and service providers to cooperate fully with people’s advocates

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- the need to strengthen the focus on, and accelerate the implementation of person centred approaches such as Supported Self Directed Living or Vision-Oriented thinking
- the need for closer involvement of the Health Service Executive(HSE) in the implementation of the National Housing Strategy
- a perceived lack of outcome measures in HSE plans that are transparent and an absence of an individual outcome measure
- problems in managerial oversight and staffing for those providing multiple units for people with varying levels of need
- the absence of a central multidisciplinary assessment and planning group for admissions and discharges to and from congregated settings
- the need for the early introduction of a fair and equitable resource allocation tool nationally

3.11 Consideration could also be given to whether the State should provide differing levels of health and social care to those with mild, moderate, severe or profound disabilities as this approach is noted elsewhere in other services.

Consultation Question 3: How can the current policy and planning framework for adults with an intellectual disability be improved?

Consultation Question 4: What should leaders in health and social care do to improve the policy implementation process

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4. Promoting Dignity and Respect

4.1 The promotion of dignity and respect for people with intellectual disability in service settings is fundamental. Being cared for with dignity and respect means recognising that everyone is unique, with intrinsic value as a person with individual needs, wishes, preferences, language and identity in terms of adulthood, race, religion, culture and sexual preference. A focus on empowerment and self-determination is key to all of the above.

4.2 People with disabilities generally wish to live an “ordinary” life, they want to maintain their links to their family and want to be part of the wider community. The task of the supporter is to provide the necessary range of supports to the person to achieve this to the fullest extent.

4.3 Most people with an intellectual disability have what can be termed “a poverty of experience”. The general population makes choices on the basis of the likely outcome/s resulting from their choice. The ability to do so is the result of making previous similar choices or an ability to process information if making a new choice or an ability to know where to seek further information before deciding. This requires a more sophisticated knowledge of the wider community than most people with an intellectual disability possess.

4.4 For many reasons people with an intellectual disability have a more limited ability to make choices: these include assumptions which we all make about the nature of disability, the severity of their intellectual disability, living in segregated, restricted or poor environments or having limited opportunity for the development of social and life skills. Broadening the experience of the residents in congregated settings by increased use of community facilities and access to lifelong learning will strengthen their ability to make informed choices.

4.5 However, for people unaccustomed to exercising choice, they will need support in doing so, choice cannot be conferred on someone overnight. For many people, living in a congregated setting is all they have ever experienced and can remember.

4.6 Being an active member of a community includes things like;

- being involved in what is going on
- connecting to other people in informal or formal ways
- being a good neighbour
- supporting or getting involved in sports, parish activities, tidy towns, politics, creative activities such as art or dance, drama or music

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- experiencing the world of work (job sampling, work experience, part-time paid work, voluntary work)
- enjoying a social life
- being known and respected in their community.

Treating people with dignity and respect requires a service for people with intellectual disability to enable people to do these things.

4.7 A culture that promotes dignity and respect requires a positive, empowering vision that focuses on the person's abilities, their interests and gifts, capacities and talents. It means first discovering and then focusing on what the person really wants to do.

4.8 A positive vision means real respect for each individual, ensuring they enjoy the same human rights as everyone else. It means informing the person of their rights, learning about the wishes and preferences of the person and, within the law, never restricting the rights of one person because of someone else's needs.

4.9 Treating people with dignity and respect also includes extending this approach to relatives and carers and also to advocates.

4.10 Such high quality services will also seek to actively empower the person receiving support, their caring relatives and advocates by:

- using formal systems that promote communication with and responding to consumer views
- enabling people (supported by families) to play an active role in discussions and decisions about their own care
- enabling people to challenge decisions made about them
- developing recruitment, appraisal and review processes that involve people who are being supported, relatives and advocates
- involving advocates/self-advocates in the governance of providers

Behaviour that challenges

4.11 People who behave in challenging ways require a particular focus. There is a danger that labels from an individual's history may continue to follow them on their journey. This is not helpful and service providers should challenge such labels as a matter of course.

4.12 At the same time, it is also worth bearing in mind that while there are many possible reasons for such behaviour, some is the product of negative interactions with others in the

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past. It is vital to seek to understand the basis for any particular behaviour rather than simply discounting it as a pathological manifestation of a wider syndrome.

