

### Global



### Advocacy Manifesto



**Including The Manifesto for Inclusive Research** 

Ownership of your dreams
By Larry O'Bryan

Pray for ownership of your dreams
People have rendered love presents
Peering through brambles
Oft times we leave our desires
Drown in fog



#### This publication is dedicated to you, and your dreams

Manifesto Concept—Clare Inclusive Research Group, Co. Clare

Design and Layout—Starfish Enterprise, Kilkee Co. Clare, Ireland

Printed by **Triest** Press CLG social enterprise Co. Roscommon, Ireland

Copyright © 2024 Clare Inclusive Research Group

All rights reserved. This book, or parts thereof,

may not be reproduced in any form without permission.

Independently published

Cover art Copyright © 2024 Brian Keating & Project Me Students

ISBN: 13 - 978-0-9562924-1-4

### Own

#### Ownership of your dreams by Larry O'Bryan



#### **Contents**

	Mate
4	Welcome by Rob Hopkins—BOC Clare Services Ireland
5	Brothers of Charity National Advocacy Council - Manifesto
6	Article 7: The Right to Safety—Olesia Stoian (Ukraine)
7	Article 8: Abilities Awareness Douwe Zwartenkot (Holland)
8	Article 27: Work– Paul Matthews & Philip Crosby (Ireland)
9	The Right to Work– Macharia and John (Kenya)
10	The Right to Work– Claire Nagle (Ireland)
11	Article 21: Awareness about Rights Pat Flaherty (Ireland)
12	Article 19: Independence, Choice Community Involvement Lisa Acheson, Kathleen O'Leary (Ireland) Yash Maurya, Anshi Simgh (India)
13	Article 25: Health & Wellbeing—Danielle Collins and Paula Molan (Ireland) Crystal Greg, Seema Narine, Luke Whiteside (Canada)
14	Article 24: The Right to Education—Dr Amitabha Mahotra (India), Jean Lizzi, Anne-Marie Camilleri (Malta)
15	Article 24: Education Bernie Bourke & Paul MacMahon (Ireland)
16	Article 23: Relationships - Janice & John Slattery (Australia), Nora Heaney, Aine McDermott (Ireland)
17	Article 18: Freedom of Movement - Larry O'Bryan (UK)
18	Article 30: Culture / Recreation - Pauline Skehan (Ireland)
19	Article 13: Justice – Joe McGrath, Ger Minogue (Ireland)
20	List of organisations connected to the Global Manifesto
21-28	Inclusive Research Manifesto *I.A.S.S.I.D.D., I.R S.I.R.G.
30	The Writer by Lisa Acheson (South Africa—Ireland)

<sup>\*</sup>International Association of Scientific Study of Intellectual & Developmental Disabilities *Inclusive Research* Special Interest Research Group Webinar 2022

#### Hello and Welcome to the Global Manifesto!

**This Booklet** is launched along with our Advocacy Manifesto Film at "Let's Get Real", BOC National Advocacy Conference 2024.

The data has been created as a result ofinternational links Clare research advocates have made over 16 years of inclusive research work. We linked advocate groups nationally with their peers in countries across five continents proposing they share their opinions and experiences of an important rights issue. We turned the filmed responses into footage and this publication.

**Issues are connected** to Articles from the UN Convention on the Rights of People with Disability. Clare advocates are proud to say we were in at the beginning when the Convention was created.

**Our 2003 film**, "Able to Work" with Joe McGrath at Seedsavers Ltd Scarriff and Kathleen Ryan at Kelly's Bar & Restaurant Kilrush, was distributed world wide by the United Nations when looking for ideas for the Convention's content. Their work was sited as "an example of people living meaningful lives in the community".

**Rights based advocacy** is now the touch stone giving force and meaning to our work. As our film's voiceover artist, Irish advocate, Pauline Skehan, puts it "We deserve equality like everyone else".

**Thanks to all the activists** in Ireland and around the world for making this project possible. We added our Manifesto for Inclusive Research to the booklet. Two manifestos for the price of one!

We believe it's guidelines apply equally to the work of advocacy, placing the ideas and interests of people with learning disability at the heart of everything. We hope you find this booklet useful.

Rob Hopkins—Advocacy and Inclusive Research Officer, Clare BOC



This is our global advocacy manifesto



Claire Nagle BOC National Advocacy Chair Person

In this day and age, it's important we know about our rights

**Daniel Hickey Clare Advocacy Platform Chair Person** 

**Article 8: The right to raise awareness about our rights** 

Joe McNamara Galway Advocacy Secretary



This
pamphlet
lets you
know
about your
rights



Olesia
Stoian—
Ukrainian
Ballroom
Dancer
"At least I
am safe."



