

***Citizens Information Board Submission
September 2015***

Aras Attracta Review Group Consultation Response

In order to complete your response using the online booklet, you will need to download it and return the completed copy as an email attachment to;

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Please describe in one or two sentences why you are submitting this response;

The Citizens Information Board (CIB) has responsibility for funding and supporting independent information, advice and advocacy services. As part of this remit, the Board funds and supports the National Advocacy Service for People with Disabilities (NAS).

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

- There is a need to distinguish clearly between legal capacity and mental capacity - legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency).
- The Assisted Decision –making (Capacity) Bill 2013 should be enacted without any further delay.
- The Decision Support Service to be established under the Assisted Decision-making (Capacity) Bill 2013 should be separate from the Courts Service and set up either under the aegis of the Department of Justice and Equality or as an independent body.
- Core provisions for assessment of need under the Disability Act 2005 need to be fully implemented as originally intended.
- The question of statutory powers for advocates as envisaged under the provisions of the Citizens Information Act 2007 should be considered in particular advocates access to services and to related information and documentation to support clients.
- The provisions of the UN Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights and the Irish incorporation of the latter (the European Convention on Human Rights Act 2003) need to be made more central to the debate around meeting the needs of people with an intellectual disability.
- The Criminal Law (Sexual Offences) Act 1993 should be amended so that persons with an intellectual disability are given the freedom to engage in normal, meaningful relations. At present consensual relationships between two people with an intellectual disability may be criminalised.

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

- A Code of Practice for Advocacy Work applicable in all care settings should be drawn up to enable the implementation of the concept of supported decision-making when the Assisted Decision-Making (Capacity) Bill is enacted.
- A review of the position of people who are currently Wards of Court should be given absolute priority once the assisted decision-making legislation is enacted.
- There should be a much stronger emphasis on reflecting the will and preferences of people (as distinct from promoting their best interests) in all actions taken with them

or on their behalf.

- People with an intellectual disability should be given meaningful access to independent advocacy (including legal representation) in accordance with the provisions of the Disability Act 2005.
- The UNCRPD should be ratified and its provisions implemented to reflect a shift from a gesture towards people's rights to an approach that is truly rights-based.

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

- The move from congregated settings needs to be expedited in tandem with the proactive implementation of the Housing Strategy for People with a Disability.
- Funding commensurate with delivering current policy aspirations needs to be available.
- An overall national strategy for fully integrating people with an intellectual disability, based on a human rights approach and reflective of current legislative provisions and policy statements, should be put in place with clearly specified timelines for implementation.
- Policies to ensure linkage with services for older people with disabilities need to be strengthened.
- A national advocacy strategy should be considered to consolidate the range of advocacy interventions across the various sectors.
- Mechanisms are required to assess the congruence between legislation, policy and planning, the actions taken by those charged with delivering services and the actual outcomes in practice for individuals and groups.
- A continuum of support structure co-ordinated nationally by the HSE is required to ensure that all needs are addressed in an integrated manner and that individuals do not fall between a number of disjointed initiatives operating separately and independently.
- There is a need to distinguish between consultation and participation – the latter is organic and bottom-up and enables the people centrally involved to define need and identify appropriate responses -- this is very different from a top-down approach where people are consulted about pre-determined policies.
- The proposal in the HSE Social Care Division Operational Plan 2015 for the establishment of a volunteer advocacy programme, if it is to work, must have an

appropriate support and co-ordinating structure with core paid staff.

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

- There is a need to move towards a much more proactive approach to developing best practice as distinct from a purely reactive approach, e.g., in response to a HIQA inspection report, which may frequently be the case at present.
- All health and social care staff should be supported to engage with and implement change in work practices and innovation based on best practice.
- There should be a much stronger emphasis on an ethical framework underpinning health and social care work – this is vitally important to deal with situations where it may not be clear what the right thing to do is.
- Provision should be made for including all quality of life domains in identifying and addressing need, e.g.,
 - The opportunity to perform activities of daily living
 - The opportunity to engage in meaningful use of time
 - Social interactions
 - Meaningful relationships
 - Achieving a good balance between positive emotion and the absence of negative emotion
- Independent and transparent governance structures should be in place, ideally with active representation of local communities.
- There should be a greater focus on responsible risk-taking and supports to manage that risk in the context of each individual's right to self-determination.

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

- Social and health care staff should always fully respect and be directed by the will and preferences of individuals.
- Every effort should be made to involve individuals in decisions which affect them to the maximum extent possible.
- Service providers should have in place policies and codes of practice on:

- Consultation with service users and their families
 - Consent
 - Protecting Vulnerable Adults
 - Communication
 - Complaints
- All information should be available to service users in formats appropriate to their way of communicating.
 - Training and continuous professional development should be available to all staff in different and innovative ways of communicating with people who are not verbal.
 - Self-reflection and reflective practices by both staff and service users should be encouraged and facilitated.
 - Linkages with local communities should be strengthened and all opportunities for engaging in 'mainstream' community-based activities should be explored.
 - The concept of community visitors to residential care facilities should be explored further and developed.