4.13 There is a wealth of excellent guidance online about managing behaviour that challenges, for example:

<http://www.challengingbehaviour.org.uk/strategy-group/resources-and-links/policy-best-practice-reports.html>

http://www.academia.edu/1124999/Supporting_People_with_Intellectual_Disabilities_who_Challenge_or_who_are_Ageing

There is also excellent training expertise available from specialist trainers or individual psychologists specialising in this area. All service providers should have access to a wide range of interventions that will be helpful.

Consultation Question 5: What practical action can providers take to ensure people are treated with dignity and respect?

Consultation Question 6: Are there specific measures you wish to see taken with regard to the support offered to people whose behaviour challenges?

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5. Culture and partnership working

5.1 There is a well-worn saying that “culture eats strategy for breakfast”. What this means is that no matter how many glossy plans or strategies are produced from the “centre”, the organisational culture among staff and managers at various levels will determine the shape and pace of change within the organisation. At the sharp end, the culture within specific settings will act to resist the implementation of change.

5.2 The best organisational cultures are both “top down” and “bottom up” in that they place equal emphasis on change initiatives that are led by senior managers and front line service improvement projects with the potential for system-wide change and improvement.

5.3 Leadership and management in these organisations is also very different. There is a strong emphasis on service improvement, the quality of the person’s experience, quality improvement systems implemented and controlled by front-line staff themselves and using mistakes, near misses or accidents as an opportunity to make things better in the future rather than promoting a blame culture.

5.4 Such organisations have sometimes been called “learning” organisations because of their openness to experimentation and learning and by their high investment in staff training and development.

5.5 There is a growing understanding that it is valid to focus on the quality of the built environment, the accreditation of services or the professionalism of staff. However, it is equally important to focus on the individual aspirations of individuals, their abilities within every-day activities and every-day living and capacities for becoming active members of their local community as well as the values and attitudes of individual staff members.

5.6 The Review Group are aware of the Value For Money Policy Review Group recommendation for a nationally appointed Director of Intellectual Disability Services reporting directly to the HSE Chief Executive and note that this has not yet been implemented. There is also a strong case for an emphasis on grounded service improvement approaches through the introduction of validated, locally led and delivered service improvement initiatives in residential services for people with intellectual disabilities. Such approaches may involve variants of specific quality improvement approaches.

5.7 The ideal partnership, as noted by the Social Care Institute for Excellence, typically involves each partner sharing power, being committed to joint decision making, respecting each other’s roles, where both have something to contribute, and where the partnership is supported by the legal system.

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5.8 One of the key partnerships in the Irish care system is between those who plan services on behalf of the taxpayer and those who provide care. In a high quality system the roles of service commissioners (those who decide what services need to be provided and who fund them), service providers (those who actually care for and support people with an intellectual disability) and regulators (those who inspect services and ensure the maintenance of standards) are clear, distinct and unambiguous, they avoid overlaps and confusion and they are complementary to each other so that the system works cohesively.

5.9 As set out in the Value For Money and Policy Review of Disability Services in Ireland (DoH, 2012), the current care system is in a process of transition from one of “group-based service delivery towards a model of person-centred and individually chosen supports”. This “migration” is taking place within the context of reducing public expenditure, governed by the use of Service Level Agreements and within the targets set in the Congregated Settings Report.

5.10 At the same time the Health Improvement and Quality Authority are introducing a new system of regulation for the sector and implementing new and consistent reporting schedules for providers. Furthermore, the National Safeguarding Office is now in the process of setting up Safeguarding and Protection teams in order to begin the implementation of the Safeguarding Vulnerable Persons at Risk of Abuse Policy 2014.

5.11 There are a range of other initiatives which have been announced by the HSE and which now require clear implementation pathways
Including:

- Establishment of a National Implementation Taskforce
- Creation of Disability Councils
- New Quality Improvement Initiative led by the HSE
- Implementation of a Volunteer Advocacy Programme
- Creation of a Confidential Recipient post

Those leading these changes might also wish to consider promoting the concept of "Experts by Experience" as part of the statutory regulation and inspection process.

5.12 Despite these measures, some critics of the current system claim that financial balance is given a higher priority than quality of care and that in order to achieve the goals of the new drive towards individualised support, more short-term transitional funding needs to be made available. In pursuit of role clarity, some care systems have created a complete separation of commissioning (or planning) and service provision (the delivery of care). There are also claims that in order to achieve the seven year planning framework for the

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implementation of the Congregated Settings Report, there will need to be a much higher annual volume of movements from such settings.

