

Time for action

Priority actions arising from
national consultation

Áras Attracta Swinford
Review Group

July 2016

Following the broadcast of the *Prime Time* programme 'Inside Bungalow 3' by RTE, the Áras Attracta Swinford Review Group was established by the Health Service Executive to undertake an independent review of the quality of care being provided in Áras Attracta. The findings of the Review Group are presented over a series of three reports.

What matters most is an assurance review that sets out the findings of the Review Group in relation to Áras Attracta itself. It includes recommendations relating to Áras Attracta management, actions for the HSE at a national level, and a 'road map' to guide all managers of congregated settings as they move towards decongregation.

Time for action deals with the wider system of service provision for people with a disability, and proposes a range of actions including 55 priority actions that emerged from a national process of consultation with stakeholders involved in disability services and the wider public.

Speaking out is a documented record of the lived experiences of people with intellectual disability and how they perceive the support they receive.

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Published by:
Áras Attracta Swinford Review Group

© July 2016

Commissioned by:
National Director, Social Care Division
Feidhmeannacht na Seirbhíse Sláinte / Health Service Executive
Dr Steevens' Hospital
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Editorial and design consultants:
Rédacteurs Limited, www.redact.ie.

Printed in Ireland

Foreword

The Áras Attracta Swinford Review Group was asked to examine submissions made from the wider disability community. In order to obtain these views, we issued a consultation paper seeking views on a range of issues relating to the development of services for people with an intellectual disability.

The views that were submitted were considered by the Review Group and form the basis of this report, *Time for action*.

Much of what we present in this report is not new, as there are many examples of good practice and innovative thinking to be found all over Ireland in relation to services for people with an intellectual disability. From our point of view, however, it is important that such good examples become the norm across the wider system. Now is indeed the time for action across a wide front, and to this end we present 55 priority actions that we believe can make a difference.

I acknowledge that change is not easy, that resources are constrained and that obstacles will have to be negotiated in order to obtain a commitment to improvement in these circumstances.

However, as you read this, I would urge you personally to consider what you can do to help bring these changes about. As often as not, leaders and 'champions for change' are to be found among those who work at the front line where services and supports are provided, as much as at the management table.

Ask yourself what you can do to help achieve the best services possible. In particular, if you are a manager, think about how you can coach the best from your staff to work on this agenda which I commend to you.



Dr Kevin McCoy,
Chairman, Áras Attracta Swinford Review Group.

Acknowledgements

The Áras Attracta Review Group wishes to acknowledge and thank those who contributed to the development of the National Consultation document, either in meetings or in writing, particularly:

- ▶ Stephen Biesty, *HSE*
- ▶ Brendan Broderick, *Muiríosa Foundation*
- ▶ Pauline Conroy, *Social Policy Analyst*
- ▶ Tara Doheny, *Genio*
- ▶ Paudie Galvin, *HSE*
- ▶ Mary Kealy, *Independent Consultant*
- ▶ Fiona Keogh, *Genio*
- ▶ Joanelle O’Cleirigh, *Arthur Cox*
- ▶ Aoife O’Toole, *Cheshire Ireland*
- ▶ Paul White, *Specialist Consultant*

We also wish to acknowledge and thank independent consultant Seamus Logan who provided support in the preparation of the National Consultation paper, the *Start Listening to us* report and this report.

Áras Attracta Swinford Review Group Members

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1

Introduction: about this report

- 1.1** The *Prime Time Investigates* programme broadcast by RTE in December, 2014 and the events it showed in Áras Attracta, Swinford had a profound impact across the nation. Subsequently, further examples of shortcomings in the residential care of people with an intellectual disability have come to light in a number of locations across the country. These events have had and will have far-reaching and long-lasting implications for how people with an intellectual disability experience life in Ireland, particularly those in supported living who rely on others in positions of trust or authority.
- 1.2** As a result of the RTE programme, the Áras Attracta Swinford Review Group (ÁASRG) was set up. Part of its remit was to ensure that any learning from the Review Group was reflected and promoted throughout the system.
- 1.3** Following the publication by the ÁASRG of a consultation document, 'Building confidence, improving lives, delivering change', 36 written responses were received from a cross-section of organisations, professional bodies, family members and individuals. In addition, the ÁASRG commissioned direct face-to-face feedback from a further 140 people with an intellectual disability at 13 separate meetings across Ireland. A separate report deals with their feedback, but there is strong agreement across both reports about what needs to happen to make things better.

Transformational change

- 1.4** It is clear that the current situation calls for transformational change involving broader society, leaders at all levels and the people who provide and manage support services. Our system of support must be human rights-based and values-driven, visibly demonstrating an ethos of dignity and respect. And it must take a zero tolerance approach to any abuse or mistreatment of people in residential care.
- 1.5** There needs to be an emphasis on the creation and maintenance of a positive, collaborative, and accountable culture aimed at promoting individualised support, the maximum attainment of independence for as many people as possible, and a system which helps people and staff to solve problems and difficulties more creatively.
- 1.6** The Review Group is determined to assist in bringing about real change and to ensure that this report will lead to fundamental, achievable and unstoppable changes to service improvement in the provision of support for people with an intellectual disability in Ireland.

Prioritising the delivery of services

- 1.7** The Review Group believes that the Government needs to make the development of services for people with an intellectual disability a priority and recommends that a Minister dedicated to these services should be appointed. The role of this Minister would be to ensure that the necessary cross-Government approach is developed, that the *Congregated Settings*¹ report is implemented in full within five years and that all Government departments and agencies are held to account for their part in ensuring that people with intellectual disabilities are enabled to take their rightful place in society.
- 1.8** The Review Group believes that an Implementation Team should be established with the task of ensuring that the actions called for in this document are fully implemented. This team could be chaired by the Minister called for above or by an independent person reporting directly to the Minister.
- 1.9** We envisage that such a team would establish local implementation processes, that it should set appropriate targets and objectives and that it should gather information on local performance against these targets and objectives for a period of not less than three years.
- 1.10** This team should have a broad membership that is reflective of the relevant departments of Government, of those with operational responsibility in the Health Service Executive (HSE) and of others with relevant corporate expertise. In addition to the actions called for in this report, the team's core task would be the full implementation of the recommendations in both the *Congregated settings* report and the *New directions*² report.