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

- Great care is needed by all service providers to ensure that people's rights are not unduly restricted and staff should have the skill sets to deal in a positive way with challenging behaviour.
- Staff should have access to appropriate psychological and behavioural management expertise to assist them in developing an individually-tailored response to an individual with challenging behaviour.
- There should be a proactive programme in place to reduce or eliminate challenging behaviour over the time and to build a person's capacity to cope.
- There is a need for a good awareness among staff of how mental health difficulties may impact on a person with an intellectual disability and a need for close collaboration between Intellectual Disability Services and Mental Health Services accordingly.

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

- The development of best practice which has been happening in recent years in many services needs to be replicated throughout the system.
- In the first instance, people should always be treated as rights-bearing individuals and the label 'intellectual disability' should not be used to define or limit these rights.
- The focus should always be on maximising capacity rather than focusing on deficiencies in agency or ability.
- Service providers should at all times be publicly accountable and thus be open to external voices e.g. independent advocacy.
- People with an intellectual disability should at all times be treated with the respect that should be afforded to all human beings – the right to privacy, the right to protection under the law and the right to bodily integrity.
- Training and team building led by senior management needs to be embedded in care settings.
- A culture of responsible whistle blowing needs to be actively promoted and appropriate safeguards for staff so doing put in place.

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

- A stronger focus on needs assessment and participative and supported decision-making
- Easy access to independent professional advocacy
- A stronger focus on meaningful quality of life in residential care facilities as distinct from standards compliance
- A more targeted approach to personal outcomes planning and related individual plans across the board but particularly for people with more profound disabilities

- Closer monitoring of progress by management

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

- There needs to be stronger linkages between the HSE, disability service providers and local authorities in respect of developing innovative responses to independent community living.
- More is required in enabling young adults with an intellectual disability to make the transition from education to employment and/or meaningful social roles.
- The local community social infrastructure, e.g., sports, drama, dance, music, health/fitness, could potentially offer much more to people with an intellectual disability – this potential needs to be actively explored at local level and local communities need to more involved in this regard.

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?

- The links between education and support services need to be strengthened significantly.
- Collaboration between HSE disability services and NGOs providing specific services may be underdeveloped – this refers in particular to assessment of need and delivering related service statement requirements.
- The provision of therapies may sometimes fall short because of a lack of clarity on the part of the end-user/family of where the responsibility for providing the service lies - HSE or NGO disability service provider.
- Linkages between HSE, local authorities and NGOs need to be strengthened in respect of housing provision for independent living.

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

- Appropriate educational and awareness programmes relating to abuse and neglect should be delivered on an ongoing basis using best practice educational and communication tools.

- Safe spaces should be available to people to talk about issues of concern relating to any matter. Ideally, there should be an appropriately skilled 'outside' person available for this purpose.
- There should be active involvement of an independent advocacy service in all residential care settings.
- Independent advocates should have as part of their remit a rights safeguarding role within which they have a watching brief role and act as witness/observer and adopt a non-instructed advocacy approach where deemed necessary.
- All disclosures of abuse or suspected abuse and neglect should be documented and referred to the appropriate body, e.g. HSE, HIQA .
- HIQA should adopt an approach of proactively exploring how services deal with actual or alleged abuse and neglect and assessing the adequacy and appropriateness of the measures in place.
- Service managers have a particular responsibility to ensure that there is adequate monitoring and surveillance and that all members of staff operate to the highest ethical and professional standards in their interactions with residents.
- All staff should be aware of and adhere to protocols for dealing with actual or alleged abuse by other staff members.
- All injuries, bruising , cuts and abrasions no matter how big or small should be documented on residents' files, reviewed by senior management on a regular basis and where bruising/injury occurs which has not been explained , an appropriate investigation carried out.
- There should be a reporting system which provides for the recording of any changes in behaviour on the part of individual residents taking into account a range of indicators – avoidance of a particular staff member, sleep disturbance, changes in daily routine, changes in appetite, unusual passivity/withdrawal, inadequate explanation of how injuries occurred.

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

- More focus on diet, exercise and opportunities for creative engagement and expression – music, art, drama;
- Raising awareness amongst people and their families as regards good health practices;

- Working with people, individually and collectively, to enhance their understanding of a healthy life-style;
- Access to physiotherapy, occupational therapy, speech and language therapies and psychological supports commensurate with assessed need in relation to these supports;
- Provision of access to social activities that enhance quality of life;
- Optimising people's ability to self-medicate;
- A stronger focus on environmental factors , e.g., transport and communication, that impact on people's quality of life;
- A greater emphasis on the importance of mainstream social networks and the active involvement of people with an intellectual disability in community-based activities

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

- The 2012 VFM Review proposed a fundamental change in approach to the governance, funding and focus of disability services with the migration from an approach that is predominantly centred on group-based service delivery towards a model of person-centred and individually chosen supports. The implementation of this approach needs to be expedited throughout the system.
- Provision by many disability service providers for setting up Human Rights Committees (HRC) and/or Rights Review Committees (RRC) , according to which all rights restrictions imposed on service-users are expected to be noted and referred for discussion and monitoring, need to be proactively implemented in all residential services.
- There is much scope for developing the role of independent advocates to assist with supported decision-making and maximising opportunities and choices for meaningful engagement in relation to all aspects of people's lives.
- The implementation of the recommendations of the *Time to Move On* Report should take place in the context of a fully integrated provision of housing and related supports involving the housing authorities, the HSE and local disability services.
- The levels of day-to-day staff support for all residents with managing money -- collecting social welfare payments, safeguarding cash, guidance in relation to the spending of weekly income, advice giving and assessing competency in financial

decision-making – should be reviewed by all providers of residential services.