5.13 Another aspect of partnership working is between those who provide services and those who regulate them. Regulation is much stronger now with the introduction of the HQIA inspection process in the disability sector around 18 months ago. Consistent monitoring information is now being gathered across a range of measures and should include the use of medication, the use of physical restraint, incidents of behaviour that is challenging, serious adverse incidents, staffing levels, the use of agency staff, staff sickness levels, frequency of staff meetings and the frequency of staff supervision among other things.

5.14 However, there is a view that the focus of the current regulation and inspection regime is too narrow, too focused on regulations rather than care standards, that it needs to be more inclusive of the consumer and lay perspective and that above all, it needs to be cognisant of the drive towards person centred planning in the context of independent living in private accommodation.

5.15 In relation to the regulatory role of HIQA, consideration might be made concerning;

- clarification on HIQA's power to investigate as opposed to inspect
- the balance of announced and unannounced inspections towards the latter
- the merits or otherwise of single reports on providers of multiple units
- the availability of training for inspectors in the social model of disability

5.16 There is also a view that the Trust in Care policy and procedures for investigating abuse (2005) involving a staff member is seen by some as too staff-orientated. There is a case for reforming this procedure in order to reflect the need for stronger protection of vulnerable adults.

5.17 One further aspect of partnership working is the informal partnership that exists between local communities and people with intellectual disability where one reaches out and seeks to include the other or where people are able to join in on an equal basis. Such partnerships rest critically on the imagination and creativity of staff working with local communities and the positive attitude of decision makers in local community organisations. To quote the 2009 Vision document by the National Federation of Voluntary Bodies, “the realisation of inclusion involves a high level of participation, engagement and the building of roles and relationships.”

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Consultation Question 7: Can you describe what needs to happen to improve organisational culture among service providers and how this can best be achieved?

Consultation Question 8: Are there specific things that can be done to introduce new quality improvement approaches?

Consultation Question 9: How can the current organisational arrangements be improved to better support true partnership working?

Consultation Question 10: Are you aware of any overlaps or confusion of roles within the current arrangements and/or is there anything you believe needs to be changed?

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6. A High Quality Service – Preventing Abuse and Promoting Health and Well-Being

Preventing Abuse

6.1 The responsibility for this lies with everyone. If there is a lack of clarity as to what constitutes abusive behaviour, most incidences will remain unreported. Training can go some way to address residents' safety but of itself is not the answer. Training is only useful if it alters behaviour for the better. Staff need to truly understand that their actions/inactions can contribute to behaviours in others that are then termed challenging.

6.2 Some staff struggle with where their primary loyalties lie. Is it with the person being supported, or their colleague who may be a relative? How robust and credible is the whistleblowing policy? Is the need to report incidents of abuse a contractual requirement?

6.3 Empowering people to believe they should not be treated badly should begin without delay if it has not already happened. The use of self-advocacy can go a long way towards giving people a sense of self-worth and entitlement otherwise denied them. A residents' committee to make representation as to how things need to change is also very useful.

6.4 People with an intellectual impairment are very often confronted with a credibility deficit: problems of communication, memory and time awareness militate against them being believed. This can give rise to a scenario where someone makes an allegation, which is not proven, then if they make another they are seen as attention-seeking and the second allegation is afforded even less credibility, making them even more vulnerable. This is equally true of people living in the community as well as those in congregated settings.

6.5 The multi-disciplinary nature of person centred reviews goes some way to protect residents, but there is no substitute for vigilance and a willingness by managers and colleagues to challenge inappropriate behaviour. But this single step or any other will never absolutely prevent the people supported by that service from being abused, neglected, mistreated or exploited. There is no magic solution. Much abuse takes places in secret.

6.6 Even with video cameras, there will always be dark corners, private places and black spots. The best approach is through a combination of strategies which, taken together, will build a well-run service thereby greatly reducing the risk of abuse of whatever kind. It is worth remembering that the more time people with intellectual disability spend mixing with others in their local communities the more "eyes and ears" there will be to reduce the risk of abuse or neglect.

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6.7 The international evidence on what works in preventing abuse is at best weak. Most studies are small-scale and with little evidence of their capacity for wider application. In fact, the most effective approach is less about the avoidance of risk or a paternalistic over-protective system and more about the promotion of individualisation and person-centred support.

