

# Global Leadership Exchange Programme

in Centre for Disability Law and Policy at the  
Institute of Life Course and Society (ILAS) University of Galway.<sup>1</sup>

**SUPPORTING LEADERSHIP AND PERSONHOOD  
within the frame of the UNCRPD from emerging and long term  
personal and family networks**

**23<sup>rd</sup> – 25<sup>th</sup> June 2024**

## **Céad Mile Fáilte** **A warm welcome to all our guests!**

Welcome to Galway. We look forward to spending time learning and sharing with you over the coming days.

If you have any needs we can assist with during your time with us drop us an email at [info@inclusivelivingnetwork.ie](mailto:info@inclusivelivingnetwork.ie)

Below you will find the programme for our time together and a brief introduction to our International and Irish delegates.

### **Sunday 23<sup>rd</sup> June 2024** **Welcome Dinner**

**6.00pm** **Elephant & Castle restaurant, Dean Hotel.**  
80 Prospect Hill, Galway H91T9C4  
This is a city centre venue. Call 091749 200  
<https://elephantandcastle.ie/locations/galway/>

Traditional music will be on afterwards in a pub a short walk for those who wish to join.



### **ABOUT THE EVENT**

The GLE is a learning event held every two years to develop connections, share experiences, and exchange information to improve lives for people with disabilities and their families

Find out more at [www.gle.world](http://www.gle.world)



<sup>1</sup> Venue address: Centre for Disability Law and Policy, Institute for Lifecourse and Society, Dangan, Upper Newcastle Road, University of Galway, Galway, Ireland, H91 C7DK Directions in this link: <https://www.universityofgalway.ie/ilas/contact-ilas/>

## Global Leadership Exchange Programme Monday 24<sup>th</sup> June

### 9.00 Registration - Tea/coffee on arrival

### 9.30 Welcome – Professor Eilionóir Flynn & Willie Walsh

#### Session 1- Introductions; what I offer.

Theme - Supporting Capacity Building for Reform

### 11.00 Tea/coffee

### 11.15 Session 2 - Individualised Supports

#### Convenor: Suzanne Moloney

- Mo Shaol Mo Thuras - **Ryan Nolan and Ursula Regan**
- Brackenridge; A New Zealand Disability Support Provider Journey - **Pip Stewart**
- Views of Current Approaches to Individualised Supports in the US; Key Values in the Disability Community vs. System Restraints - **Jennifer Johnson**
- The Australian Journey - **Andrew Whitecross**

### 1.00 Lunch - Selection of Sandwiches

### 2.00 Session 3- Individualised Funding – what works

#### Convenors: Aisling Hunt & Aoife O´Toole

- “My Story” - **Paul Alford**
- The Foundations for Individualised Support - **Mary Gardener**
- Individualised supports + true personalisation = transformation<sup>2</sup> - **Karen McCormick**
- Personal Budget Demonstration Project – Leaders Experiences - **Willie Walsh**
- Inter-generational legacy planning - **Moll O´Keefe**

### 3.30 Tea/coffee

### 3.45 Session 4 UNCRPD - Personhood

#### Convenor: Dharragh Hunt

- Evolution and Importance of the Right to Legal Personhood - **Anna Arstein-Kerslake**
- Accessible Training for people with Intellectual Disability on Assisted Decision Making & the Decision Support Service - **Petria Malone**
- Realising Personhood - **Maria Walls**

### 5.15 Close

### 6.30pm Dinner Blackrock Cottage, Salthill.

See <https://www.blackrockcottage.ie>

Traditional music will be on afterwards in a pub a short walk or those who wish to join.

