

Submission COVER PAGE(s)

Sent on behalf of the **Galway Disability Forum** and **people with disabilities and their families living in North West Connemara**

by:

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Outline of why we are making the submission: Members of the **Galway Disability Forum** and **people with disabilities and their families living in North West Connemara** anticipate that many real changes will be bought about as Ireland sets out its work to implement the UNCRPD. The Forum have collectively contributed to this submission and look forward to working in partnership with the Joint Committee going forward. Specifically, the Forum intend to highlight the experiences and issues affecting people with disabilities **living in County Galway** in this submission. This Forum would like the Joint Committee to be aware of these issues and take appropriate actions to address these. The Forum would like the issues contained in this submission to be reflected in the Joint Committee's Terms of Reference

Would be willing to appear in public session at a committee meeting: **YES**

About the Galway Disability Forum:

The Galway Disability Forum is a newly formed group which was established in response to the feedback received when the Galway County Public Participation Network¹ organised a Make Way Day event in September 2020 in conjunction with the Disability Federation of Ireland. At the event, Minister of State with responsibility for Disability, Anne Rabbitte, T.D., addressed this group and presented at its subsequent inaugural meeting, the launch of the Galway Disability Forum, in October 2020.

Individuals with disabilities, carers, family members of persons with disabilities and those providing services for persons with disabilities constitute the Galway Disability Forum. The aim of the Forum is to improve the lives of persons with disabilities **residing in County Galway** by driving real change on those issues of common interest and concern which have arisen in discussion and debate at our regularly attended meetings. The Forum seeks to plan and coordinate actions that actively addresses these same issues of interest and concern.

The Galway Disability Forum includes representatives from a group of people with disabilities and their families living in North West Connemara. This group have provided 3 illustrative case studies that highlight the experiences of people with disabilities living in County Galway and which reflect what is noted in this submission.²

The Galway Disability Forum commend the Committee for its initiative in involve people with disabilities in the development of policy and legislation in a more meaningful way. The Galway Disability Forum welcomes the opportunity presented by the Joint Committee to impact upon the formulation of its Terms of Reference (hereafter TOR) by describing the lived experiences of people with disabilities in County Galway. Basing the TOR on the submissions received ensures that the future work of the Committee is best suited to address the issues that concern people with disabilities, their carers and providers of disability services in County Galway.

¹ The Galway County Public Participation Network is a network of over 960 community and voluntary groups in County Galway. Since the Local Government Reform Act of 2014, PPNs have been established to ensure that the voice of the community is heard in local policy making. Each Local Authority must engage with its PPN as the primary means with which to support, communicate and consult with community groups.

² Report by Jean Mullen on the the lived experiences of people with disabilities and their families living in North West Connemara.

Area of expertise:

As part of the Public Participation Network, the Galway Disability Forum is a community group which comprises experts with long standing and vested interests in **inclusive and participatory community development**. The Galway Disability Forum comprises a diverse range of individuals with different needs. Each member is an **expert by experience** and takes part in the Galway Disability Forum as a **self-advocate**, a **natural advocate** for a loved one or an **advocate on behalf** of persons with disabilities. The Galway Disability Forum therefore represents the voices of individuals with disabilities and their carers who are experts by experience; professionals who are aware of the issues concerning people with disabilities because they provide direct services to them; and elected members of the community, including Councillors, whose role it is to address the needs of all of their constituents.

Factual information:

According to data gathered as part of the 2016 census, in **County Galway 12.6% of people live with a disability**.

The Galway Disability Forum welcome the opportunity to hear about the lived experiences of persons with disabilities and their families as, according the National Ability Supports Systems Bulletin of 2019 (which replaces the former National Intellectual Disability Database Report) issued by the Health Research Board, most people registered with the NIDD **reside with family members** (67% of a total of 22,434 services users registered on the Database). This indicates that **people intellectual disabilities, predominantly, live at home** and are cared for by their families.