Priority actions: an agenda for change

- 1.11** While this report contains many points about how our system of support could be improved (and we commend all for implementation), we have drawn attention to those *priority actions* (PAs) on which the proposed implementation team should focus – by assigning numbers in brackets after each *priority action*. Taken together and including the other improvements we have identified, these actions constitute an agenda for change which we believe the entire sector can get behind and seek to deliver in the coming years.

¹ Health Service Executive, 2011. *Time to move on from congregated settings: a strategy for community inclusion*.

² Health Service Executive, 2012. *New directions: review of HSE day services and implementation plan 2012–2016 – personal support service for adults with disabilities*.

2

Improving the legislative framework

How can the current legislative framework for adults with an intellectual disability be improved and what needs to be done to ensure any legislative changes are implemented?

2.1 We do not believe that everything can be done all at once to meet the legislative challenges that lie ahead. The starting point is the development of a mechanism to ensure that people with an intellectual disability and their advocates are routinely consulted during the formulation of relevant law. This is different from standard written consultation processes; it means finding a method of proactively reaching out to the people who are affected by such law. (PA 1)

Ireland and the Convention on the Rights of Persons with Disabilities

2.2 Ireland has signed, but has not yet ratified, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).³ Ratification will entail a wide range of provisions to promote equality for disabled people.

2.3 Article 12.2 of UNCRPD deals with consent and requires states to ensure that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. The recent signing into law of the *Assisted Decision-Making (Capacity) Act 2015* removes a significant barrier to the ratification of the UNCRPD.

Existing legislation

2.4 Many of the provisions of the *Equality Act 2004*, the *Education for Persons with Special Educational Needs Act 2004* and the *Disability Act 2005* have not resulted in the improvements which were envisaged (for a variety of reasons). There are resource implications associated with full implementation of these three Acts. Similarly, Building Regulations to ensure access for persons with disabilities to public places such as GP surgeries or public conveniences are currently not being fully enforced, and to do so will have resourcing consequences. (PA 2)

2.5 The Review Group believes that there is a need to review, repeal or replace existing laws on sexual offences as recommended by the Law Reform Commission. This is crucial in order to ensure that persons with an intellectual disability can enjoy, or be supported to enjoy, appropriate relationships in the same way as any other citizen. (PA 3)

³ United Nations, 2006. *Convention on the Rights of Persons with Disabilities*. New York: UN.

Garda vetting

- 2.6** The provisions of the *National Vetting Bureau Act 2012* are not functioning as they were intended. The role of An Garda Síochána in making these provisions work smoothly, promptly and efficiently is crucial. There is a good case for a review of these provisions, particularly with regard to determining if a review process for individuals is required and workable (for example, every three years) and in the use of so-called 'soft' information. Soft information is referred to as specified information under the 2012 Act and is information concerning a finding or allegation of harm which is of such a nature as to reasonably give rise to a bona fide concern that the person may be a risk to a child or vulnerable person (PA 4)

The role of advocates and legal support

- 2.7** There is already provision within the *Citizens Information Act 2007* s.5 for advocates to enter any place where day care, residential care or training is provided and make such enquiries in relation to the person as he or she considers appropriate. They may also obtain from a statutory body or voluntary body any information relating to the person that the personal advocate considers necessary, and attend and represent the person at any meetings, consultations or discussions at which the interests of the person are being considered. They may also require a statutory body or voluntary body that provides social services to cooperate with them in the performance of their functions. These provisions should be enacted without delay.
- 2.8** The role of advocates will be crucial in assisting those with limited capacity, and access to advocacy should be universal. The Department of Social Protection should develop, in consultation with stakeholders, a strategy for the development of advocacy (including voluntary advocacy) and a code of practice for advocates, clearly setting out how the provisions of the law can be fully realised. (PA 5)
- 2.9** People with an intellectual disability are seriously disadvantaged when trying to access the legal system. Legal support should be available to people with an intellectual disability when they are seeking to uphold their human and civil rights before the courts. (PA 6)

Safeguarding procedures

- 2.10** The HSE's safeguarding⁴ procedures are now being put in place and activated throughout Ireland. In order for these procedures to have 'teeth', however, they require to be placed on a statutory basis. This would ensure that they are fully implemented and supported by a comprehensive national training programme that is designed and delivered with the involvement of people with an intellectual disability. (PA 7)

⁴ Health Service Executive, 2014. *Safeguarding vulnerable persons at risk of abuse – national policy and procedures*.

3

Improving the policy and planning framework

How can the current policy and planning framework for adults with an intellectual disability be improved, and what should leaders in health and social care do to improve the policy implementation process?

Required policy improvements

3.1 The Review Group has identified the following policy improvements, which are required immediately:

- ▶ Sufficient community resources to minimise any requirement for admissions to institutional settings – for example, funding to develop support teams to assist local services in responding to people whose behaviours challenge. (PA 8)
- ▶ A policy requirement for agencies and service providers to cooperate fully with people’s advocates. (PA 9)
- ▶ Strengthening of the focus on, and accelerating the implementation of person-centred approaches. (PA 10)
- ▶ A national integration strategy for people with an intellectual disability that links with plans from other sectors – for example, older people. (PA 11)
- ▶ Closer involvement of the HSE in the implementation of the *National Housing Strategy*.⁵ (PA 12)
- ▶ Clearer outcome measures in HSE social care plans – these should be consistent with a SMARTER approach (**s**pecific, **m**easurable, **a**ttainable, **r**elevant, **t**ime-bounded, **e**valuated and **r**eviewed). (PA 13)
- ▶ More robust line management and senior management oversight of staff, particularly where there are diverse locations or where people with high support needs live. (PA 14)
- ▶ The establishment of a central monitoring group to gather data on admissions to and discharges from congregated settings; this group should include appropriate representation from professionals involved in assessments and the delivery of support. (PA 15)
- ▶ Deployment of a tool⁶ to establish the resource needs of individuals with an intellectual disability and so determine the aggregate of such needs at national level. Use the information so gathered to inform resource allocation. (PA 16)
- ▶ Full implementation of the recommendations in the *Vision for change*⁷ document, especially with regard to the establishment of MHID teams. (PA 17)

⁵ Department of the Environment, Community & Local Government, 2011. *National housing strategy for people with a disability*.