## Global Leadership Exchange Programme Tuesday 25<sup>th</sup> June

### 9.00 Session 5 – Supporting Decision-Making Convenor: Joe Mc Grath

- The 'Now and Next' Project - **Kylie Aekins**
- Listen Up Creating spaces for hearing the voice of disabled people - **Sarah Gimson**
- Supporting Decision-Making – A policy reform approach - **Andrew Whitecross**
- US Approaches to Decisional Supports across the Lifespan - **Jennifer Johnson**
- UNCRPD Foundational Principles - **Eilionóir Flynn**

### 11.30 Break - Tea/coffee

### 11.45 Session 6 - Round up and Conclusions Convenors: Aoife O'Toole & Maria Walls

### 1.00 Hot Lunch

### 2.30 Afternoon Informal Programme

Walking tour of Galway – time for conversations

### 6.30pm Dinner at Ard Bia Restaurant (TBC)

## Wednesday 26<sup>th</sup> June

Those going to the full GLE conference will **TRAVEL to Utrecht**

This work is made possible with Made possible, with partnership from CDLP, HSE funding and support from the Global Leadership Exchange



## Bios of International Exchange Delegates

### Kylie Aekins



Kylie Aekins has been a parent peer worker since 2018, delivering a range of peer supports and parenting programs, including the Now & Next program, to over 1,200 parents of children with developmental delays or disabilities. She is a mother of two, one of whom is autistic, and her entire family is neurodivergent. Kylie is passionate about family-centred services, mentoring, and supporting families with evidence-based, child-led, strengths-based approaches. She values learning from other parents in these empowering groups and enjoys working with her innovative team. An experienced family leader, Kylie has presented at conferences, worked on community projects to promote inclusion, and advocated for systemic change.

### Mary Gardner



Mary Gardner is an enthusiastic, highly motivated leader with work history within the private, public and voluntary sector and a change management expert. Mary has extensive experience of building quality assurance into social care environments and am currently leading a personalisation transformation programme in Sheffield. I have also arranged and directed my own support for the last 25 years, employing a team of Personal Assistants to support me in both my personal and professional life. I am a member of the Department of Health and Social Care Workforce Advisory Group, representing Individual Employers and the Personal Assistants workforce. My passion is to ensure that everybody has a say and any change comes from the collective voice.

### Sarah Gimson



Sarah Gimson is a British American who has worked internationally for disabled people since 1985. She has lifted the voices of those who are not always heard. This has happened through Person Centred Planning facilitating and training, innovative use of Individualised Funding, Supported Decision Making development and practice, Quality of Life interviews (conducting interviews, training and data analysis), and organisational change. Creating spaces for liberation, freedom to live a life designed by the person, and full expression of personhood of disabled people is her passion and life's work. She holds a BA in Psychology and MA in Human Service Management.

### Jennifer Johnson



Dr. Jennifer Johnson is currently serving as the Acting Commissioner of the Administration on Disabilities (AoD), Administration for Community Living (ACL), U.S. Department of Health and Human Services'. AoD funds programs that are changing and improving the lives of the estimated 61 million individuals with disabilities in the US by advancing opportunities for inclusion and participation in the community, employment and financial well-being, and independence and self-determination. Her 30-year career in government, academia, national organizations, and local school systems demonstrates a clear commitment to improving opportunities for people with disabilities to lead full lives in the community, with emphases on diversity, inclusion, and advancing a diverse array of programs for underserved and unserved individuals and communities. Dr. Johnson earned her doctorate in Special Education from The George Washington University.

### **Pip Stewart**

Pip Stewart joined Brackenridge as CEO in August 2014, after working in senior management roles for the Hawkes Bay, Southern, and Otago District Health Boards. Originally a Registered Nurse, Pip also holds a Master's in Business Administration (MBA) and Public Health (MPH), along with being a member of the Institute of Directors. Pip is very proud to lead Brackenridge - an organisation of like-minded people committed to delivering mana enhancing support, empowering disabled people to live great lives of their choosing. Pip believes strongly in the ability and rights of all people. She is passionate about supporting people and their families to have greater choice and control over the support they receive and the lives they lead. Originally from Cheviot, Pip enjoys a rural, outdoor lifestyle and lives with her partner Marty in North Canterbury amongst a few acres of land, full of animals and a large garden.

### **Andrew Whitecross**



Andrew Whitecross has worked as a government policy advisor for over 3 decades in social policy, primarily income support, housing and disability. He led the work to establish the NDIS Quality and Safeguards Commission and was Deputy Head of the Secretariat for the National Disability Insurance Scheme (NDIS) Review. Andrew is currently responsible for the programs to fund systemic advocacy, individual advocacy, information and capacity building programs, carer supports, and Australian Government support obligations under the UN Convention on the Rights of Persons with Disability.

