

# Participation & Rights



See a person's Ability  
not  
Disability!!

**INCLUSION IRELAND  
ANNUAL REPORT 2013**



## **Our Vision**

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential.

## **Our Mission**

Our mission is to be the independent champion of people with an intellectual disability and their families, whose standing and expertise in is acknowledged and to ensure that people with an intellectual disability have their voices heard, are not isolated or segregated and can lead more independent and healthier lives.

## **Our Patron**

Michael D. Higgins, President of Ireland

## **Table of Contents**

Advocating for Change	5
Case Studies	11
Growing Community Networks of Families	15
Growing Community Networks of Self-Advocates	18
Building Capacity	24
Training and Development	24
Feeding into National Structures	26
Collaboration	28
Organisational Information	30
Acknowledgments	34

## A message from the Chairperson

There are three things that come to mind when I look back on the past year. Firstly the commencement of the inspection of disability services by HIQA. After a campaign of 20 years we welcome the implementation of standards in disability services on a statutory basis. Secondly on International Disability Day last December, powerful presentations were made by self advocates to members of the Oireachtas. It was a privilege to hear the speakers and Brendan O'Connor who chaired the event was very impressed.



This year also saw the publication of the Assisted Decision-Making (Capacity) Bill. It is great to see that the Bill includes a presumption of capacity and guidelines for supported decision-making. While there are some aspects of the bill that we would like to see changed it is a huge improvement on the existing wardship procedure. The bill recognises functional capacity and the importance of providing appropriate supports to empower people to make their own decisions. The following quotation attributed to Albert Einstein is worth remembering: “Everybody is a genius, but if you judge a fish by its ability to climb a tree it will live its whole life believing that it is stupid”.

I wish to thank all the members of Inclusion Ireland, the Board of Directors, our Chief Executive Paddy Connolly and all the staff for your support during the past two years.

Máirín McCartney

*Chairperson*

## A message from the Chief Executive

Inclusion Ireland's priority for the year ahead can be summarised in three words – Participation, Accessibility & Rights. Much of the focus of our work in 2013 has been laying the ground work to build genuine participation of people with a disability and their family members in the structures and processes which are driving the changes underway in disability services and supports.



Change and reform will only come about if all stakeholders believe and see that they have a part to play. Access to information; to the structures where plans and decisions are made; and to opportunities to evaluate and comment on progress, are key components of a partnership approach. They are also fundamental to recognising the right to self-determination of people with a disability.

The future is not simply the implementation of the recommendations of New Directions, the Value for Money review and Progressing Children's Disability Services. The future is what evolves through a process of consultation and collaboration between all stakeholders.

Inclusion Ireland is committed to advocating for change for people with a disability and their families and to working in partnership with all stakeholders.

Paddy Connolly

*Chief Executive Officer*

## **Advocating for Change**

### **Where we are**

Inclusion Ireland strongly believes that the voice of people with an intellectual disability and their family members should be heard by politicians and people who make policy and law in Ireland.

Ireland must ratify the United Nations Convention on the Rights of Persons with Disabilities. The Convention sets out in one document all of the rights and fundamental freedoms that belong to people with a disability. These include the right to access justice, health, education, and to live a life free from exploitation, violence and abuse.

The government must ensure that everyone with a disability in Ireland has these rights protected and promoted.

There are a number of issues we have campaigned on in the last number of years. We welcome the positive developments in a number of areas over the past twelve months.

One of these is the reform of the law as it relates to capacity and decision-making. Inclusion Ireland is acknowledged as the leading campaigning organisation on this issue for many years. In 2013 we

welcomed publication of the long-awaited Assisted Decision-Making (Capacity) Bill 2013. The new law provides for an improved legal framework for supporting people to make decisions. The law is a very positive development. We hope this new law will be introduced in 2014 and that the UN Convention on the Rights of Persons with Disabilities can finally be ratified by Ireland.

Inclusion Ireland has also led the campaign for regulation and inspection of residential services for adults and children with a disability. We finally saw change in October 2013 when the Health Information and Quality Authority (HIQA) started inspecting residential services for people with a disability. In 2014 the first set of reports on inspections were published. While it is great that we are at this point, we must always work towards higher standards and more choice and control for people accessing services and supports.