⁶ For example, the American Association on Intellectual and Developmental Disability’s Supports Intensity Scale – Adults)

⁷ Government of Ireland, 2006. *A vision for change: report of the Expert Group on mental health policy*.

Funding and person-centred planning

- 3.2** The Review Group recognises that funding constraints are not necessarily an impediment to mainstreaming new thinking. However, the current annual targets for moving people out of congregated settings should be revised upwards, setting out a measurable implementation plan with associated transitional funding. In addition, consideration should be given to how a broad range of professional and managerial expertise could be brought to the planning and management process. (PA 18)
- 3.3** Consideration should be given to ways of promoting independent living – for example, individualised budgets and direct payments to service users. (PA 19)
- 3.4** A special focus is required on transition planning to help young adults who are leaving education or training but who may require continuing support – this should begin with a comprehensive assessment of the needs of this population. (PA 20)
- 3.5** Local HSE management structures need to reflect more adequately a focus on person-centred planning and individualised budgets as well as financial and corporate planning. This can be achieved by the nomination of a local implementation ‘champion’ who can give leadership to the promotion of these approaches and possibly chair any local implementation structures. (PA 21)

Review of compliance processes

- 3.6** The Review Group recognises the pressures on managers and staff brought about by a more robust compliance culture. We therefore believe that HIQA and the HSE should carry out a review of current paper-based compliance processes with a view to eliminating duplication and reducing the burden of paperwork on service providers, with particular regard to critical incident reporting. (PA 22)

4

Promoting dignity and respect

What practical action can providers take to ensure people are treated with dignity and respect? What specific measures can be taken with regard to the support offered to people with behaviours that challenge?

Positive vision

- 4.1 The promotion of dignity and respect is based on 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.
- 4.2 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 their wishes and preferences and, within the law, never restricting the rights of one person because of someone else's needs. Treating people with dignity and respect also includes extending this approach to relatives and support staff and also to advocates.
- 4.3 We believe that every organisation currently providing support services to people with an intellectual disability should carry out a training audit to identify those staff who have had no formal training in human rights and person-centred planning (PA 23).

Active empowerment

- 4.4 High quality services will also seek to actively empower the person receiving support, as well as their caring relatives and advocates by:
 - ▶ Using formal systems that promote communication with people who need support, and enabling people (and their families/advocates) to play an active role in discussions and decisions about their own support – for example, through regular house meetings, family meetings and advocacy group meetings.
 - ▶ Enabling people to challenge decisions made about them.
 - ▶ Developing recruitment and performance review processes that involve people who are being supported, their relatives and advocates.
 - ▶ Involving people receiving support, family members and advocates/self-advocates in the governance of services – for example, through a seat on the management board.

Self-assessment

- 4.5** We believe that measures such as those outlined in this section should be commonplace, and we suggest that the Implementation Team should request providers to conduct a self-assessment audit of the extent to which these measures are in place throughout the system, and should monitor the implementation of this audit. (PA 24)
- 4.6** The audit referred to at **4.5** should also examine the accessibility of formal complaints mechanisms, the use of information in appropriate formats and the availability of volunteer advocates in local communities.

Personal support: personal choice

- 4.7** Everyone should have a personal choice with regard to the gender of the person involved in the provision of intimate personal support. People should be advised that they have this choice and this needs to be specified in contracts with providers in order to ensure compliance. (PA 25)

Promoting best known practice

- 4.8** A mechanism should be identified to ensure that examples of best known practice in services are promoted across the system. (PA 26)

This could be supported by internal staff rotation schemes as a way of exposing people to different ideas (balanced with the need to maintain continuity).

Wider national awareness

- 4.9** There is a need for a national awareness campaign. This would be aimed at educating the wider public about the needs of people with an intellectual disability to participate in the structures of wider society and the typical accommodations that might be required to allow this – for example, when they are using public services. (PA 27)

Behaviours that challenge

- 4.10** People with behaviours that challenge require a particular focus. There is a danger that negative '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.
- 4.11** At the same time, it is also worth bearing in mind that while there are many possible reasons for such behaviour, sometimes it is the product of negative interactions with others in the past. It is vital to seek to understand the basis for a particular behaviour (for example, boredom, frustration or conflict with others) rather than simply regarding it as a pathological manifestation of a wider syndrome.

- 4.12** We have already made reference to the need for specialist support to assist local staff teams in every region. However, every staff member should have a basic level of knowledge about behaviours that challenge, their causes and how to respond to them.
- 4.13** There should be at least one person in each service team who has a higher level of skill and knowledge in relation to behaviours that challenge, and who can build capacity within the service. An audit of the current situation will help to reveal any gaps in this regard (PA 28).
- 4.14** Such an audit could also establish how many services have a 'quiet area' – such areas have a valuable role to play in helping to deal with behaviour that challenges.
- 4.15** The use of physical restraint should be eliminated except in the most exceptional circumstances. It should only be used as a measure of last resort where there is imminent risk of physical harm. It should only be used as a temporary measure, in the least restrictive way and for the least amount of time necessary. The HSE must make it clear to all provider organisations that this is a firm policy position. (PA 29)
- 4.16** It is unclear to what extent an assessment of need has been conducted with regard to ageing carers, who are currently managing people whose behaviours challenge, with limited or no support. Such an assessment would identify any need for further investment in respite services. (PA 30)
- 4.17** The response that a service makes to any critical incident involving behaviours that challenge must follow established procedures. All services are required to have such procedures in place. (PA 31)

5

Changing organisational culture

What needs to happen to change organisational culture among service providers so that they can achieve faster service improvement? How can the current organisational arrangements be improved to better support a culture of partnership?