6.8 The following risk factors have been identified in the literature;

- poor social skills
- poor judgement
- poor communication skills
- physical dependence (for example need for help with personal hygiene and intimate body care)
- a lack of education about appropriate sexual behaviour
- a lack of knowledge about how to defend against abuse.
- a lack of practice in making independent decisions in everyday life.

6.9 In addition, at least six (statistically significant) characteristics have been associated with abuse by various authors i.e. people with intellectual disabilities were more likely to be abused if they were:

- physically mobile,
- displayed aggressive behaviour
- were young,
- non-verbal
- unsociable or engaged in self-injury

6.10 The literature also identifies a high risk of abuse during intimate and personal care for people with learning disabilities and complex needs. This highlights the need for specific preventative measures in this area.

6.11 The Review Group have developed a three stage model of intervention to help identify risk and prevent abuse;

Type of Intervention	Definition	Example
Primary interventions	Prevention of abuse occurring	<ul style="list-style-type: none"> • Information on rights • Identification of those most at risk • Use of individual risk assessments • Use of system risk assessments (e.g. staffing levels, geographic or community isolation, routine

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		<p>monitoring of falls, injuries, accidents, occupancy etc)</p> <ul style="list-style-type: none"> • Universal access to advocacy • Clear policies and procedures, especially in relation to the management of individuals with known risk indicators and for the delivery of intimate care • Zero tolerance approach
Secondary interventions	Identifying and responding to allegations of abuse	<ul style="list-style-type: none"> • Swift and decisive management action when allegations are made • Implementation of Safeguarding process and procedures • Training and education • Clear policies and procedures • Openness and transparency
Tertiary interventions	Measures to prevent the risk of abuse	<ul style="list-style-type: none"> • Recruitment practices that ensure the right people for the job • Local consumer committees with a strong carer presence • Visible management in the care setting • Staff support systems • Staff vetting and barring systems

6.12 Reducing the isolation of service and avoiding stagnation in the delivery of care is crucial. When services become isolated (geographically remote, cut off from local communities, low levels of external contact), abusive or neglectful practices can become normalised. One of the most crucial ways of achieving this is to ensure that there is universal access to advocacy services and to require service providers to cooperate fully with advocates.

6.13 When staff groups are properly supported (e.g. provided with individual opportunities for debriefing, offered regular staff meetings with open agendas, coached and mentored rather than managed or provided with opportunities to learn from examples of good practice), the risk of abusive or neglectful practice can be diminished.

6.14 The concept of Zero Tolerance is helpful. It simply means that everyone in an organisation is aware what the consequences will be if abusive or neglectful practice occurs.

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6.15 There is a case for providers to audit and identify those persons who have no known relative visiting or those who are Wards of Court and what steps can be taken to enhance their protection from abuse.

6.16 Providers need to also consider whether sufficient attention has been paid to the communication needs of residents. There are a growing variety of methodologies including new communication technologies and their use or lack of it is worthy of immediate attention and action.

6.17 A further issue for consideration is the type of complaints system that will work best in which setting. These need careful consideration based on the profile of needs for those who need to rely on a robust complaints process.

Promoting Health and Well-Being

6.18 There are various features of a service fully concerned with people's well-being, for example:

- cooperation with other service providers to promote health and development through information and education
- access to individually chosen recreation, interests and activities
- access to general medical services through registration with a GP and a commitment to an annual comprehensive health check
- access to screening, early detection and the full range of universal general health and welfare services in the community including dental, optical and aural services that any member of the community could expect to receive
- adequate diet and nutrition and where necessary, a focus on weight, body mass index (BMIs), the needs of those with swallowing problems and those who need oral nutritional supplements (ONS)
- a timely, comprehensive multidisciplinary assessment of their health needs based on consultation with the person and, where appropriate, their family
- timely access to mental health services and where necessary, a review of medication and behaviour support plans
- good end of life care

6.19 All of these features of a quality service are contained within the national standards for residential services for adults with a disability and now inspected upon by the Health Information and Quality Authority. Yet the evidence presented by them through Inspection Reports demonstrates that there are worrying gaps in the quality of care support provided. The concern is that what happened in Aras Attracta may in fact be occurring in other locations even now.

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Consultation Question 11: What are the most important measures that can be taken to identify and prevent abuse and/or neglect?

Consultation Question 12: What needs to happen to achieve better health outcomes for people with an intellectual disability?