There have been some other important developments since our last annual report. These include the publication of a plan to implement the recommendations of the Value for Money and Policy Review of Disability Services report. If these recommendations are implemented, people using disability services should have greater choice and control over the services they receive.

We have seen important developments in Education. The publication by the National Council for Special Education of 'Supporting Students With Special Education Needs' is the biggest report on education for children with special educational needs and is to be welcomed. As is the Minister for Education's commitment to review how special education supports are provided to schools. These are welcome milestones. But there is still a long way to go before achieving the vision of an inclusive education system.

Children and adults are waiting too long for basic therapy services, including speech and language and occupational therapy. This issue requires urgent response from the government and the Health Services Executive (HSE).

People with an intellectual disability are very angry that the Criminal Law (Sexual Offences) Act 1993 is still law in Ireland. This law can mean that it is illegal for people with an intellectual disability to have a sexual relationship. People with a disability have a right to have a relationship and a family life and want this law changed.

Important laws including the Disability Act 2005 and the Education for Persons with Special Education Needs Act 2004 are still not fully implemented. Among other things, this means that the majority of

children and young people with a disability do not have the right to health and education assessments.

## **What we do**

Inclusion Ireland believes that listening to how different issues affect people with an intellectual disability is essential when deciding on what policies to change. Policy areas important to people with a disability include social welfare, education; employment; health and housing. When Inclusion Ireland members tell us about an issue, we tell people who make laws and policies. We do this by:

- Meeting with government and other politicians;
- Use the consultation structures of the HSE;
- Highlighting issues in the media

In 2013 we held a joint pre-budget press conference with Irish Autism Action and Down Syndrome Ireland to highlight how people with a disability and their families have experienced cuts to incomes and public services in recent years.

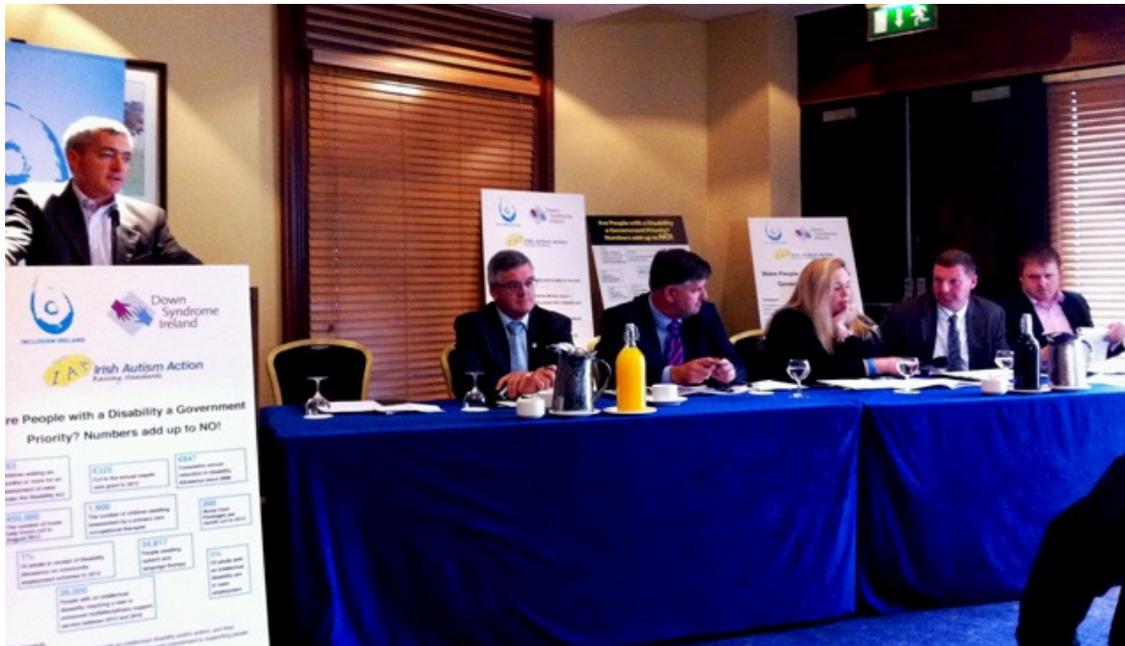
The three organisations submitted a report to government calling for people with a disability and families to be protected from further cuts in the Budget. This report provided the facts and figures on how people with a disability had been affected by cuts. Two people with an intellectual disability and a parent of a child with a disability spoke at the event, which covered by the RTÉ news and national newspapers.