- 5.1 The best organisational cultures are both 'top down' and 'bottom up' in that they place emphasis on change initiatives that are led by senior managers supporting frontline service improvements that have the potential for system-wide application.

Emphasis on service improvement

- 5.2 Leadership and management in such organisations place a strong emphasis on continuous service improvement, on listening to the experiences of individual people and the quality of their experience, on quality improvement systems led and implemented by frontline staff themselves, and on using mistakes, near misses and accidents as learning opportunities for the future. These are learning organisations because of their openness to experimentation and learning and because of their high investment in staff training and development.
- 5.3 There is strong evidence internationally of the value of developing locally-led and locally delivered service improvement initiatives in residential services for people with intellectual disabilities.

Whistle-blowing

- 5.4 No organisation should fear the implementation of whistle-blowing procedures, which provide for protections for workers who disclose information relating to wrongdoing which comes to their attention in the workplace. During this consultation, we have learned how some whistle-blowers can experience harassment, intimidation and even the loss of their chosen career. This is unacceptable. Individuals can refer issues of concern to HIQA and can seek legal redress if they suffer any detrimental consequences arising from their whistle-blowing.
- 5.5 Whistle-blowers should document all allegations of abuse and ensure that copies of these records are shared with relevant people – local managers, HIQA or the HSE. Under the *Protected Disclosures Act 2014*, there is now statutory protection for whistle-blowers.

Values and attitudes of staff

- 5.6** There is also a need to focus on the values and attitudes of individual staff members – particularly in relation to human rights, the promotion of dignity and respect, and social as well as health needs. Positive and informed risk taking should be encouraged in the context of proper risk assessments. Recruitment, induction and orientation processes for new staff should reflect appropriate values and attitudes.
- 5.7** The Review Group endorses the recommendation in the *Value for money*⁸ review that a National Director of Disability Services should be appointed, to report directly to the HSE Director General. (PA 32)

Initiatives already under way

- 5.8** The range of improvement initiatives that have already been announced by the HSE are very welcome, but they require clear implementation pathways and better communication so that people who use the services are fully aware of these new developments. (PA 33)
- 5.9** As mentioned earlier, in order to achieve the seven-year planning framework for the implementation of the *Congregated settings* report there needs to be a much stronger commitment (at national policy level) to moving to community living. Revised national targets should reflect this. (PA 34)
- 5.10** The Review Group believes that the focus of the current regulation and inspection regime is too narrow and that it needs to take greater account of the perspectives of service users and of the wider community. Meaningful quality of life indicators (which are not always reflected in compliance standards) are vitally important, and should be integrated into the statutory regulation and inspection process. HIQA should recruit self-advocates who are ‘experts by experience’ to help achieve this. (PA 35)
- 5.11** The Review Group believes that the HSE’s *Trust in care*⁹ policy requires reform. Implementation of any new policy or procedure should be accompanied by a significant programme of training so that it is implemented consistently across the country. (PA 38)

HIQA inspections

- 5.12** HIQA inspections should reflect the drive towards person-centred planning in the context of independent living in private accommodation. To this end, HIQA inspectors should be trained in the social model of disability, person-centred planning and individualised budgets. (PA 36)
- 5.13** HIQA should also consider a stronger, demonstrable shift towards a greater number of unannounced inspections; and in reports on providers of multiple units, HIQA should differentiate the different units more clearly. (PA 37)

⁸ Department of Health, 2012. *Value for money and policy review of disability services in Ireland*.

⁹ HSE, 2005. *Trust in care: policy for health service employers on upholding the dignity and welfare of patients/clients and the procedure for managing allegations of abuse against staff members*.

Working with the voluntary sector

5.14 The HSE should develop a *memorandum of understanding* with the voluntary sector to determine the best ways of achieving the cultural change required to improve service delivery for those with an intellectual disability. This might involve national and local voluntary organisation forums, workshops, seminars and conferences in order to help break down barriers to positive change. (PA 39)

External support

5.15 Some provider organisations may find it more difficult to achieve the cultural change necessary for them to improve service delivery, and they should consider accessing external expert support to help them do this. (PA 40)

6

Preventing abuse and neglect

What are the most important measures that can be taken to identify and prevent abuse and neglect?

Responsibility to prevent

6.1 The responsibility to prevent and identify abuse or neglect is a system-wide responsibility that requires everyone's attention. Absolute clarity as to what constitutes abusive behaviour is crucial and the reporting of incidents of abuse should be a contractual requirement for employees as part of their duty of care. There is no substitute for vigilance and a willingness by managers and colleagues to challenge inappropriate behaviour.

Duty to report

6.2 All new employees should be required to acknowledge in writing that they have read and understood their duty to report abuse/neglect and in particular any action, practice or event that they believe might be criminal in nature. Their understanding of this should be recorded on their employment file. (PA 41)

Value of self-advocacy

6.3 Self-advocacy is an important protective step and helps give people a stronger sense of their own worth and entitlement. Many service providers have established rights review committees to review all restrictions on fundamental human rights that those in their care might be subject to – including freedom of movement, the right to own personal property, bodily integrity, and so on. This helps create a rights-conscious culture, particularly where the committee has an independent chairperson and where referrals are welcomed from individuals, their families, support staff and volunteers. This practice should be in place among all service providers. (PA 42)

Access to the wider community

6.4 The more time people with an 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. Everyone with a disability should have access to a wider community beyond their immediate paid carers. Service providers should identify anyone who lacks this 'unpaid presence' in their lives and take necessary protective steps where appropriate. (PA 43)

- 6.5** An understanding of abuse, the ability to communicate and the presence of a trusted adult in their lives – these are perhaps the best protections a person can have against abuse.

Characteristics of vulnerable people

- 6.6** Some individual characteristics have been associated with abuse by various authors. People with intellectual disabilities were more likely to be abused if they were:

- ▶ Physically mobile
- ▶ Displaying aggressive behaviour
- ▶ Young
- ▶ Non-verbal
- ▶ Unsociable or engaged in self-injury
- ▶ Lacking social skills
- ▶ Exhibiting poor judgement
- ▶ Lacking communication skills
- ▶ Physically dependent – for example, if they require help with personal hygiene and intimate body care
- ▶ Lacking knowledge of appropriate sexual behaviour
- ▶ Lacking understanding of how to defend themselves against abuse
- ▶ Lacking practice in making independent decisions in everyday life
- ▶ In a situation where there is a significant power imbalance in terms of age, gender, ability, role or experience.