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7. Leadership – High Quality Management and Human Resources practice

7.1 The role of management as leaders in promoting human rights, developing and encouraging best practice and championing a vision of better support cannot be overstated. Modern managers are no longer supervisors or bosses in the traditional sense; they are coaches, champions for service improvement and leaders for change. At the heart of what they do is the concept of empowerment. Set out below are some of the features that the Review Group believe should be visible within a high quality management system.

7.2 In an ideal world, only highly committed staff with a demonstrable commitment to service improvement should be promoted to management positions. It has been suggested to the Review Group that no management appointment should be made without some involvement by people receiving support or their relatives or advocates.

7.3 It is increasingly clear that having the right attitudes, entrepreneurial imagination, strong values, a sense of vision and a strong focus on discovery and empowerment in intellectual disability leadership is as important as professional or management qualifications.

7.4 All levels of management should be living the values and supporting the vision of the service. A person-centred focus should be central to all decisions. Honest feedback should be welcomed by managers as contributing to improving the service. There is no substitute for “on the ground” leadership.

7.5 No supervisor or manager in a position of authority should have excessive influence or power over his/her staff team, resulting in team members being reluctant to report concerns to more senior managers.

7.6 Managers should ensure they are in continuing contact with the people supported by the service not least by being visible to them and their families. Senior managers need to be visible, regularly “walking the floor” at varied times, so as to gain a rounded understanding over 24 hours of how things are going. There is considerable symbolic value in doing this, rather than perceived as being remotely office based.

7.7 Junior managers also need to have a 24-hour appreciation of how things are. A way of addressing this in relation to weekends and during the night, when traditionally staffing levels are lower and less supervised, is crucial.

7.8 All first line managers should conduct team meetings in the place where the person or persons being supported lives and some middle or line-management meetings should occur in such settings on a rotational basis so that each and every location is demonstrably part of

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the system. Team meetings should have service improvement, risk management and the implementation of individualised support as standing agenda items.

7.9 Written policies must be implemented and regularly reviewed. They should be brief statements of the organisation's position on some aspect of supporting people with disabilities. They should be as simple as possible so that all staff are familiar with them. This is particularly true of policies relating to Human Rights, Advocacy, Complaints, Protection from Abuse and Protected Disclosures.

7.10 If it is not recorded, it did not happen. The importance of accurate, timely, accessible recording cannot be overstated. Staff at all levels need to be clear about what and how to record. Recording needs to be non-judgmental and truthful. Myth and falsehood in recording can follow people around and serve to provide a skewed account to those newly working with them, resulting in inappropriate interventions.

7.11 Easy read versions of all policies that directly affect people with disabilities should be readily accessible to residents and their families. This is particularly true of policies relating to Human Rights, Advocacy, Complaints, Protection from Abuse and Protected Disclosures.

7.12 One of the key management tasks is the recruitment of staff. It is the gateway through which staff become part of the service team. That gateway should be well guarded to ensure that only the right staff are selected. The process begins with the job advertisement which should briefly set out the vision and values of the organisation, and the kind of applicant required, not just the training, qualifications or experience, but also the personal values and qualities.

7.13 Interviewees should be advised to visit the service's website which should reflect the same positive vision and values. The job application form should reflect a strong person-centred focus. The interview panel should include someone with a disability who has been adequately prepared for that role or, if that is not possible, a relative or advocate. The interview should be competency-based (e.g. "Give an example of how you supported someone who was distressed.") and should yield some evidence of the person's attitude to empowering people with disabilities.

7.14 Staff induction should include input from a person with a disability highlighting the issues they consider important. It might also include input from a family member focusing on family involvement and their good and bad experiences of services. All staff and especially new staff should understand their duty of care and their obligation to challenge and report poor practice by colleagues. Ideally, they should be asked to sign off that this has been discussed in detail with them and they are clear about what zero tolerance means.

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7.15 As already mentioned, on-going support for staff is essential as is the provision of on-going learning opportunities, regular individual supervision and feedback and the use of probation and performance appraisal meetings. The importance of staff team meetings has already been highlighted where the focus is on support, development and the regular review of person centred plans.

7.16 Staff groups, when faced with fundamental change, will weigh up what the proposed change will mean for them individually and collectively and, by extension what is no longer in it for them. To address this, there is a requirement to hold regular positive briefing sessions where there is genuine two-way communication between staff and managers. This is an opportunity to highlight good practice, to ensure staff can feel they are part of the change process and can influence it rather than having it imposed on them.

7.17 Staff are likely to feel pressure from regular inspection, especially if something has gone wrong. They may feel undervalued and vilified so it is important they are involved in putting things right.