Substantive points:

Education: Members of the Forum wish to highlight the segregation of children with disabilities from and within mainstream schooling. From the Forum members' experiences, a major barrier to the full inclusion of children with disabilities in the classroom is the prevalent presumption that their inclusion would negatively impact upon the progress of children without disabilities. It is therefore important that the work of the Joint Committee address this misinformed prejudice via a **public awareness campaign** and dispel such myths. Article [24 UNCRPD](#) highlights how important inclusion in education is and should be adopted unreservedly and supported via a public awareness campaign.³

Ireland goes a long way back in terms of commitment to the right to education of its citizens.⁴ Ireland ratified the UN Convention on the Rights of the Child in 1992 and has a duty to ensure its fully implemented. The [UNCRC notes in Article 23](#) that it is 'specifically concerned with disabled children, in recognition of their vulnerability to segregation and discrimination'. Accordingly, the Article urges States Parties to recognize the rights of children with disabilities to a full and decent life and to special care.

The Irish Government has been proactive in adhering to international instruments intending full integration and rejecting discrimination on any grounds. To that effect, the State has introduced legislative measures aiming at ensuring the implementation of their international committees.

Crucial for the achievement of inclusive education is the [Education for Persons with Special Educational Needs Act 2004](#) which aims to achieve inclusive education and assess and address special educational needs. The EPSEN Act 2004 cannot function separately from the legislation already established and must be considered in conjunction with the current legislative framework for education in Ireland. Beginning

³ in particular, 24(2)(b) determines that persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live.

⁴ The Irish government was represented at the 1994 World Conference on Special Needs Education, together with 92 other participating States. At the Conference, the 'Salamanca Statement' on the right to education of children with disabilities was agreed calling for inclusion and integration to be rule and adopting a Framework for Action. Moreover, the Conference adopted a Framework for Action establishing some guidance on the kind of aims that were to be achieved for the implementation of the Statement, declaring: 'Ordinary schools should accommodate all children, regardless of their physical, intellectual, social, emotional, linguistic or other conditions. All educational policies, says the Framework, should stipulate that disabled children attend the neighbourhood school 'that would be attended if the child did not have a disability'.

with the Constitution's right to education and including all the international instruments adopted by this jurisdiction.⁵

Ireland has seen some development in terms of legislative measures, yet these regulations have not been translated into improvements on the ground. Families, children and advocates continue to suffer due to ongoing challenges. Nevertheless, The Galway County Disability Forum welcomes the commitment of Minister for Children, Disability, Equality and Integration and Youth, Deputy O' Gorman, and specifically applauds the Minister statement to the Oireachtas Committee on the 3rd of November last:

'One of the Department's key priorities will be to advance the implementation of the UNCRPD. Our approach to meeting the terms of the Convention is one of progressive realisation. What this means in effect is that work is continuing apace on the reforms needed for an optimum level of compliance with the convention's requirements. As we continue to advance the implementation of the convention, it is vital the Government hears the voices of persons who have lived experiences of disability. The experiences and perspectives of people with disabilities are paramount in developing policies and programmes that directly address the real needs in their lives'.

We fully agree with the Minister.

In the words of a Forum member:

'What do we mean by Education? By Education do we mean the driver towards cultivating a happy and 'successful' life. If so, greater pathways to life-long learning opportunities are necessary whereby the person with a disability may decide to retrain at different junctions of his or her life. However, the path to an NFQ level 7, 8, 9 or 10 qualification starts at primary school. Primary school is often where the child with a disability can first encounter othering, bullying, exclusion, isolation. It is important therefore that the primary school environment is prepared to meet the needs of a child with a disability. Unfortunately, there remains a degree of 'winging it.'

Preparation should begin at Teacher Training College and the Forum, along with other fora would like to open dialogue with the various Colleges of Education around the country towards the teaching profession, in general and, in particular, trainee teacher's perceptions and attitudes towards disability. For persons with a disability (namely the present writer) the career goal from a school going age was simply to be 'not disabled.'

⁵ The implementation of the EPSEN can only be achieved when operating simultaneously with other regulations, i.e. the Education Act, 1998, the Education (Welfare) Act 2000, the Equal Status Act 2000, as amended by the Equal Status 2004 and the 2018 Act and the Disability Act 2005.