All staff and managers should be trained to focus on the individual needs of each person and on how to implement measures to protect against abuse/neglect.

- 6.7** There is a particular risk of abuse during intimate and personal care for people with intellectual disabilities and complex needs. There should be a focus on ensuring the person's dignity in these situations. In so far as is practical, the person should choose their support worker and individual guidelines should be developed to ensure adequate protection for both the person and the support worker. (PA 44)

Requirement for formal independent investigation

- 6.8** Underpinning all of these measures, a formal and independent system for the investigation of abuse or neglect should be established – where this is required over and above local action. (PA 45)

7

Achieving better health outcomes

What needs to happen to achieve better health outcomes for people with an intellectual disability?

Health and well-being service characteristics

7.1 A service fully concerned with the health and well-being of people with an intellectual disability includes features such as:

- ▶ Health promoting activities such as smoking cessation classes, healthy eating groups, regular physical activity where appropriate, creative expression and engagement, and the provision of good information on healthy living (in accessible formats)
- ▶ Access to screening, early detection and the full range of universal general health and welfare services (including dental, optical and aural services) that any member of the community could expect to receive
- ▶ Access to general medical services through registration with a GP, and a commitment to ensuring a comprehensive, annual health check
- ▶ Where appropriate, a timely, comprehensive multidisciplinary assessment of health needs based on consultation with the person and, where appropriate, with their family
- ▶ Adequate diet and nutrition and, where necessary, access to a dietician
- ▶ Where there are concerns, a focus on weight change and body mass index; addressing the needs of those with swallowing problems and those who need oral nutritional supplements
- ▶ Timely access to mental health services and, where necessary, a review of medication and behaviour support plans
- ▶ Access to support services for those people with behaviours that challenge
- ▶ Access to interpreters where necessary
- ▶ Good end-of-life care
- ▶ Bereavement support.

Administration of medication

7.2 Most of us take for granted the ability to administer medications to ourselves. This is not always the case for someone with an intellectual disability. Service providers need to look at their practices and where appropriate, based on a risk assessment and an assessment of capacity, encourage and support individuals to take prescribed medication themselves and make sensible use of over-the-counter medications.

Primary care alerts

- 7.3** There is a strong case, based on research evidence, for stronger preventative healthcare, for example in dental hygiene and general health screening. Those who provide support must take the lead in encouraging take-up of these services (PA 46). There may also be value in an alert system in primary care files for people with a recognised intellectual disability – for example, the simple use of colour coding on medical records.

Gaps in quality of support

- 7.4** Many of the service features that promote a healthy life referenced in HIQA's *National standards*¹⁰ are now included in HIQA inspections. However, there is strong evidence presented in HIQA's inspection reports that there are worrying gaps in the quality of support provided.

Ensuring national standards are adhered to

- 7.5** The Review Group believes that the only way to ensure the *National standards* become the norm is through their inclusion in individual person-centred plans. Rather than relying on the inspection system, we need to see positive action to make adherence to these standards a routine aspect of support. We believe that all person-centred plans should include a dedicated section on healthy living and should respond to specific individual health issues. (PA 47)

¹⁰ HIQA, 2013. *National standards for residential services for children and adults with disabilities*.

8

Managing residential services

What steps should be taken to improve the management of residential services for people with an intellectual disability; and what can be done to ensure the most effective recruitment practices?

What good management looks like

- 8.1** The best service managers give leadership based on the vision and values of the service that they are managing. Their management style is participative and their attitude to others is typically based on how they themselves would wish to be treated.
- 8.2** For these managers, there is no substitute for visible on-the-ground leadership. Honest feedback is welcomed by them in so far as it contributes to improving the service. A person-centred focus is central to all their decisions.
- 8.3** As well as having professional or management qualifications, good managers of residential services need to have excellent managerial and personal attributes, including an entrepreneurial imagination, a commitment to empowering people with intellectual disabilities to achieve their potential, appropriate attitudes in relation to human rights, the promotion of dignity and respect, and the ability to focus on social as well as health needs.
- 8.4** Senior managers need to be visible to their teams, and should 'walk the floor' at different times of the day and night to gain a rounded understanding of how the service is performing. This is also a way for managers to show a good 'hands-on' behaviour, and to avoid being perceived as remote from the day-to-day operations. This is especially important at weekends and during the night, when staffing levels are lower and subject to less supervision.
- 8.5** 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.
- 8.6** Managers should conduct team meetings in or close to the place where the persons being supported live. Some middle or line-management meetings should occur in such settings on a rotational basis so that each and every location is demonstrably connected and engaged. Standing agenda items at such team meetings should include service improvement, the promotion of national policy and values, risk management and the implementation of individualised support.
- 8.7** As a means of demonstrating the value of this approach, the Implementation Team should rotate the location of their meetings to the different HSE regions around the country. The organisation/agency hosting the meeting should facilitate a site visit and present evidence of progress on implementing the targets and objectives outlined in this report (PA 48).

- 8.8** 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.
- 8.9** No supervisor or manager should have excessive influence or power over his/her staff team. Senior managers need to be alert to this possibility and should facilitate open communication among themselves.
- 8.10** Only highly committed staff with a demonstrable commitment to service improvement should be promoted to management positions.
- 8.11** The Review Group believes that no management appointment should be made without representation on the appointments panel by people receiving support or their relatives or advocates (PA 49). Such participation does not necessarily require formal training nor does the person on the panel require a vote in order to influence the process, but they do need to be prepared for and supported in the process to ensure that their participation is meaningful.

