

The Alcohol Forum



Challenging & changing Ireland's problematic relationship with Alcohol

1. The Alcohol Forum

The Alcohol Forum is a national charity that provides support, information and services to individuals, families and communities impacted by alcohol harm, while working at a wider level to change Ireland's problematic relationship with alcohol.

2: Alcohol-Related Brain Injury

Long term excessive consumption of alcohol has a harmful effect on almost all organs in the body. While the impact of alcohol on the liver, heart and the gastro-intestinal system are widely referenced in national discourses, alcohol's impact on the brain has traditionally received little attention in Ireland. Alcohol-Related Brain Injury (ARBI) describes a clinical syndrome due to structural and functional brain changes which occur as a consequence of chronic, heavy alcohol use. There is no single cause of ARBI, which usually results from a combination of factors - these include the toxic effects of alcohol on brain cells, vitamin and nutritional deficiencies, head injury and disturbances to the blood supply to the brainⁱ.

The common characteristics of ARBI are disorders of cognitive functions, which interfere with the individual's ability to lead an independent life. These may include problems with memory, attention, planning, judgement and processing new information. In addition, change of personality and behaviour are commonly associated with ARBI. Thus, the affected individual may become apathetic, unmotivated, neglectful of personal care or disinhibited and impulsive.

As a result of comorbid brain injury and addiction issues, people with ARBI can be exposed to risks to their health, safety and wellbeing including poor mobility, exacerbation or neglect of medical comorbidities and falls and traumatic injuries. They may be subject to external risks such as assault from others, domestic fires and road traffic accidents. They can be vulnerable to both financial and physical exploitationⁱⁱ.

Despite these vulnerabilities, individual characteristics and circumstances result in many people with ARBI becoming socially excluded from both their families and services, leaving them with no natural advocates or support systems, further compounding the persons deterioration.

ARBI tends to affect people in their 40s and 50s, with females presenting a decade younger than males. Approximately 25% of people presenting with severe ARBI will be left with significant brain injury requiring long-term care. Over 75% of people with ARBI can achieve different degrees of recovery when the right supports are provided.

Current Context

Lack of experience in the assessment of this type of brain injury, the pervasive stigma associated with long-term alcohol misuse and the lack of understanding by health professionals mean that the condition is rarely identified by clinicians with up to 80% of people affected being diagnostically missed. Consequently, this hidden problem is reflected in the absence of any national policies or strategies, standards of care or established pathways of care across the Republic of Ireland for this client group.

It is widely recognised that the needs of people with ARBI span the boundaries between many services and professional disciplines: social care, mental health, dementia, acquired brain injury, neurological conditions as well as addiction services.

People with ARBI require well-integrated care in the community, which presents significant challenges to a health and social care system that is increasingly fragmented or 'siloed'. This fragmentation often results in poor, or in many cases, no provision for people with ARBI.

- **Many addiction services will adopt a policy of individual responsibility.** Alcohol treatment services in Ireland are currently established in a fashion that meets the needs of those who recognise they have an alcohol problem - that is, the will and motivation to stop drinking has to be somewhat evident so that work can progressⁱⁱⁱ. Many people, because of the impairments associated with their brain injury are not able to recognise that they have an issue with alcohol and may fail to engage or benefit from this approach when it is offered in isolation of other multidisciplinary approaches.
- **ARBI falls outside of the remit of many neuro-rehabilitation and mental health services in Ireland:** Currently ARBI is not recognised under national disability, neurological/ neuro-rehabilitation or mental health policy or strategy. Consequently, people affected by ARBI receive little or no input from professions and services which will be crucial to their over-all rehabilitation, ongoing support and/or recovery.

In the presence of these dual barriers, people affected by ARBI are recognised as a group who are '*passed between pillar and post*', '*falling between all stools*' and existing as outcasts from the services they require most.

The continued neglect and burden of this condition is becoming increasingly evident internationally with ARBI now accounting for:

- 10%^{iv} of the dementia population and for 12.5% of dementias in people under the age of 65^v.
- 21% of homeless hostel dwellers^{vi}
- A 6 million euro burden to acute hospitals in the CHO1 area between 2012-2016
- Alcohol problems and alcohol-related cognitive impairment are hugely over-represented in acute hospital in-patients who are hard to discharge and contributes to lost bed days^{vii}.
- An average long-term care cost of one million euro per person affected
- Decades of life-long disability for the individual.
- Families who suffer through the emotional turmoil of watching a loved one deteriorate cognitively, psychologically, physically and functionally over a period of many years without support.

The Case for Rehabilitation in Alcohol-Related Brain Injury

There is now considerable international evidence to support the case for prioritising Alcohol-Related Brain Injury service development. This evidence hinges on two critical factors

It works: The financial implications for health service providers and commissioners are self-evident and consistent across the research^{viii}.

85% reduction in hospital bed day usage

75% of affected people can be supported to live in non-institutional community settings.

90% of supported people maintain abstinence in the long run - improved health and social well-being

10% relapse rate into further alcohol use

10% mortality rate.

It represents good value for money: ARBI service provision in different sites have demonstrated the high benefit-cost ratios and rates of return for this population.