Orla McMahan, Clare researcher
"How did you feel about your
country being at war?" - "At first I
was sad like everyone. I tell myself
I must be calm and fight my fears.
And I should make the most of the
opportunities that come my way.

Article 7:
The right
to be safe
in times
of natural
disaster
and war



### **Article 8: Tell people about our abilities**



I come from Holland. Because of my disability, getting my driver's licence was not easy for me. Now I have it, I can move freely and more independently. Access is important in many areas: transport, roads, buildings & information



\*LFB - Landelijke Belangenbehartiging - National Advocacy Holland

### **Article 27: We have the right to work**

Paul Matthews South East Advocacy Chair



Work is a right and we want to get paid

Philip Crosby South West Advocacy Chair



Is that OK?





### **Article 27: The right to work**

My name is Macharia. I live in Kenya. I work using a power cleaner for different jobs; car wash cattle trucks and carpets. I love my job. It helps me earn money.











My name is John I'm also from Kenya. I work as a herdsman. I love my job and I respect my employer.



### **Article 27: The right to work**

Work is a right. It makes us feel useful



We work on panels to interview our support staff and we get paid



### **Article 21: Talk about our rights**

Pat Flaherty Galway
Advocacy Chair:
"There's a wrong
and a right about
everything. But I
always say we have
every right to be
involved in our
communities"







Dr Amitabh Mehotra, Uttar Pradesh, India, "All that we want is an inclusive society where disabled persons have equal rights. We want policies at the state level to ensure that persons with disabilities are given their due rights."

# Article 19: Independence, choice and involvement in the community





#### Lisa Acheson, poet & advocate:

I was waiting over 11 years to get my own place. Now I live independently. It was hard at first but it gave me great confidence

Kathleen O'Leary Clare
advocate "Because I'm
over 60 I can't get funding
to live independently and
that's not right"





My name is Yash
Maurya, I live with
my parents. I
choose to live with
them. They help me
with my learning

My name is Anshi Singh. I live with my brother and sister. If there is any problem they will help me.



#### **Article 25: The right to health & well-being**

Danielle Collins
"Health & wellbeing is
a human right. We
need your support."

Paula Malon
"Everyone should
have mental health
support"







Advocates Alliance, Ontario, spokespeople: Crystal Greg, Seema Narine and Luke Whiteside



"We shouldn't have to advocate for health care but we know how and we will" "If we don't, who else will?"

### **Article 24: The right to education**





Dr Amitabha Mahotra, North India: despite experiencing Cerebral Palsy he founded S.P.A.R.C. (School for Potential Advancement & Restoration of Confidence) in 1996, now serving 36 centres in Uttar Pradesh: "My loving parents treated me as a non-disabled

person. This inspired me to study hard. I then went on to create SPARC training centres where people get support to find fulfilment in their lives"



Anna-Marie Camilleri from Malta: "Thanks to my support I have learnt self care skills; I do my hair, my nails, wash my clothes. I also enjoy cooking sewing & meditation." Jean Mizzi from Malta: "I have learnt about independence. Now I work in the community on a car wash project. I do valeting, take bookings and check cleaning supplies. The business is a great success."





### **Article 24: The right to education**



#### **Bernie Burke:**

Education is a human right. My experience as Advocacy Chair for Limerick BOC has given me great confidence learning about people's issues and speaking up

David McMahon, Activist:

We think article 24 is very important. We discussed our access to lifelong learning. We have the right to choose

activities and say no to activities.

Sometimes people had to stay home and not continue their lifelong learning because of lack of funding for staff cover. Activists discussed feeling sad, bad, upset, mad and disappointed when classes were stopped. This had an impact on our right to education.



### **Article 23: Respect our relationships**

Janice & John Slattery Australian relationships trainers





"We've been married 32 years. The most important thing is having a partner that respects you"

"You can do lots of nice things. That makes me very happy. We're bound together. Its really lovely"







Nora Heaney Roscommon Advocacy Chair "Relationships is a right. We want your support" Aine McDermott Galway
Advocacy Rep
"The issue of relationships is
important to us. Boyfriends,
girl friends or just friends.
We want to be serious."