This attitude seems to be common, from anecdotal experience, and suggests that the Disabled Community sets itself very limited goals from an early age contrary to the role of education as a ‘feeder of dreams.’ As a consequence, it is the view of the Forum that all second level schools and colleges should take a more proactive approach in engaging with learners with a disability. To achieve this the Forum recommends the provision of a more enlightened and informed career guidance service in order to assist learners with disability maximise their full potential. This revised approach should be ‘fit for purpose’ and to incorporate the services of specially trained Occupational Therapists and other ancillary health professionals. Hand in hand, with this approach is a greater involvement with the young learner and counselling services in the educational context. Greater guidance on issues arising from being othered, bullying, exclusion, and/or the difficulties a young mind may have with coping with a physical disability is necessary to engender positive mental health in a young learner with a disability trying to navigate the turmoil of pre and post-pubescent school life (...).

Transport: County Galway is Ireland’s second largest county and is populated with many rural towns and villages outside of its main population centres. For many people with disabilities and their family carers this means that they need to **travel long distances** to get to services. The provision of public transport currently doesn’t reflect this reality. The service at present may be characterised as patchy, irregular, and not serving the needs of the community as a whole. It is distinctly lacking in the innovation necessary to provide an attractive 21st century service. Suggestions include, a revised timetable reflecting a night or late evening service to combat rural isolation and loneliness, wheelchair accessible mini-buses (to service smaller towns and villages) and a shuttle service to transport hubs such as existing rail stations. The Forum would therefore like to highlight the need for **increased (transport and general) service provision in rural areas**, alongside better, more connected **public transport** that is **accessible**. In addition, the Forum members would welcome greater engagement with the Taxi Regulator’s office regarding a means of incentivising a rural based wheelchair accessible Taxi and hackney service.⁶

Due to the current restrictions imposed in response to the pandemic the Forum would like the work of the Joint Committee to ensure the limited transport service provision is fully restored in the future. In general, the Forum anticipates that the Committee’s TOR include an item that **addresses the negative impact of Covid-19 on services** and aim to correct these. The Forum would also like the Joint Committee to

⁶ Whether this service should receive state subvention or subsidies is a discussion for another time.

note **the frequent mis-use of disabled parking** spaces by the general public which should be addressed in its future work with fines to enforce compliance.

The Forum would like to highlight that public transport in County Galway is still largely inaccessible for many people with disabilities. The Forum therefore call on the Joint Committee to engage with the National Transport Authority of Ireland, Bus Éireann and other relevant bodies to ensure that the **accessibility of public transport improves**. The Forum recommend increasing the existing Rural Link services. The Forum would also like to draw attention to the important work of **Independent Living Centres** across the Country, such as the **Galway Centre for Independent Living** which provides vital transport and PA services for people with disabilities and older persons. These services are entirely self-funded and receive no funding from Transport authorities. The Forum hope the Joint Committee will recognise the work of such centres and their **essential role in promoting independent living**.

Forum members also anticipate that the Joint Committee will address the fact that the primary medical cert scheme is currently suspended with no new certs being issued. This is a major concern for disabled drivers (hand amputees should be given this) and disabled passengers. The Forum hope that the Joint Committee will work to **reinstate the motorised transport grant and mobility allowance**.⁷

The Forum would also encourage the work of the Joint Committee to focus on helping disability organisations network and **develop relationships with other organisations**, such as Age Action which may be considered as natural allies in seeking to overhaul transport services in our region to meet our mutual needs.

Case Study 1 from the lived experiences of people with disabilities and their families living in North West Connemara

Issues:

- Lack of access to social/cultural activities
- No assisted IL facilities
- Distance to access appointments in Galway
- Lack of transport options

‘Roisín is in her thirties, has an intellectual disability and lives with her parents in a very rural part of the country. She attends a very well-run day centre but as numbers are small, access to many social activities is limited. She would love to take part in more

⁷ especially for those persons with disabilities who may require the benefits of this important scheme and to ringfence and secure these provisions for those already in the scheme.

drama, dance and music activities but is very restricted by distances to larger towns where such activities are available.

If there was a managed and completely funded bus available (tax, insurance, maintenance and driver paid) so that Roisín and her peers could expand their horizons, it would make a difference to their lives.

Roisín had hoped to be living in an assisted living complex at this stage of her life. There is no purpose-built accommodation in this area provided by the State for adults with intellectual disability, this makes it impossible for her and her family to plan for the future. Suitable housing is a basic right and providing suitable assisted living accommodation should be part of every town's planning.