- The provisions of the Convention on the Rights of Persons with Disabilities should be reflected in policies and codes of practice.
- There should be more hands-on involvement by managers both to ensure that quality standards are maintained and to assure residents that the person-in-charge is looking out for their welfare.
- Key workers for each resident should be easily accessible to the individual, the family, friendship networks and independent advocates and should have a real presence in the person's life.
- Managers should identify core areas of training and professional development and ensure that all staff meet these within specific time scales.
- Early retirement incentives should be explored for people who have been working in residential care services for many years and who may not wish or be able to develop new approaches to their support and caring role.

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

- Staff selection procedures should be fair, consistent and transparent in accordance with best recruitment practice.
- Job descriptions should accurately and comprehensively reflect the tasks and responsibilities involved in the role with particular reference to ensuring that all of the human rights of people with an intellectual disability are protected;
- The skills, experience and qualities which staff are required to have should be such as to reflect a rights-based approach taking into account social needs as well as medical needs.
- Appropriately qualified people (both internal and external) should be involved in the recruitment and selection process.
- All posts should be publicly advertised in order to maximise the potential to find the right people from the widest possible field.

- The selection process followed, including both the outcome and the reasons for decisions made, will be fully documented.
- People with an intellectual disability, their relatives and/or significant people in their lives should be involved in the selection process.

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?

- There should be clear and publicly available policies and operational guidelines covering all areas of care and support which are reviewed on an ongoing basis.
- There should be a range of opportunities for engagement and consultation (focus groups, working groups and issue-based committees) involving service recipients, their families and relevant professionals.
- Feedback should be provided in respect of actions taken as a result of these forums.
- All service providers should carry out an independent review of their operation and have transparent mechanisms in place for implementing proposals arising out of such reviews.
- Unannounced HIQA Inspections should be carried out more frequently.

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

- Staff need to receive ongoing education/training which enables them to continually examine and evaluate their own values, attitudes and ways of communicating with individuals and groups. This education/training should have at its core the following principles:
 - Respect for each individual
 - Protecting people against infringement of basic human rights (e.g., privacy and bodily integrity)
 - Involving individuals in all decisions that affect them directly or indirectly
 - Modulating risk through the provision of appropriate supports

- Residents, individually and collectively, should have access to an advocate or support person skilled in communicating with people who have a cognitive impairment.
- Enhanced mechanisms are required to ensure that individual care and support plans are truly reflective of people's needs and aspirations and that implementation of these plans is done proactively.
- All staff in residential care facilities should be aware of, have some understanding of, and receive ongoing training in:
 - Safeguarding Vulnerable Persons at Risk of Abuse: National Policy & Procedures (HSE)
 - HSE National Consent Policy
 - HIQA Guidance for Designated Centres, Restrictive Procedures
 - The Assisted Decision-making (Capacity) Bill which includes provision for supported decision-making
- More provision needs to be made for external support for staff to ensure best practice in both self-care and carrying out their support and caring role.
- More education/training around the nature of intellectual disability and its manifestations and different ways needs to be available to staff on an ongoing basis - Key to this is an understanding of the difference between the social model of disability and the medical model.

CONSULTATION QUESTION 17: Is there anything else that you would like to comment on, specifically something that you would wish the Review Team 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 (please see below).

The provision of support to people with an intellectual disability, whether in the community or in residential care facilities needs to be clearly located within a rights-based framework which includes:

- Making provision for people's right to self-determination
- Supporting people in responsible risk-taking and decision-making accordingly
- Maximising capacity across a range of domains of living
- Meaningful social engagement

There are a number of policy options that have been already been identified which, if implemented fully, would make a significant contribution to addressing some of the core issues identified. These include, in particular,

- The Move from Congregated Settings
- The Individualised Funding Model
- The National Housing Strategy for People with a Disability

There is a need to enhance the role of independent advocacy services in residential care facilities so that advocacy becomes an integral part of the service and support infrastructure. This would include all individuals having access to an advocate, advocates working more with residents' groups and residential care staff and managers working in a fully collaborative manner with advocacy providers. There are some examples of good practice in this regard that have been developed by NAS and by organisations working with older persons – Sage, the Alzheimer Society, Cork Advocacy Service and, in Northern Ireland, Age NI Advice and Advocacy Service.

The importance of community connectedness for people in residential care facilities cannot be overstated. There is thus a need for the development of a range of initiatives to enable this. The situation at present where many people with an intellectual disability in residential care facilities are supported only by people who are paid to do so or by family members (where the latter are available and involved) needs to be addressed.