### **Where we want to be**

In this report you will read how Inclusion Ireland has worked with people with an intellectual disability, parents and family members to build their capacity and provide them with opportunities to be effective advocates and partners in decision-making.

Inclusion Ireland wants people with an intellectual disability and their families to have a strong voice that is heard by people who make laws and policies. Inclusion Ireland wants politicians to understand that every person requires support at different times in their lives, and that people with an intellectual disability have a right to access these supports.

Inclusion Ireland wants people with a disability to enjoy the human rights and fundamental freedoms which are set out in the UN Convention on the Rights of Persons with Disabilities.



Paddy Connolly, Inclusion Ireland Chief Executive, speaking at the launch of the joint submission to government from Inclusion Ireland, Down Syndrome Ireland and Autism Action Ireland. November, 2013

## **Case Studies**

### **Alan's story**

Every parent looks forward to the day their child begins school. However, when a child has a disability this often marks the beginning of a long and difficult journey.

Alan is a young boy with autism who is entering secondary school. He had access to a special class with extra support while in primary school. His local secondary school does not have an autism class and has refused to open one.

Alan's parents were forced to apply to more than 20 schools before they found a school with the supports he needed. This school was more than an hour away from Alan's home. As a result, Alan has to travel away from his friends and local community every day. There is no legal obligation on the school to open a special class.

Inclusion Ireland supported Alan's parents to appeal the school's decision not to enrol Alan.

## **Anne's story**

Many children with a disability require speech and language therapy, physiotherapy and occupational therapy to reach their full potential. However, there are long waiting lists even to be assessed for these services. As a result many children are having their development curtailed.

Anne contacted Inclusion Ireland when her daughter was about to move from junior school to a senior primary school. Anne's daughter attended a special autism class in junior school. The senior school autism class did not have enough spaces for all of the children making the transition. As a result, Anne's daughter was offered a place in a mainstream class. However, the HSE would not supply the vital therapy support to Anne's daughter if she attended the mainstream class.

Inclusion Ireland supported Anne to appeal the decision not to enrol her daughter in the senior autism class.

## **Louise's story**

Louise attends a day service and lives at home. Louise lives in the family home with her sister. Before she died, Louise's mother opened a joint bank account because the bank would not allow Louise to open an account in her own name. Now Louise has been refused access to the joint account. The bank is concerned that she lacks the capacity to manage her financial affairs.

Louise is concerned that her disability allowance might be taken away because she has inherited a share in the family home. A solicitor has told Louise that she might be made a ward of court.

Inclusion Ireland is supporting Louise to understand their rights when it comes to financial matters. We explained how there is nothing in Irish law to say that Louise cannot inherit property or have a bank account.

Inclusion Ireland told Louise and her sister about the new decision-making law and how it will provide supports for people who may require support to make decisions.

## **Joan's story**

Joan is a 25 year-old with a diagnosis of moderate intellectual disability and autism. Joan does not communicate verbally. Joan attends a day service and receives some home support. This gives Joan's mother Alice some respite. Over the years, Alice has had to fight for every service and support for Joan. There is only one disability service provider operating in the area. Alice and Joan are totally dependent on this service.

Alice has become increasingly frustrated at the quality of service Joan is receiving, and has raised this with the service on a number of occasions. The service decided to make changes to Joan's service. According to Alice, this was done without any consultation with herself or Joan.

Alice would like the family to have more of a say in how the services and supports are provided to Joan. Alice wants a person-centred plan for Joan, rather than making Joan fit into a service that is not meeting her needs. The HSE has told Joan that individualised funding is many years away. Inclusion Ireland is supporting Alice in her meetings with the service provider and the HSE.