We can never be sure if funding will be available for our family members with intellectual disability, we can't always reassure them that an activity started or a project begun will continue or that a time away in respite can be guaranteed, this level of uncertainty adds to the anxiety which is part of living with an intellectual disability'.

Possible solutions:

- local rural bus service, as mentioned above. There are already bus services to facilitate older people to attend day centres. Look into possibility of making one available to people with disabilities at certain times.
- Assisted living centres could be set up in rural towns using the model of Cluid.
- Local people and groups providing drama and dance classes should be funded.
- Locally based therapies and services should be promoted and funded. [Connemara Therapeutic Riding CLG](#) was set up 5 years ago near Clifden to provide a therapeutic riding service. Government support would be greatly appreciated.

Independent Living: Rural County Galway has very few if any, assisted living facilities. There needs to be more living facilities for people with disabilities besides those for older people. The Forum suggests that the Joint Committee aim to achieve that 7.5% of all new builds are provided to disabled people in mixed tenure social housing projects. The Forum would like to draw attention to **good housing models** such as [CLUID Housing](#), which could be expanded to focus on the need for housing for people with disabilities which promotes social inclusion and independent living in accordance with [Article 19, UNCRPD](#).

The Forum anticipates that the work of the Joint Committee promotes the idea and awareness that new builds in County Galway be designed beyond existing part M

requirements, following the [IWA's Best Practise Guidelines](#), promoting lifelong accessibility. This would recognise the fact that the majority of disabilities are acquired during a person's lifetime. The Forum would also suggest that Joint Committee promote a more assiduous policing of building regulations to include punitive penalties and fines regarding new builds in the public commercial realm vis-à-vis, accessibility particularly in terms of primary points of ingress, secondary doorways, steps and ramps and the elimination of obstacles that hinder or prevent the inclusiveness of persons with disabilities.

Members of the Forum also wish to draw the Joint Committee's attention to the need for improved and increased funding to support independent living so that person with disabilities can live on their own. The current process for receiving allowances and grants that are intended to help people live independently is burdensome. In many cases, obtaining the Occupational Therapist's report required to obtain these grants can take weeks/months. On a practical level the Joint Committee must work towards **speeding up this process** and increasing the **efficiency of the HSE** in this respect. Moreover, the Forum highlight that an **increase for Housing adaptation grants is needed to reflect current building costs** as set levels have not changed for 12 years. Testing criteria needs to be reviewed and income thresholds should be raised to reflect the costs of disability on families. The Form also hope that the Joint Committee can address the need **for timely access to the funding** given that many conditions can deteriorate / occur rapidly.

Case study 2 from the lived experiences of people with disabilities and their families living in North West Connemara

Issues:

- Lack of childcare
- Lack of respite
- Distance to access appointments in Galway
- Long waiting lists for assessments and resources
- Lack of access to professional help/advice by phone
- High turnover of professionals

'I am a widowed mother with two boys (aged 12 and 13) with extra needs (12-year-old has autism). No childcare. Here are the issues facing us:

How do I attend appointments in Galway which are 4 hours away (return) and be back in time for my other son? Usually have to take both kids with me and therefore miss a very valuable day of school and respite.

Long waiting lists for assessments and for resources that are not there. Doesn't encourage me to apply for supports. No respite to teach my child independence skills and enable me to go to normal activities with my other child which he really needs for his development. Therefore, affecting his future skills. No respite due to lack of families with home support.

No immediate help or advice on the other end of the phone. All professionals very good but change regularly no consistency'.

Possible solutions:

- Need to rationalise provision of speech therapists, OTs, psychologists etc. who are currently employed by a myriad of services eg Brothers and Sisters of Charity, Ability West etc. A rota of visits by professionals to outlying towns and villages in the county should be set up as it much easier for them to travel.
- Need to recruit more people to provide in home respite for exhausted parents.

Locally based community groups like [Lámh Linn](#) provide support, advocacy, and social activities for people with disabilities and their families. Government funding without a huge amount of bureaucracy and insurance costs would help.