## Bios of University of Galway: Centre for Disability Law and Policy and Irish Centre for Human Rights delegates

### Eilionóir Flynn



Eilionóir Flynn is an Established Chair in Law and Director of the Centre for Disability Law and Policy at the University of Galway. Her research focuses on disability and social justice, with a particular emphasis on legal capacity, advocacy and access to justice. Her first book, "From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities" was published by Cambridge University Press in 2011) and since then she has gone on to publish extensively in the domain of disability rights. Eilionóir was the Scientific Co-ordinator of the Disability Advocacy Research in Europe (DARE) Marie Curie Training Network, made up of 15 PhD researchers across seven European countries. Her work has attracted significant research funding, including a Starting Grant from the European Research Council, and an Investigator Award from Wellcome Trust. She has acted as a board member and advisor in a range of local, national and international bodies working on the rights of disabled people, and regularly advises policy-makers at national and international levels, including providing support to the Secretariat of the UN Committee on the Rights of Persons with Disabilities, and in particular the working group which developed General Comment 1.

### Anna Arstein-Kerslake



Professor Anna Arstein-Kerslake is an international leader in the fields of human rights, disability rights, gender justice, and legal personhood. She has published widely in these areas, including her recent sole-authored books, Restoring Voice to People (Cambridge University Press 2017) and Legal Capacity and Gender (Springer 2020). She was the Programme Director of the LLM in International Human Rights Law at the Irish Centre for Human Rights (ICHR) at University of Galway (2021-22) and the Programme Director for the BA Connect in Human Rights at ICHR (2022-23). She is also the Associate Head of Equality, Diversity and Inclusion at the School of Law and is the Athena SWAN Lead for self-evaluating gender equality at the School of Law. In addition, she is the Vice Dean of Graduate Studies in the College of Business, Public Policy, and Law.

## **Bios on Irish exchange delegates from Health Service Executive (HSE) and Dept of Children, Equality, Disability, Integration and Youth (DCEDIY), National Disability Authority (NDA), Inclusion Ireland**

### **Aisling Hunt**



Aisling Hunt is currently working with the Health Service Executive (Ireland) and is the National lead for the Pilot Personalised Budget Demonstration Project. Aisling has worked for over 30 years in the area of disability and education. Aisling developed and enhanced her interest in education and disability whilst in the US with the Council on International Educational Exchange and on her return to Ireland worked as a lecturer with the South East Technological University. Aisling has previously worked with the Rehab Group and now with the Health Service Executive. Aisling holds a degree from Trinity College and a Masters in Rehabilitation Studies from University College Dublin. Aisling also enjoys volunteering in her local community café or immersed in flower arranging.

### **Dharragh Hunt**



Dharragh Hunt is a Senior Policy and Public Affairs Advisor at the National Disability Authority (NDA). Dharragh's work in the NDA relates to health and social care, education and children with disabilities. Dharragh is a council member of the National Council for Special Education (NCSE). Through his NDA work Dharragh worked with the Department of Children and Youth Affairs on the development of the AIM programme of supports for children with disabilities in early years. Dharragh was secretary to the advisory group (largely self-advocates and family members) of the Taskforce on Personalised Budgets. Dharragh is currently working with the HSE on the development of an outcomes-focused monitoring system for adult day services. During Dharragh's time on the NCSE Council, the NCSE published An Inclusive Education for an Inclusive Society - Policy Advice Paper on Special Schools and Classes, which recommends the progressive realisation of a model of inclusive education where "all students receive their education in their local schools and within their local communities".

### **Suzanne Moloney**

Suzanne Moloney has worked in the Disability sector for over 20 years. I managed services at a local and regional level before moving into strategic and leadership roles where I worked to drive forward the reform programme for services for people with disabilities. In my current post I work with voluntary providers and other key stakeholders to address the many challenges in delivering quality supports and ensuring the long term stability and sustainability of disability services for people in Ireland. I hold a B.Sc. in Podiatry and an MSc in Healthcare Management and Leadership.