Recruitment, induction and support of staff

- 8.12** One of the key management tasks is the recruitment of staff. The process begins with the job description and person specification which should highlight the need for the new member of staff to have the right values and attitudes – in particular, a commitment to protect human rights, to promote dignity and respect, and to understand the need for a focus on social needs as well as health needs.
- 8.13** As reflected in feedback from the *Start listening to us* report, people who use support services want workers who are helpful, happy, pleasant and kind, who are good listeners, fun to be with and good company. They also referenced a current gender imbalance with an under-representation of males.
- 8.14** Services should have a core of permanent staff. Agency staff should be used only in exceptional circumstances where necessary to ensure safe staffing levels.
- 8.15** The job advertisement should include a brief description of the mission and values of the organisation, and the kind of applicant required, not only in terms of their training, qualifications and experience but also their personal values and qualities.
- 8.16** Interviewees should be advised to visit the service's website which should reflect the same positive mission and values.
- 8.17** The job application form should reflect the need for a strong person-centred focus and could ask applicants to demonstrate their understanding of this concept.
- 8.18** Interview panels should ideally include a person with an intellectual disability who has been suitably prepared for participation in the recruitment process. The interview should be competency-based (for example, 'give an example of how you supported someone who was distressed') and should yield some evidence of the person's attitude to promoting dignity and respect and their approach to empowering people with disabilities.

- 8.19** References should be taken up in every instance, including verbal references. The practice of allowing a new employee to commence their post without having received the appropriate vetting papers from An Garda Síochána is not acceptable. (PA 50)
- 8.20** 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.
- 8.21** The key worker system is an essential component of person-centred planning. Where it has fallen into abeyance, it should be immediately reintroduced.
- 8.22** All staff and especially new staff should understand their duty of care and their obligation to challenge and report poor practice by colleagues. Attention is drawn to the relevant HSE policy in this area which can be found at:
- <http://www.hse.ie/eng/staff/Resources/hrppg/Good_Faith_Reporting_Policy_2011.pdf>
- All staff should be asked to acknowledge in writing that this policy has been discussed in detail with them. Agencies should have a zero tolerance approach to any kind of abuse and their staff should be aware of this.
- 8.23** Ongoing support for staff is essential as is the provision of in-service learning opportunities, regular individual supervision/coaching and feedback and the use of probationary employment periods and regular performance review meetings. Ongoing feedback influences and impacts on behaviour and the conversations with staff should reference the organisation/agency's vision, mission and values as well as its overall change strategy.

Change is challenging

- 8.24** Staff members often find change challenging and it is a core management task to hold regular positive briefing sessions about change processes where there is an opportunity to highlight good practice, to ensure staff feel they are part of the change and that they can influence the change rather than having it imposed upon them. (PA 51)
- 8.25** For some staff, change may be too difficult and the HSE should have in place a system for offering redeployment, voluntary redundancy or early retirement as appropriate.

Keeping residents close to home

- 8.26** People with intellectual disabilities who are unable to live with their families should be supported as close to their families and communities as possible. The admission of residents to centres far from their homes should be the exception and should always be subject to external scrutiny by the local HSE Disability Manager. (PA 52)

9

Governance and accountability

What are the key governance and accountability priorities for those people who lead and manage agencies supporting people with an intellectual disability?

What good governance looks like

- 9.1** Good governance is about adequate oversight, control and audit of the key functions of the service, and it should result in clear lines of accountability.
- 9.2** In order to ensure good governance, agencies must:
- ▶ Have clarity about structures, processes, roles and functions
 - ▶ Manage risk appropriately
 - ▶ Be transparent in their decision-making
 - ▶ Engage appropriately and effectively with key stakeholders
 - ▶ Ensure accountability for their actions.
- 9.3** Examples of strong governance processes include:
- ▶ Management processes to identify, control and mitigate against known risks
 - ▶ Assurance processes in areas such as sub-contractor control, emergency preparedness, fire safety, health and safety, human resources, professional conduct and records management
 - ▶ A focus on service improvement, quality initiatives and performance management
 - ▶ Routine and regular scrutiny of existing policies, procedures and guidelines
 - ▶ The presence of people with an intellectual disability on boards of management – as long as they are suitably prepared to carry out that role.
- 9.4** High quality agencies demonstrate good governance by ensuring that the strong governance processes identified immediately above receive at least as much attention as corporate planning and financial management (PA 53).
- 9.5** High quality agencies also ensure that ownership and accountability for specific elements of governance are clearly assigned to individual board members and senior managers. There must be clear unbroken lines of accountability to the management board in relation to each setting where support is delivered.

Other elements of good governance

- 9.6** Board members should be formally inducted into their role and should have regular opportunities to learn about best known practice.
- 9.7** Management boards should have a place for a person with an intellectual disability including a supporter, if necessary, and a relative.
- 9.8** Commitment to and leadership for this approach must come from and be demonstrated by the Chairperson and the Chief Executive of the agency.
- 9.9** Implementation of one of the standard codes of governance practice will ensure strong governance and adequate oversight of the service.¹¹
- 9.10** The Implementation Team should also consider how best to ensure that agencies providing support have suitable governance processes in place. (PA 55)

¹¹ For information on the Code of practice for governance of state bodies, see:

<www.ipa.ie/index.php?lang=en&p=page&id=416>

For the Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland, see:
<www.governancecode.ie>

For the HSE Code of governance, see:

<<http://www.hse.ie/eng/services/publications/corporate/codeofgovernance.pdf>>

10

Key education priorities

What are the key priorities in terms of education, training and support for staff and residents?

Training: mandatory, desirable and priority

10.1 The Review Group offers the three tables below as a classification of training for staff working with people with an intellectual disability:

- ▶ Mandatory training – should be completed by all staff
- ▶ Desirable training – if possible, should be completed by all staff
- ▶ Priority training – should be prioritised for inclusion on individual training and development plans.

These are summarised in the following tables.