Personal Assistants: The Galway Disability Forum is concerned that there is a growing, unmet need of **access to PA hours** on behalf of persons with disabilities which is not addressed in the 2021 Budget. The current levels of funding in CHO2 are not adequate to meet the demand of PA services. The current levels of Home support / Home help only address the minimal, very basic care needs and are insufficient in ensuring that people with disabilities are able to lead independent lives. The Forum hope that the Joint Committee will address this urgent impasse, addressing the current expectation that family carers 'look after' their adult children with disabilities. Members describe scenarios where a lack of PA services mean that people

- Reside in acute hospital settings (sometimes for years due to complex medical needs)
- move to a nursing home
- are unable to maintain homes in the community
- are compelled forced to move to residential settings accommodation,
- are unable accept an offer of social housing from their Local Authority.

The Forum would also like the Joint Committee to work on ensuring that **older people with disabilities** should not **lose PA and other supports after they reach retirement**

age. Moreover, the Forum welcomes the 6 new respite houses Minister Rabbitte has mentioned for 2021, but wish to highlight that respite should also be available in a person's home (to accommodate a carer's break) including nursing, PA and overnight support.

Employment: Having a job is recognised by the Forum as being central to be accepted, included and has many benefits including mental stimulation, socialisation, self-actualisation and material wealth. There are many reasons why persons with a disability are excluded from the workplace. That said, they are not insurmountable reasons. The Joint Committee can assist by **supporting and actively promoting the work of Employability**, a semi-state disability employment agency. Allied to this, the Forum would like to see **greater incentives** for the Multinationals and SMEs located in county Galway to employ persons with disabilities. These can include greater tax breaks and/or improved wage subsidies than those in place and not already working. The Forum would also like to see actual positive incentives for disability employment quotas to be met and that these **quotas be extended** from the public sector to also include the private sector.

The Galway Disability Forum would like the Joint Committee to finally address the so called 'benefit trap'. Many people with disabilities who go back to work **lose their medical card** and therefore prefer to stay out of the labour market. The Joint Committee must therefore work with the DEASP to **individualise services and benefit packages** for people with disabilities to better reflect the supports required to live full and inclusive lives.

In addition, the Forum suggest that the work of the Joint Committee to encourage engagement with the local employment offices, Employability, the ETBs and other interested organisations to develop retraining schemes and greater assistance for persons with disabilities who wish to set up their **own businesses**.

Case Study 3 from the lived experiences of people with disabilities and their families living in North West Connemara

Issues:

- No assisted IL
- No social network
- No employment
- Distance to access appointments in Galway

'K is 31 and was diagnosed with Asperger's syndrome and a mild learning disability at the age of 13. She has no friends, no social activities, no job and lives with her parents in Northwest Connemara, a remote, rural area.

Positives in her life: She spends 2 days a week at the Elm Tree Centre in Clifden. This is a day centre for people with mental health issues. They run crafts/ cooking / pottery / art classes, IT classes and provide sessions with a psychotherapist and life counsellor. An HSE psychiatrist and psychologist visit the centre one day every 2 weeks and are available by appointment to the service users. K is a volunteer at Connemara Community Radio where she works as a sound technician and a DJ.

K would love to have paid employment. She has been registered with Employability for over 2 years. This service does not live up to its remit. The staff lack an understanding of disability issues and the supports needed to facilitate the employment of a person with a disability. Likewise, potential employers are not well informed. Govt needs to facilitate staff training and mandate disability awareness training for employers seeking to avail of financial incentives provided.

There are no assisted IL centres suitable for her in this area or Galway city. Most of the focus around IL is on providing accessible accommodation for people with physical disabilities with personal assistants. Would need support worker available 24/7 and access to additional psychological / healthcare supports, social activities, etc. on a regular basis'.

Possible solutions:

- Access to an IL centre either locally or in Galway city.
- More robust Employability-type service with more incentives for Employers willing to employ people with disabilities and more disability awareness training for agency staff and potential employers.
- Expansion of services like [Elm Tree Centre](#) especially for young people with disabilities. Most of their current service users are 50 +.
- Extension and expansion of the [Ability programme](#) which is currently being piloted nationwide. Forum Connemara has led this initiative for young people aged 15 – 29 years living in Connemara. It has been a great success in promoting positive pathways into training, education, voluntary opportunities and work experience. There is a huge **lack of services and support for young people with disabilities over the age of 18.**

Services: The Galway Disability Forum members note that for many children and young people with disabilities there are no services at the weekend and a lack of social and cultural activities. This leaves many with nowhere to go or nothing to do at the weekend. Moreover, the members note that the **quality of the disability services** and activities needs to be addressed by the Joint Committee to avoid these consisting simply of, '**trips to the local McDonalds**'. The Forum members work particularly towards ensuring that people with disabilities are included in **mainstream spaces**, such as regular sporting clubs, rather than having separate clubs which keep them segregated. The Forum urge the Joint Committee to address the lack of services at the weekend and also monitor the activities on offer by service providers to ensure they are **personalised, meaningful** and aim to **include people in mainstream society**.