7.18 The urge to train en-masse when things go wrong is often offered to provide evidence of something being done. This may be justified if the training addresses fitness to practice or regulatory requirements but staff teams can only absorb so much new information at a time and there is a danger that other values based training can get lost. Training does not have to take place in a lecture room with an external trainer: agencies should seek to tap the excellence within the staff group and/or encourage “champions” to cascade their expertise.

7.19 Managers should be clear about their role in ensuring policy implementation and review, in particular using mistakes, near misses and accidents as opportunities for learning. The admission of new residents from outside the catchment area of the service should be regarded as a serious adverse incident and managed accordingly.

Consultation Question 13: What steps should be taken to improve the management of residential services for people with intellectual disability?

Consultation Question 14: What can be done to ensure the most effective recruitment practices?

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8. Leadership – Good Governance and Accountability

8.1 Agencies that are providing residential services for people with an intellectual disability have a duty to ensure that they exemplify good governance and clearly assigned responsibilities at all levels.

8.2 Good governance in this context means the systems and processes by which agencies are controlled and directed. In social care, it means that agencies have clarity about structures, processes, roles and functions, that they manage risk appropriately, that their decision making is transparent, that they engage appropriately and effectively with key stakeholders and that they ensure accountability for actions.

8.3 In agencies that enjoy good governance, accountability flows naturally. Where it is absent, the opposite is true. An obvious example of where this approach did not occur can be found in the detail of the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry known as the Francis Report.

8.4 In practice, this means that a clear chain exists from the Boardroom to the direct support staff. Good governance would be typified by the use of:

- Management processes to identify, control and mitigate against known risks
- Controls assurance processes in areas such as contractor control, emergency preparedness, fire safety, health and safety, human resources, professional conduct and records management

8.5 These matters should be standing items on Board and senior management agendas. High quality agencies would ensure that these matters would receive at least as much attention as corporate planning and financial management.

8.6 High quality agencies ensure that ownership and accountability for specific elements are clearly assigned to individual Board members and senior managers with clear lines of accountability to each and every setting where care is delivered so that an unbroken line of accountability exists.

8.7 Commitment and leadership for this approach must come from the Chairperson and Chief Executive of the Agency.

Consultation Question 15: In terms of ensuring that services operate to the highest standards, what do you think the key governance and accountability priorities are for those people who lead and manage agencies supporting people with an intellectual disability?

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9. Education to prevent abuse, on-going training and development and support

9.1 Education for staff is a key element in the prevention of abuse and neglect but it is also a key factor for people with intellectual disability.

9.2 Education should be seen as a lifelong goal, not something which ends with the first qualification and employment. There are obvious training programmes that should be available for all staff in care settings. The list below, while not exhaustive, should be seen as mandatory for all staff:

- Identification and prevention of abuse
- Safeguarding Procedures
- Communication (verbal and non-verbal rapport-building strategies)
- Providing positive behavioural supports
- Lifting and Moving

9.3 Staff can reasonably expect to receive the training they need in order to do their job and to have time to reflect on how the training can impact on their practice. This can be achieved in a number of ways, for example informal discussion on shift with a mentor or a more senior member of staff or formally in an individual supervision session or in a formal team meeting.

9.4 All staff, including managers at all levels should have an annual personal training plan and a Personal Development Plan with achievable individual targets and with an agency commitment to a specific number of training and development opportunities.

9.5 Support has already been mentioned but service providers should also focus on this issue when considering the training needs of staff:

- helping workers to deal with the challenges of the job
- a focus on values-based training
- ensuring attention is paid to debriefing, especially after a challenging or stressful incident
- problem solving and the promotion of reflective practice
- staff development and team building
- record keeping

9.6 There is also good evidence in the literature supporting the use of training processes for people with intellectual disability in protecting themselves from abuse, recognising when it

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occurs and what they should do if it happens. The evidence suggests that such programmes are most effective when they combine information giving, instruction, modelling, rehearsal and role-play.

9.7 There will also be value in simply developing individual assertiveness skills and building personal confidence as a general protective measure. Tailored programmes in sex education, self-defence skills and awareness of community resources can also be helpful.

9.8 Special mention must be made in regard to the need for training staff in the management of behaviour that is challenging.