## **Growing Community Networks of Families**

### **Where we are**

All around Ireland, there are many groups supporting parents and families of people with a disability. Inclusion Ireland works with other national groups such as Down Syndrome Ireland and Irish Autism Action in supporting families. However, there remains a need for a coordinated family voice at local, regional and national levels. Inclusion Ireland wants family members to have the opportunity to support each other and to influence the development and provision of services.

The HSE is currently reforming how disability services are planned and delivered. These significant reforms cover residential; day; respite and therapy services to children and adults with a disability and their families.

The involvement of parents and family members in these reforms is essential if they are to be successful. However, parents and family members face a number of barriers to participation. These barriers include the timing of meetings, lack of information, the need for capacity building around negotiation and advocacy skills. There is a need for other supports, including financial support, to enable parents and family members to have meaningful participation in the reform programmes.

## **What we are doing**

Inclusion Ireland supports parents and family members to have their voice heard. Inclusion Ireland is developing a parent and family network. Inclusion Ireland is working with the HSE and other organisations to make this happen.

This work involves;

- Providing information and support to local parent and family groups;
- Hosting national, regional and local meetings;
- Capacity-building and training initiatives for parents and family members.

## **Where we want to be**

Parents and family members want to have a greater say in how services are planned and delivered. The HSE wants to involve parents and family members. Inclusion Ireland has a key role in making this happen.

A coordinated and supported parent and family network will

- Give parents and family members a stake in the reform of disability services;
- Make services to people with a disability effective and efficient;
- Support community-based, inclusive services;
- Enable family members to have a meaningful involvement in decision-making

## **Growing Community Networks of Self-Advocates**

### **Where we are**

Inclusion Ireland supports people with an intellectual disability to have more of a say, control and choice in their lives.

The human rights of people with a disability are gaining more recognition. Government policies are starting to consider disability as a human rights issue. A plan to implement the National Disability Strategy was published in 2013. In 2013, the Assisted Decision-Making (Capacity) Bill 2013 was introduced. A National Housing Strategy for People with Disabilities has also been published.

### **What we are doing**

Self-advocacy means self-representation – taking action on things that are important to a person or a group of people. A self-advocate is a person with a disability speaking up and taking action.

## **Inclusion Ireland Self-Advocacy Committee**

Inclusion Ireland supports the work of a self-advocacy committee which meets every two months in Dublin. This committee is made up of 12 experienced self-advocates.



In December 2013, the self-advocacy committee was invited to a meeting in Leinster House by Minister Kathleen Lynch. The committee discussed cuts to residential services, the increase in prescriptions charges, medical card reviews and the rights of people with a disability to have relationships

On the 3<sup>rd</sup> of December, the International Day of Persons with Disabilities, the committee held a meeting with other politicians on issues that are important to people with a disability. Members of the committee attended other meetings during 2013, including a consultation on the Assisted Decision-Making (Capacity) Bill in Dublin Castle and a conference on decision-making in Belfast.



### **Marie Wolfe**

“People with disabilities have the right to have the same opportunities as everyone else. To live the life we want we need the right support so we can have real independence and control in our lives. For this to happen we need real change.”

### **Sam O’Connor**

“We want to be part of all decisions that affect our lives. We can make decisions for ourselves because we are speaking from experience, so give us the control. Talk to us, not about us. In order to give us the chance to live our dreams and our lives the way we want, money needs to go into the right support services. We are disability advocates. We are not going away. We are just getting stronger and stronger. You have not heard the last of us.”





Inclusion Ireland continues to support the **National Platform of Self-Advocates**. The Platform received funding to hire its own facilitator to support the group to think about the big issues affecting people with an intellectual disability and how to work better together. The Platform wants to establish a network of self-advocacy groups throughout Ireland that will be run by people with an intellectual disability, for people with an intellectual disability. The Platform is looking for funding to make this happen. It will hold a national conference for self-advocates in 2014.