Table 10.1 *Mandatory training options*

Education, training and support topic	Residents	Relatives	Management	Staff
Local induction and familiarisation			✓	✓
HSE corporate induction			✓	✓
Fire safety, fire training and drills	✓		✓	✓
Manual handling and people handling			✓	✓
Safeguarding and staying safe	✓	✓	✓	✓
Trust in care			✓	✓
Managing behaviours that challenge		✓	✓	✓
Social model of disability	✓	✓	✓	✓
Person centred planning	✓	✓	✓	✓
Key worker	✓	✓	✓	✓
Communicating with people with an intellectual disability	✓	✓	✓	✓
Complaints procedures	✓	✓	✓	✓

Table 10.2 *Desirable training options*

Education, training and support topic	Residents	Relatives	Management	Staff
Cardiac first response / CPR / basic life support			✓	✓
First aid and epilepsy training				✓
Food hygiene	✓		✓	✓
Hand hygiene and infection control	✓		✓	✓
Positive behaviour support			✓	✓
Risk management			✓	✓
Nutrition and hydration / MUST				✓
Assisting people at meal times		✓		✓
Medication management (nurses), safe administration of medication (non-nursing staff), self-administration (residents)	✓			✓
Record keeping and documentation			✓	✓

Table 10.3 *Priority training options*

Education, training and support topic	Residents	Relatives	Management	Staff
Consent	✓	✓	✓	✓
Use of restrictive procedures		✓	✓	✓
Supporting people involvement / assisted decision making	✓	✓	✓	✓
Controlling my money	✓	✓		✓
Health promotion	✓			✓
Advocacy	✓	✓	✓	✓
Coaching/mentoring			✓	✓
Information technology	✓		✓	✓
Human rights and equality	✓	✓	✓	✓

Training for residents

- 10.2** There is good evidence of the value of training people with an intellectual disability in protecting themselves from abuse, in recognising when it occurs and in what they should do if it does. Such training is most effective when it combines information-giving, instruction, modelling, rehearsal and role-play. For these reasons, the tables above include columns indicating the topics that are relevant to residents and their relatives. In some instances it may be helpful to include residents and/or relatives in specific training events.
- 10.3** For individual residents, there will also be value in developing assertiveness skills and in building personal confidence as a general protective measure. Tailored programmes in bereavement, relationships and sex education, self-defence skills and awareness of community resources should be considered as appropriate.

Mentoring and further support for staff

- 10.4** Staff should not only receive the training they need in order to do their job but should have time to reflect on how the training can impact on their practice. This can be achieved in a number of ways – for example, through informal discussion with a mentor or a more senior member of staff or through formal individual supervision or in a formal team meeting.
- 10.5** All staff, including managers at all levels should have a *personal development plan* with achievable individual targets, and this should be supported by an agency commitment to training and development opportunities. (PA 56)
- 10.6** An important aspect of staff welfare is the provision of support aimed at promoting self-care – for example, through an Employee Assistance Programme. Such initiatives should be external to the organisation and confidential to those attending.
- 10.7** The individual needs of people with an intellectual disability (for example, in relation to job coaching, communication or nursing care) should be reflected in the skills of the support team. This may require buying in a specialised service as needed, employing someone on a sessional basis, or accessing it through Community Care services.

Changes in skill mix: a matter for concern

- 10.8** During consultation, some concerns were expressed that changes in skill mix have led to a reduction in the proportion of professionally qualified staff. There are also major access issues in relation to areas such as speech and language therapy, occupational therapy, physiotherapy and psychology.

A

Appendix

Summary of priority actions

The Review Group believes that the Government needs to make the development of services for people with an intellectual disability a priority and recommends that a Minister dedicated to these services should be appointed. The role of this Minister would be to ensure that the necessary cross-Government approach is developed, that the recommendations of the *Congregated Settings* report are implemented in full within five years, and that all Government departments and agencies are held to account for their part in ensuring that people with intellectual disabilities are enabled to take their rightful place in society.

The Review Group believes that an Implementation Team should be established with the task of ensuring that the actions called for in this document are fully implemented. This team could be chaired by the Minister called for above or by an independent person reporting directly to the Minister.

Priority actions (PAs)

-
- PA 1** In relation to new legislation, the starting point is the development of a mechanism that ensures people with an intellectual disability and their advocates are routinely consulted during the formulation of relevant law.
-
- PA 2** Fully implement the outstanding provisions of the *Equality Act 2004*, the *Education for Persons With Special Educational Needs Act 2004*, the *Disability Act 2005* and the current Building Regulations.
-
- PA 3** Review, repeal or replace existing laws on sexual offences as recommended by the Law Reform Commission.
-
- PA 4** Review the provisions of the *National Vetting Bureau Act 2012*, particularly with regard to the use of so-called 'soft' information and to decide if a review process for individuals is required and workable.
-
- PA 5** The Department of Social Protection should develop, in consultation with stakeholders, a strategy for developing advocacy (including voluntary advocacy) and a code of practice for advocates, clearly setting out how the provisions of the law will be enacted.
-
- PA 6** Make access to legal support available to people with an intellectual disability when they are seeking to uphold their human and civil rights before the courts.
-
- PA 7** The HSE's 2014 *Safeguarding*¹ procedures should be placed on a statutory basis and supported by a comprehensive national training programme that involves people with an intellectual disability in its design and delivery.
-

PA 8	Provide funding to develop support teams to assist local services in responding to people whose behaviours challenge.
PA 9	Agencies and service providers should cooperate fully with advocates of people with an intellectual disability.
PA 10	Accelerate the implementation of person-centred approaches in relation to people with an intellectual disability.
PA 11	Develop a national integration strategy for people with intellectual disability that links with plans from other sectors.
PA 12	The HSE should be closely involved in the implementation of the <i>National Housing Strategy</i> . ¹²
PA 13	The HSE should develop plans that are transparent and consistent with a SMARTER approach (specific, measurable, attainable, relevant, time-bounded, evaluated and reviewed).
PA 14	There should be more robust line management and senior management oversight of staff, particularly where there are diverse locations or where people with high support needs live.
PA 15	Establish a central monitoring group to gather data on admissions to and discharges from congregated settings. This should include appropriate representation from those professions involved in assessments and the delivery of support.
PA 16	Deploy a tool to establish the resource needs of individuals with an intellectual disability, and so determine the aggregate of such needs at national level. Use the information so gathered to inform resource allocation.
PA 17	Fully implement the recommendations of the <i>Vision for change</i> ¹³ document, especially those relating to the establishment of MHID teams.
PA 18	Revise upwards the current annual targets for moving people out of congregated settings, and formulate a measurable implementation plan with associated transitional funding.
PA 19	Consider introducing individualised budgets and direct payments to service users with an intellectual disability.
PA 20	Undertake a comprehensive assessment of the needs of young adults with an intellectual disability who are leaving education or training.
PA 21	Identify local implementation 'champions' who can give leadership to the promotion of person-centred planning and individualised budgets as well as financial and corporate planning.
PA 22	HIQA and the HSE should carry out a review of current paper-based compliance processes aimed at eliminating duplication.