### **Aoife O'Toole**



Aoife has worked for over 30 years in a variety of leadership and senior management roles in social care in Ireland and Australia, in both the voluntary sector and government agencies. Aoife is driven by a strong belief that we all have the capacity to live a good life and her work focuses on challenging the assumptions, practices and systems that limit the potential of people with a disability to have access to the good things in life. Aoife is a member of the Inclusive Living Network and her current role is General Manager, HSE National Day Services.

## Gerry Tully



Gerry is an Assistant National Director in the Health Service Executive, in Access and Integration. He holds responsibility for Stability and Sustainability across the Disability sector. This aligns to the HSE's corporate plan, reimagining services to be the most responsive possible and ensuring the transition, over the medium term, to the provision of high quality co-designed supports. These services should meet the needs, abilities and potential of citizens with a disability or with mental health specialist support needs. The services align with an agreed service delivery model, to focus on empowerment and enablement and engagement and participation in all areas of society, are appropriately and sustainably resourced and are supported by strong governance mechanisms.

## Guillaume Jacquinot



Originally from France, I hold a Masters in Human rights and completed a LLM on International Disability Law and Policy in the Centre for Disability Law and Policy of Galway in 2016. I worked at the national, European and international in the disability policy sector with a particular interest in the areas of independent living, legal capacity and participation in political life for a number of organisations such as Handicap International, the EU Fundamental Rights Agency for Fundamental Rights (FRA), Inclusion Europe and now Inclusion Ireland. Additionally, I am co-chairing an international group on Deinstitutionalisation for Inclusion International and was recently elected as Secretary General for Inclusion Europe.



## Bios on Irish exchange delegates from the Inclusive Living Network and the National Platform of Self-Advocates.

### Paul Alford



Paul Alford is part of ILN. He also works for inclusion Ireland. He is living in Navan and owns his own place. He loves going to bingo, playing table tennis, meeting other people at the special Olympics, going to the pub to listening to Irish music, going on holidays, doing the 5km park run – He has 154 done so far and has volunteered 18 times to coach people to finish the park run! He gets support from my support worker with cooking, cleaning, doing things for myself and getting out and about.

### Christina Burke



Christina Burke represents the National Platform of Self-advocates on the ILN. Christina moved out of living out in institutions in Limerick and Gort after many years and now lives in an apartment in the community in Galway. She has been an active advocate on committees for many years including the Inclusive Research Network and the BOC Council.

### Rachel Cassen



Rachel is the Director and Co-Founder of Leap, an organisation that exists to:

Inspire - Share really useful knowledge to encourage families to dream big and believe in possibilities.

Imagine - Assist families to find and connect their allies, convene their network and create a vision and plan.

Include - Build their family members roles, relationships and belonging

### The Healy Family

SallyAnn, Tom and Mary Jo have been pushing the boundaries around inclusion in Ireland for 40 years. Following the O’Hanlon judgement on the right of every child to a full primary school education Mary Kealy led the design and build for the first fully inclusive facility in the country at the local secondary school in Clifden. Tom served as chair of Inclusion Ireland. His breadth of vision supported the early transformation of that organisation to



be a recognised force for advocacy and change and inclusive practice in its focus and in the way it conducts its business. SallyAnn’s quiet voice continues to challenge everyone around her to do better for herself and in particular for all other persons living with a disability who live at the farthest geographic remove from institutional and service ‘hubs’.

### Mary Kealy



Mary Kealy was the Chief Executive of Brothers of Charity Clare Services since 1999. She lead a radical reform programme in how people are supported. The focus changed from segregated, congregated group settings to become responsive to each individual, intentionally expanding opportunities in order to access the good things of life. This enabled people to live in meaningful relationships, having a home of one’s own, finding interesting paid work and valued social roles. She supported families through a Family Leadership Series. Mary shares her experience of the leadership

challenges in the reform of an organisation from segregation to one of inclusion and interdependence.