## **National Standards for Residential Services**

Inclusion Ireland supported 15 people with an intellectual disability to deliver information workshops on the national standards. A total of 15 information workshops were delivered across the country. The National Standards are monitored by inspectors from the Health and Information Quality Authority (Hiqa). Inclusion Ireland would like to see people with a disability as part of the inspection teams. Inclusion Ireland also worked with Hiqa to develop easy-to-read versions of the national standards.

### **Where do we want to be?**

Inclusion Ireland is working towards a future where:

- People have a real choice of where and with whom they live;
- People control their own money and those people who require support receive it;
- People have a greater say in how money is spent on disability services



## **Adrian Noonan**

“People with a disability need to be sitting around the table in board rooms as partners in decision-making.”

## **Paul Alford**

“The focus should be on the person. Staff should support people to live a life of their own choosing”



## **Building Capacity Training and Development**

### **Where we are**

A key focus of the work of Inclusion Ireland is on building the capacity of people with a disability, parents and family members to be effective advocates and agents for change. To support this, we provide talks, seminars, workshops and conferences on a broad range of topics that are important to people with a disability.

In 2013, Inclusion Ireland received funding from Department of Justice and Equality, the Department of the Environment, and Genio to provide training and capacity building to people with a disability and families. These areas included decision-making, capacity building and training for parent representatives, citizen advocates and training for self-advocates on the national standards for disability services.

## **What we are doing**

In 2013, Inclusion Ireland developed its first training calendar to meet the demand of people with an intellectual disability, parents and family members and staff working in disability services.

The training calendar covered a range of topics including, making a will; decision-making, capacity and consent; how to start a support group; disability law and policy; and voting. The workshops will be held in Dublin, Cork, Waterford, Westmeath and Kildare. Additional venues will be added on demand.

## **Where we want to be**

Inclusion Ireland has seen an increase in demand for capacity building and training. The more members we have, the more our work is guided by the lived experience of people with a disability and their families.

Inclusion Ireland plans to develop an annual training and events calendar. As a national organisation, we will hold these events in as many locations as possible.

## **Feeding into National Structures**

Inclusion Ireland continues to represent the view of its members - people with an intellectual disability, parents and family members - on a number of national structures. These structures are concerned with monitoring implementation of key policies and programmes, that impact on the lives of people with a disability.

In 2013, a key focus of our work was on the There are major reforms underway in the development and provision of health and personal social services for children and adults with a disability. These reforms include:

- New Directions (the reform of day services);
- Congregated Settings (the programme to close institutions);
- Progressing Children (the reform of services to children)

Inclusion Ireland represents the views and concerns of its members on the national groups monitoring implementation of these reforms. These groups report to the HSE national consultative forum, of which Inclusion Ireland is a member.

The national consultative forum is the main group where the HSE disability management and the national disability organisations meet to discuss disability issues.

Inclusion Ireland also represents its membership on a number of other national implementation groups. One group is the National Disability Strategy Implementation Group. Kathleen Lynch TD, the Minister with specific responsibility for disability issues, chairs the meetings of the group. It is a high level group. It is an opportunity for Inclusion Ireland to raise issues with the Minister.

The Value for Money (VFM) Steering Group is another important monitoring group. This group will report on the progress in supporting people with a disability to have more control over the services they receive. It is a key part of the reform of how services will be planned and delivered into the future.

As well as being a member of these national monitoring structures, Inclusion Ireland works with other national organisations on a broad range of issues.

## Collaboration

Collaboration involves working together for change.

An example of our collaborative work is the campaign for modern decision-making legislation. This alliance of civil society organisations and groups has made a number of submissions on the law relating to decision-making. Inclusion Ireland is also a member of the civil society coalition that is monitoring Ireland's compliance with human rights law. This is facilitated by the Irish Council of Civil Liberties.

In addition, Inclusion Ireland is a member of a number of other national and international alliances, which include:

- **Equality & Rights Alliance.** A coalition of groups and individuals working together to strengthen Ireland's equality and human rights infrastructure.
- **Children's Rights Alliance.** Organisations working together to make Ireland one of the best places in the world to be a child by ensuring that children's rights are protected in Irish law, policy and practice.