9.9 For some support staff at the point of recruitment, appropriate professional qualifications in nursing or social work/social care will be mandatory. However, the Value For Money Report highlighted that increasing skill mix had led to a percentage reduction in the proportion of professionally qualified staff. There are also emerging concerns about access to and a lack of specific skills in certain areas such as Speech and Language Therapy, Occupational Therapy, Physiotherapy and Psychology.

9.10 A focus on individual needs being addressed e.g. in relation to the person's need to communicate, or their need for some specific aids and appliances, or need for nursing care, etc. and having timely access to same should have an impact on the skills that are required on a staff team. This could include buying in a specialised service as needed, employing someone on a sessional basis, or accessing it through Community Care services.

9.11 It may be of value for the HSE, as commissioner, to set out minimum expectations with regard to people's access to staff with certain skills and to recommend standards with regard to skill mix, over and above those set out in regulations.

9.12 Management boards seeking to demonstrate best practice leadership should seek to include a seat on their Board for a person with intellectual disability and/or a parent or relative.

Consultation Question 16: What do you see as the key priorities in terms of education, training and support for staff and residents?

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10. Conclusion

This consultation paper has set out some ideas, suggestions and questions which we would now like to hear your views on. It is by no means a comprehensive suite of actions that should or could be taken to reduce the risk of abuse or neglect. As has been already said, there is no guarantee that concerted action will forever eliminate the possibility of abuse, rather the focus is on reducing risk. The final consultation question is very open to the possibility that there is something that this paper has not included and which we would now like to hear from you about.

Consultation Question 17. Is there anything else that you would like to comment on, specifically something that you would wish the Review Group to include in their final report and/or Good Practice Guide to be produced later this year? We would specifically wish to hear about any examples of good practice that you believe we should know about.

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Appendix 1; Membership of the Review Group

Dr Kevin McCoy, Chair, former Chief Inspector of Social Services in Northern Ireland ,former member of the Commission to Inquire into Child Abuse in Ireland and Independent Social Care Consultant.

Deirdre Carroll, is a former Chief Executive of Inclusion Ireland and was a member of the Value for Money and Policy Review of Disability Services in Ireland Expert Reference Group. She is currently a member of the Value for Money Implementation Steering Group.

Ann Judge, Hazelbrook Consulting, Management and Organisation Development practitioner and former senior HR manager in the Irish Health Services

Dr Bob McCormack, is the Chief Executive Officer of Dara Residential Services and has written extensively in the field of Intellectual Disability in Ireland

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Appendix 2 Consultation Questions

CONSULTATION QUESTION 1: How can the current legislative framework for adults with an intellectual disability be improved?

CONSULTATION QUESTION 2: What needs to be done to ensure any changes are implemented?

CONSULTATION QUESTION 3: How can the current policy and planning framework for adults with an intellectual disability be improved?

CONSULTATION QUESTION 4: What should leaders in health and social care do to improve the policy implementation process?

CONSULTATION QUESTION 5: What practical action can providers take to ensure people are treated with dignity and respect?

CONSULTATION QUESTION 6: Are there specific measures you wish to see taken with regard to the support offered to people whose behaviour challenges?

CONSULTATION QUESTION 7: Can you describe what needs to happen to improve organisational culture among service providers and how this can best be achieved?

CONSULTATION QUESTION 8: Are there specific things that can be done to introduce new quality improvement approaches?

CONSULTATION QUESTION 9: How can the current organisational arrangements be improved to better support true partnership working?

CONSULTATION QUESTION 10: Are you aware of any overlaps or confusion of roles within the current arrangements and/or is there anything you believe needs to be changed?

CONSULTATION QUESTION 11: What are the most important measures that can be taken to identify and prevent abuse and/or neglect?

CONSULTATION QUESTION 12: What needs to happen to achieve better health outcomes for people with an intellectual disability?

CONSULTATION QUESTION 13: What steps should be taken to improve the management of residential services for people with intellectual disability?

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CONSULTATION QUESTION 14: What can be done to ensure the most effective recruitment practices?

CONSULTATION QUESTION 15: In terms of ensuring that services operate to the highest standards, what do you think the key governance and accountability priorities are for those people who lead and manage agencies supporting people with an intellectual disability?

CONSULTATION QUESTION 16: What do you see as the key priorities in terms of education, training and support for staff and residents?

CONSULTATION QUESTION 17: Is there anything else that you would like to comment on, specifically something that you would wish the Review Group to include in their final report and/or Good Practice Guide to be produced later this year? We would specifically wish to hear about any examples of good practice that you believe we should know about.

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