The Forum believe that the planned move of, 'disability services' currently under the auspices of the Department of Health, to the Department of Children, Disability, Equality, Integration and Youth is an opportune moment at which to address the **underlying deficits in disability service** provision at regional level. The Joint Committee must work with the HSE and CHOs to improve the provision of services. The Forum highlight that **additional funding for service development at local level is required** to improve accessibility, inclusion, person centred disability employment. The planned move is also an opportune moment to consider disability issues from culturally and linguistically diverse perspectives and with the needs of diverse communities in mind.

The Forum also wish to highlight that **Local Authorities provide many services directly to citizens and these must therefore be identified** by the Joint Committee as **key partners** in implementing the UNCRPD. The Joint Committees' TOR must include an action to centrally involve and engage with Local Authorities. This is essential to ensure that change is felt at local level and practically implemented.

Accessibility: Accessibility issues are a major concern for the Galway Disability Forum. The Forum hope that the Joint Committee's work will focus on achieving better accessibility in rural towns and villages. This includes accessible footpaths, crosswalks and better lighting. Greater physical accessibility will enable people with disabilities to live on their own and move freely. The Forum anticipate that the Joint Committee will work to support practical, accessibility projects such as **accessible toilet facilities** that include **changing places** that are **open 24/7**.

Members of the Forum experience **significant difficulties, arduous bureaucracy** and red tape when **attempting to implement small, practical changes** around the County to improve the lives of persons with disabilities. The Joint Committee should therefore include an objective to facilitate **small scale, ‘on the ground’ projects to be carried out with minimal administrative burden**. The Joint Committee must work with Local Authorities to increase accessibility when implementing all/any projects and have a dedicated team that specifically works to **mainstream disability issues within all departments of each Local Authority**.

Parks and playgrounds in County Galway are often inaccessible. Forum members note that the ‘lock down’ restrictions imposed due to the Pandemic have particularly highlighted how important it is to have access to public, outdoor spaces. The Forum suggest that the Joint Committee aim to call on all Local Authorities to **audit their recreational areas/ facilities, key routes and footpaths**. From experience, ‘accessible equipment’ such as ramps and swings on playgrounds, are costly items. To reduce the **financial burden that can hamper the development of accessible amenities**, the Forum suggest the **introduction of the exemption on paying VAT** on these items. This would significantly increase the provision of accessible infrastructures and benefit all members of society.

Monitoring of the Convention: With regard to the monitoring of the UN Convention on the Rights of Persons with Disabilities which Ireland ratified in 2018, the Galway Disability Forum suggests that the Joint Committee’s TOR must include a **mandate to assess the actions and implementations at local, county level**. This should include **reporting on behalf of the Local Authorities** to be orchestrated via the Local Government Management Authority. The Joint Committee must work to ensure that people with disabilities are included in all forums and committees across all sectors, this is vital to ensure representation and inclusion at all levels.

The Forum hope that the TOR will reflect the need to target rural areas of the Country and specially monitor the actions happening at local level. We suggest that Local Authorities, such as the County Councils and the CHOs of the HSE are tasked with compiling plans with concrete actions towards UNCRPD compliance. Galway County Council, for example, currently has no strategy, action plan or resources in place to deliver on any actions towards the inclusion of people with disabilities, nor does it have any coordinated actions to ensure the UNCRPD is implemented in its work. Local Authorities provide many direct services to people with disabilities and the wider

community; thus it is important that disability rights and issues are mainstreamed through local government to have a real impact.

Overall, the Galway Disability Forum wish to highlight the need to **link the national action under the UNCRPD with local level actions**. The Joint Committee must therefore recognise the **central role** that Local Authorities will play, otherwise no change at practical, local level will be achieved.

The Galway Disability Forum is grateful for the opportunity to participate in this consultation process and looks forward to working with the Joint Committee in the future.