- **Mental Health Reform.** A coalition of organisations working to bring about structural and cultural changes in mental health matters.
- **Victims' Rights Alliance.** An Alliance of support and human rights organisations to ensure the Victims' Rights Directive is implemented.
- **Fundamental Rights Platform** of the European Union Agency for Fundamental Rights.
- **Inclusion Europe** - the European association of people with an intellectual disability and their families

## Organisational Information

### Information and Advocacy Support Data 2013

- 5,744 people received updates on HSE reforms, social welfare, and other information ,every six weeks;
- 5,461 people were in regular contact with Inclusion Ireland in 2013;
- 782 new people contacted Inclusion Ireland with enquires and requests for support in 2013;
- 1,272 organisations or groups are in regular contact with Inclusion Ireland;
- 64 new organisations or groups contacted Inclusion Ireland in 2013;
- Inclusion Ireland received 2,428 requests for information and advocacy support in 2013

Enquiries relate to legal issues, education, health and personal social services; complaints to HSE and other public bodies; money matters, social welfare, access to justice and legal capacity.

## **Policy Submissions**

Position paper on Implementing the National Disability Strategy (January 2013)

Submission to the Department of Social Protection in advance of Budget 2014 (June 2013)

Joint pre-budget submission with Irish Autism Action and Down Syndrome Ireland (October 2013)

Submission on a Comprehensive Employment Strategy for People with a Disability (October 2013)

Submission to the National Council for Special Education on Resource Teaching Hours (October 2013)

Submission to the Oireachtas Committee on Education and Social Protection on the Draft Regulations for School Enrolments (November 2013)

All submissions are available on [www.inclusionireland.ie](http://www.inclusionireland.ie)

## **Board of Directors**

Ms. Máirín McCartney (Chairperson)

Mr. Tom Healy (Vice-Chairperson)

Mr. John Hannigan

Mr. David Kiernan

Ms. Anne Gunning

Mr. Eamonn Tierney

Mr. Eamon Slevin

Mr. Sam O'Connor

Ms. Phil Davy

Ms. Katherine O'Leary

Ms. Theresa Tonna

Mr. Stephen McDermott

Ms. Beverly Smith

Ms. Lorraine Dempsey

## **Inclusion Ireland Staff**

Paddy Connolly (Chief Executive Officer)

Paul Alford (Self-Advocacy Officer)

Fiona Duignan (Policy & Project Manager)

Edel Gilchrist (Accounts and HR)

Karen Horan (Administrator)

Celine O'Brien (Administrator)

Siobhán Kane (Communications Manager)

Sarah Lennon (Training & Development Officer)

Áine Ní Aileagáin (Advocacy Officer)

Mark O'Connor (Advocacy Project Worker)

Jim Winters (Advocacy & Rights Officer)

## Acknowledgments

The work of Inclusion Ireland would not be possible without the support of many people - too many for us to name here. To our individual members; parent & family groups; self-advocacy groups; those of you who represent us on committees and working groups; academics and legal practitioners who have volunteered your time and expertise – thank you. A particular thanks to:

- Pauline Conroy;
- Conor Murray (Hyperlink);
- Brendan O'Connor;
- Lorraine Lally, BL;
- Bo McDowell, BL;
- Colm O'Dwyer, BL;
- Cathy Smith, BL;
- Michael Lynn, BL;
- The staff at the Public Interest Law Alliance (PILA)

## **Thank you to our funders:**

- The Health Services Executive;
- The Department of Environment, Community and Local Government;
- The Genio Trust;
- The National Lottery;
- The Citizens Information Board;
- The Department of Justice and Equality;
- The Family Support Agency

Inclusion Ireland is adopting the code of governance for voluntary organisations. Accounts for 2013 have been sent to all members and are available on request from Inclusion Ireland offices.







## **INCLUSION IRELAND**

**National Association for People with an Intellectual Disability**

Unit C2, The Steelworks,

Foley Street, Dublin 1

Tel: 01 855 9891

Fax: 01 855 9904

Email: [info@inclusionireland.ie](mailto:info@inclusionireland.ie)

Website: [www.inclusionireland.ie](http://www.inclusionireland.ie)

Find us on Twitter and Facebook