### **Petria Malone**



Petria Malone is primarily a family member, but also professionally in her advocacy role with Inclusion Ireland. It is through advocacy with her daughter that I began to organise and agitate for her voice and her rights to be foremost in discussion and in decisions around her support. I have accompanied her to the UN under the banner of the Ombudsman for Children to report on the rights of the child in Ireland under the United Nations Convention on the Rights of the Child. This expands out into my work as an Advocacy Project Worker, since 2016, with the National Organisation for People with intellectual Disability. Our platform is the UNCRPD. I am passionate in my work around building capacity with people to realise and vocalise their rights and engaging with others in visioning and in campaigns to build this future.

### **Karen McCormick**



Karen McCormick is a parent of 4 children. She has been a PA employer for over 2 years, employing 3 personal assistants to support her eldest daughter to live well at home with her family and included in her own community. The self-direction journey has directly influenced Karen's career path. She has founded inCharge, a values driven company pioneering enabling technology for better person-centred outcomes in self-directed and shared family care. She believes in co-producing solutions for better outcomes. Karen supports other families onto and during the self-direction journey. She is working with Care City and In Control partnership in the UK.

### **Joe McGrath**



Joe McGrath is the Vice-Chair of the National Platform is Self-Advocates. Joe has been a co-trainer on the Assisted Decision Making (Capacity) Act 2015 with the CDLP, University of Galway. Joe also works in Irish Seed Savers Association.

### **Ryan Nolan**



I am 23yrs old. I live in my own home, where I am supported by my mum and dad and my PA's. I have a younger sister, but she doesn't live with me. I love music and travelling. I also love spending time in my home watching movies and relaxing in my hammock swing

### **Carol O'Donnell**



My name is Carol O'Donnell and I am the CEO in DARA in Celbridge in Kildare. Dara is a Section 39 disability support service for adults with an Intellectual Disability. I have been the C.E.O in DARA for the last three years. My role involves overall responsibility for the governance and management of the supports DARA provides on a daily basis to the people with an intellectual disability. Previously I worked as an Occupational Therapy Manager. I believe people with an intellectual disability need access to the good things in life similar to you and I for e.g. a home, employment, having a voice, being treated as an individual, being connected with family and friends and having opportunities and expectancies that enable one to discover and develop one's abilities, skills, gifts, and talents.

### **Moll O’Keeffe**



Moll O’Keeffe, Family Member, ILN Member, In Conversation Series (ICS) Co-creator, Founder of Positive Pathways, Regional Manager Cope Foundation, Believer in the power of community and valued social roles.

### **Ursula Regan**



I am parent to my son Ryan. I have shared this journey so far with Ryan for 23yrs. I am currently studying a master’s by research through disability law in Galway University where I spend 50% of my time. For the other 50% I live and share a home with Ryan in Drogheda Co Louth, which is on the east coast of Ireland. I also own and operate a childcare setting in Drogheda. When Ryan left school I secured him a place on the Demonstration project for personalised budgets, which I managed.

### **Maria Walls**



Maria Walls’ commitment in the area of disability is driven from supporting and learning from family members to live the lives of their choosing. Maria is a PhD candidate in the CDLP, UG and received an IRCHSS scholarship. Previously, Maria was National Manager of the National Advocacy Service, and Director of Research and Policy Development in the NFVB. Maria’s research interests are; personhood and legal capacity, supporting decision-making, inclusive individualised supports, and de-institutionalisation. In 2007-2008 Maria researched disability support systems in New Zealand and USA. Maria was a member of Disability Stakeholders Group and NDISG 2018 - 2021. She holds an LLM. in International Human Rights, M.Ed., B.Sc. and C.Q.S.W..

### **Willie Walsh**



Willie hails from Westport, seven of us in family, all gifted, beautiful people. I am proud of lots of the things I do; most recently the One Breath project, working with the wonderful InConversation Series team, Chair of the Inclusive Living Network, Director of the Clan Beo collaborative. I am indebted to teachers from all corners but especially those insights gained from 'outsider' collaborators, guides steeped in the SRV tradition, my family and friends. I start connecting with people through relationship, in ordinary places over a cuppa (or a beer); that's never a waste of time. I look for quality of life experiences and the contributions of people living with disability. I walk alongside by listening carefully, connecting up with useful people and resources, help set up 'one person at a time' arrangements and planning for ordinary lives at home in community.