# Article 18: The right to move freely from country to country





Larry O'Bryan: Former Clare advocate "For free choice you must have good reasons to choose"

(Expressed through Facilitated Communication) Like choosing what country to live in? "Yes!"

Larry emigrated to Ireland from 2003-2021 "This will be our plan. It has been decided. Larry live in a cottage in Kilrush... Yes!" Then with his determined repeat-the-phrase style he campaigned to return to UK from 2019-21, "Larry, live in a house.... in England!" where he now lives...

# Article 30: A right to be involved in the cultural life, leisure and recreation of our countries



It's important that we are all part of the Community. I've been involved in community radio over 25 years. I host an award winning poetry program, the longest running show on *RCB.ie.* It's been a joy!

### **Article 13: Access to justice**



### Joe McGrath - National Platform of Self Advocates, Ireland

"Without funding, our choice is limited and our rights are being denied. I have brought this issue up at Government level. There's no point talking about rights unless we get funded support."

### **Ger Minogue - Disabilty rights** campaigner

"Countries must sign the Optional Protocol so we can stand up for our rights"

The Protocol gives a person the option of appealing to the United Nations if they believe their rights are being denied.



#### Who has and who hasn't fully signed up to the UN Convention on the Rights of People with Disability?

Country	Ratified CRPD	Optional Protocol	Full Agreement
Australia		Full Marks!	17 July 2008 🗸
Kenya	5 May 2008	Could do better	×
Canada		Full Marks!	3 Dec 2018 🗸
Malta		Full Marks!	9 Nov 2012 🗸
Netherlands	16 June 2016 🗸	Could do better	×
Ireland		Full Marks!	8 Oct 2024 🗸

#### The organisations who made this Manifesto possible























### Strong Together - Dutch Self - Advocacy













The Advocacy Alliance "Our Rights and the Rights of Others"

Malta - Gozo





### Manifesto of Inclusive Research

(These guidelines can be applied equally to Advocacy Work)



"Let's talk about doing good research"

Points 1-5 easy read versions of 5 principles from Walmsley J, Strnadova I and Johnson K. (2017) 'The added value of inclusive research' p 759: JARID

#### **INCLUSIVE RESEARCH SHOULD...**

#### 1. AIM TO MAKE OUR LIVES BETTER

Research which aims to change our lives,



our communities and our society for the better.

### 2. BE ABOUT OUR ISSUES & MAKE SENSE TO US

Research about our issues which makes sense to us and where our experience helps shape the form the research takes.



### 3. REFLECT OUR EXPERIENCE

Research which records, values and talks about the experience of people with a learning disability.



### 4. SUPPORT OUR CAMPAIGNS

Research where its information can be used by people with disability to campaign for change.



#### 5. RESEARCHERS SHOULD STAND TOGETHER

Academic researchers should co-work with researchers with learning disabilities on their issues respecting the essential partnership. Academic Inclusive



Researchers & Advocate Inclusive Researchers (A.I.R.)

### 6. MAKE THE RESEARCH ACCESSIBLE

All inclusive research should aim to make the materials of the research, proposals, questionnaires, surveys and **especially** the findings and recommendations of the research accessible to as wide an audience as possible.



#### 7. BE CLEAR ABOUT ETHICS

Where will the research will take place?

How will the research be carried out? In focus groups,

1:1 interviews? Say how individuals will be fully supported. Tell people they can stop at any time.

Who will be involved in creating the research?

Why is the research being done?

This must be made clear to all the researchers and to the responders before the research starts.





#### 8. GIVE ALL THE RESEARCHERS THE CHANCE TO SHARE IN ALL THE TASKS

**Advocate Inclusive** 

Researchers and Academic Inclusive Researchers should work together on ethical approval, training, separating out the data, thinking through research methods, ways of



recording and communicating/promoting findings.

### 9. VALUE EXPERTISE AND EXPERIENCE

Inclusive researchers bring
their knowledge and life
experience to the work. When
research is carried out and
presented the value of the
work should be reflected in an
agreed fee paid to all the researchers.



#### 10. SAY "NO" TO TOKENISM

"It's a lonely road when you're the only person with a learning disability in a group." Advocates and all people relevant to the research should be well represented on the Research Team and Advisory Groups.



## 11. RESPECT, ENCOURAGE AND CELEBRATE THE WORK OF THE TEAM

Every part of the work is important:
Whatever roles you play, thinking of questions, asking questions, recording answers, looking at what the research might mean, telling people about the findings, should be valued and appreciated.