¹² Department of the Environment, Community & Local Government, 2011. *National housing strategy for people with a disability*.

¹³ Government of Ireland, 2006. *A vision for change: report of the Expert Group on mental health policy*. and the procedure for managing allegations of abuse against staff members.

PA 23	Every organisation currently providing support services to people with an intellectual disability should carry out a training audit to identify those staff that have had no formal training in human rights and person-centred planning.
PA 24	The Implementation Team should request providers to conduct a self-assessment audit to investigate the extent to which measures promoting dignity and respect are in place throughout the system and should monitor the implementation of this audit.
PA 25	All people with an intellectual disability should have a personal choice in regard to the gender of the person who provides them with intimate personal support.
PA 26	Identify a mechanism to ensure that examples of best known practice in services are promoted across the system.
PA 27	Launch a national awareness campaign to educate the wider public about the needs of people with an intellectual disability.
PA 28	There should be at least one person in each service team who has a higher level of skill and knowledge and can build capacity within the service relating to behaviours that challenge.
PA 29	Eliminate the use of physical restraint except in the most exceptional circumstances.
PA 30	Conduct an assessment of need with regard to ageing carers who are currently managing people whose behaviours challenge, with no or limited support.
PA 31	All services should have measures in place to respond to critical incidents involving behaviours that challenge.
PA 32	Appoint a National Director of Disability Services, reporting directly to the HSE Director General.
PA 33	Clearly communicated implementation pathways are required to ensure the range of improvement initiatives already announced by the HSE are understood by everyone.
PA 34	Revised national targets are required for the <i>Congregated settings</i> report. ¹⁴
PA 35	Self-advocates should be recruited by HIQA to participate in the statutory regulation and inspection process.
PA 36	The HSE's <i>Trust in care</i> ¹⁵ policy and procedures for investigating abuse (2005) should be reviewed and reformed.
PA 37	HIQA inspectors should be trained in the social model of disability, person-centred planning and individualised budgets.
PA 38	HIQA should consider a demonstrable shift towards more unannounced inspections and differentiated reports on individual units where a provider has more than one unit.

¹⁴ Health Service Executive, 2011. *Time to move on from congregated settings: a strategy for community inclusion*.

¹⁵ HSE, 2005. *Trust in care: policy for health service employers on upholding the dignity and welfare of patients/clients and the procedure for managing allegations of abuse against staff members*.

PA 39	The HSE should develop a <i>memorandum of understanding</i> with the voluntary sector to determine the best ways of achieving the cultural change required to improve service delivery for those with an intellectual disability.
PA 40	Provider organisations who find cultural change more difficult should be able to access expert support.
PA 41	All new employees should be required to sign off that they have read and understood their duty to report abuse and poor professional practice that constitutes a criminal offence.
PA 42	Service providers should establish a rights review committee or similar for their service.
PA 43	Service providers should identify anyone in supported living who lacks an unpaid presence in their lives.
PA 44	Because of the high risk of abuse during intimate and personal care, there is a need for specific preventative measures in this area.
PA 45	A formal and independent system for the investigation of abuse or neglect should be established where this is required over and above local action.
PA 46	Stronger preventative healthcare, for example in dental hygiene and general health screening, is required.
PA 47	All person-centred plans should include a dedicated section on healthy living and should respond to specific individual health issues.
PA 48	The Implementation Team should rotate the location of their meetings in HSE regions around the country. The organisation/ agency hosting the meeting should facilitate a site visit and present evidence of progress made on implementing the targets and objectives outlined in this report.
PA 49	No management appointment should be made without representation on the appointments panel by people receiving support or their relatives or advocates.
PA 50	The practice of allowing a new employee to commence their post without having received the appropriate vetting papers from An Garda Síochána is not acceptable.
PA 51	It is a core management task to hold regular positive briefing sessions about change processes.
PA 52	The admission of residents to centres far from their homes should be the exception, and where it occurs, should be subject to external scrutiny by the local HSE Disability Manager.
PA 53	Strong governance processes should receive at least as much attention as corporate planning and financial management by the Board of Directors – these processes include risk management, assurance processes, service improvement, performance management, policy review and the presence of someone with an intellectual disability on the Board.

PA 54 The Implementation Team should also consider how best to ensure that agencies providing support have suitable governance processes in place.

PA 55 All staff, including managers at all levels should have a personal development plan.

B

Appendix

Respondents to the consultation

AG (citizen)	MC (parent)
Anonymous (relative)	MD (citizen)
BC (parent)	MH (parent)
Citizens Information Board	MQ (parent)
College of Psychiatrists of Ireland (Faculty of Learning Disability)	National Advocacy Services for People with Disabilities
Cope Foundation	National Federation of Voluntary Bodies
Dental Health Foundation	People First Advocacy Group, Muiríosa Foundation
EH (parent)	PMcC (parent)
EO'D (parent)	Psychiatric Nurses Association
FF (citizen)	Psychology Services Ireland/ Psychological Society of Ireland
FH (parent)	Rehab Care
GD (parent)	Rehab Group
Irish Nurses and Midwives Organisation (RNID Section)	Residents of the Talbot Group
JK (Care Assistant)	Speech and Language Therapy (Adult Intellectual Disability Special Interest Group)
KB (Clinical Nurse Specialist)	SR (citizen)
KO'B (citizen)	The Alzheimer Society of Ireland
LD (Care Assistant)	WALK
Learning Disability Special Interest Group – Joint Submission	
LSS and MGMcG (citizens)	
MB (relative)	