The Alcohol Forum in Donegal has employed one case coordinator for Alcohol-Related Brain Injury:

- As a result expenditure at **Letterkenny University Hospital was €853,551 less than Sligo University Hospital and €703,566 less than Cavan General Hospital** in responding to this condition between 2012-2016.
- Letterkenny University Hospital used 939 less bed days over 5 years in responding to ARBI, despite having a comparable number of cases to both Cavan and Sligo hospital – **the equivalent of freeing up one hospital bed for 2 and a half years.**
- In Donegal, we have demonstrated that the amount saved by using best practice in just two ARBI cases was €1,994,071 over the course of their lifetime.

The Alcohol Forum has recently applied through the SlainteCare Fund for the expansion of this service to extend the cost saving to 4 additional counties – Sligo/Leitrim and Cavan/Monaghan – to facilitate the early hospital discharge of clients from both Cavan General Hospital and Sligo University Hospital whilst working proactively in the community to promote recovery and prevent readmission.

Recommendations

We propose the following recommendation and seek the support of the Department on Health in ensuring its implementation:

- 1) The establishment of a multidisciplinary cross directorate national working group on Alcohol-Related Brain Injury who's function would be:
 - To provide a forum for greater coordination and integration between services areas in relation to ARBI nationally by involving a range of cross directorate stakeholders, service users and their carers and international experts in the process of discussion, with a view to seeking consensus as to the way forward.
 - Provide guidance, leadership and proposals to the Department of Health on the clinical configuration of care pathways and service responses for this group across the Island of Ireland.

3. Fetal Alcohol Spectrum Disorder

Pre-natal alcohol exposure is the leading cause of preventable intellectual disability in the world. Fetal Alcohol Spectrum Disorders are brain-based impairments resulting from pre-natal alcohol exposure that affect one million babies born across the globe every year. Primary manifestations of the teratogenic effects of alcohol are demonstrated by changes in brain structure and / or function. Children and adults with FASD can experience behavioural deficits, difficulties with regulation of mood or behaviour, cognitive deficits, impaired executive functioning. Longstanding research shows that people with this condition are likely to face serious difficulties across their lifespan:

92% will receive a formal mental health diagnosis
60% experience trouble with the law
50% have a history of confinement in jail, residential drug treatment facility or psychiatric hospital
Estimated that 30% of global population of children in alternative care have an FASD
61% of children and adolescents with FASD have significant school disruptions

428 co-occurring conditions have been identified from 127 studies of children impacted by pre-natal alcohol exposure (Centre for Addiction and Mental Health, 2016), including central nervous system dysfunction, epilepsy, heart defects, compromised auditory function and compromised immune system.

Prevalence in Ireland: In an international review last year, Ireland featured as one of the five countries with the highest prevalence of Fetal Alcohol Syndrome (the most severe end of the FASD spectrum, with the greatest alcohol effects including physical malformations). It is estimated that 600 babies are born with Fetal Alcohol Syndrome each year in Ireland and 40,000 Irish persons are living with the condition. If those estimates are correct, the numbers of those impacted by FASD (ranging from mild to severe) could be ten times that number as international evidence indicated that for every case of FAS there are at least 10 cases of FASD.

Case for Clinical Guidelines and Diagnostics: There has been progress in relation to FASD prevention here in Ireland with the appointment of a national clinical lead in the HSE and the establishment of the HSE FASD Sub group of the AIG. The role of that group relates to prevention, education (leaflets, posters, training), care pathways and screening for pregnant women and evaluation of interventions. The HSE group, however, has clearly indicated that their role is 'not diagnosis' and 'not care and intervention for cases and families'. Ireland currently lacks diagnostic capacity and currently no intervention and/ or care pathways exist for individuals with FASD and their families. Development and adoption of clear diagnostic criteria will assist clinicians in assignment of more accurate diagnoses of FASD and will lead the way to more widespread early intervention and improved prevention efforts (Hoyme, 2016)

- Early diagnosis of FASD is associated with fewer adverse outcomes later in life and is critical for improving quality of life
- Although FASD is a permanent disability, with the implementation of early intervention strategies and supports, there is considerable potential to reduce the development of adverse consequences and associated costs. Diagnosis supports identification of developmentally appropriate interventions by health, education, and social service providers.
- The importance of supporting diagnosed individuals and their families throughout the lifespan is also critical to achieving and maintaining successful outcomes.
- Over their life time, the Canadian Federal Government estimates it costs taxpayers the equivalent of 1.2 million Euros (\$1.75 m CND) extra for every person born prenatally alcohol exposed. International evidence indicates that savings are to be achieved when early diagnosis and intervention and family support are available.

Recommendations

1. We propose that clinical guidelines for diagnosing FASD are developed and adopted here in Ireland. We recommend that a multidisciplinary working group is established to propose clinical guidelines for diagnosing FASD. We ask that this committee would ask that the Minister of Health establish such a committee.
2. We recommend the involvement of families and advocacy organisations (Alcohol Forum and the eND-PAE Alliance Ireland) in that multidisciplinary group.
3. FASD should be linked with Government efforts to improve mental health; stakeholders including Tusla and mental health services should be engaged.
4. Research on FASD in Ireland (prevalence studies, needs of families) is required.
5. We further recommend that the eNDpae Alliance Ireland be invited to present to this group to ensure that the needs of families are central to further developments in this area. With support from the Alcohol Forum, this group, which now has a membership of 40 has just completed the first ever survey of families impacted by FASD in Ireland. We recommend that a future opportunity be created for that work to be presented before the Health Committee.

References

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