#### 12. BE FLEXIBLE

...be prepared to challenge and change your ideas and opinions ...be prepared to challenge and change your research structure.



#### 13. THINK OUTSIDE THE BOX

AIM TO EXPLORE DIFFERENT VIEWS AND DIFFERENT IDEAS.

Work with advocates with different experiences, people on personal budgets, in congregated settings, group homes, shared and individual homes, family situations. We



should look at a broad range of topics raised by individuals and groups, the environment, travel, work, beliefs, different types of relationships etc... etc...

#### 14. FUN & FUNKY

Harness the creative skills of the research team (such



as dance, poetry, drama, artwork, photos, music, film) to carry out and promote the research. Create new ways to get the information and tell the stories and give the ideas more impact.

### 15. DO RESEARCH IN NEW, EXCITING WAYS

Different places, different ways, different subjects, environment, climate change, new technology, zoom etc...



### Manifesto of Inclusive Research

The Process...

#### 1. CHALLENGE THE GATEKEEPERS

Assume the competence of all potential responders. Seek the will and preference of the



individual, respect the role of service managers but look to reach and uphold the rights of individuals to take part.

#### 2. REDUCE PEER PRESSURE

Setup research situations which reduce the peer pressure on individuals to agree or conform.

Create small groups and one to one situations rather than large groups where people might agree or go along with the majority without asking themselves



the question, "Is this what I think?"

### 3. PROMOTE A QUESTIONING APPROACH

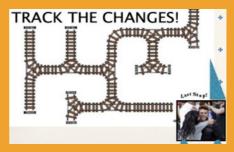
Are we putting words in people's mouths?

Are people only saying what they want us to hear? We should use open ended questions



#### 4. TRACKING THE CHANGES...

After we've worked on a research project, what will the follow up be?
Who needs to hear about our findings?



What changes are people asking for?

A study can be a powerful tool for change...

<sup>&</sup>quot;Tell us about..."

<sup>&</sup>quot;How would you describe ...?"





James Sheppard and Sonia Posada Alarcon with their son Martin, valued supporters and promoters of our work in Ireland

#### Article 10:

The Right To Life - By signing the United Nations Convention on the Rights of People with Disability (UNCRPD) countries are saying everyone has the right to life.

Their governments agree to do all they can to make sure people who experience disability have the same rights as people who, at present, do not.

#### The Writer

Writer said many things
I disagreed
Its about accepting to learn
Its in our nature to learn
Without it,
We aren't human at all
Just robots going from A to B
I agree
We can't learn anything
Without understanding





What it is to us

We can't have a friendly connection

Without learning the boundaries

We can't develop as a person

Without learning

From our ups and downs in our lives

Lisa Acheson

1st published in Stories of Citizenship Palgrave MacMillan 2023

### Report in the Hindustan Times of a joint action of ablebodied and disabled people in India demanding equal rights—Dec 2019



 Braving the winter chill, a large number of disabled people, with their walking aids and wheelchairs, participated in the 'Able joining disabled marathon' on Thursday.

#### THE DEMANDS

A policy for disabled linked to other welfare schemes in UP

Increase in reserved seats for government jobs.

Free travel in all government roadways buses of all classes.

Scholarships for disabled children be increased

Empowerment of disabled welfare officers to work for disabled persons' rights

Increase in pensions from R 300 to R 1,500 per month

Reservation of 3% in national livelihood mission and skill development mission

Inclusion in below poverty line

Disabled-friendly infrastructure in all public buildings

"It is wonderful to see and hear the words of people with disabilities from around the world arguing for their rights... a unique and incredibly valuable contribution to people gaining their rights and leading good lives"

Kelley Johnson, (Hon) Professor of Deakin University, Melbourne and University New South Wales, Sydney Australia

"This booklet is an important support to advocacy around the world. It's about time someone did this, and no better team than this one.

Congratulations, and thank you"

Fionn Crombie Angus, Chairperson, S.I.R.G. Inclusive Research
I.A.S.S.D.D. & Global Liaison Officer,
Inclusive Research Network Ireland



# ISBN 13 978-0-9562924-1-4 Published by Clare Inclusive Research Group Ennis Co. Clare, Ireland. Est. 2008

Printed by Triest Press CLG social enterprise
Co. Roscommon, Ireland. Est. 2009
... meaningful employment and training
for people with intellectual disabilities

Price: €10.00 EU, KSh1,400.00 Kenya, R920 India, \$11.00 US, \$15.00 Canada, £8.50 UK, \$16.00 Australia