

# **What Individuals and Families Need Governance to Deliver?**

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# A Little Bit About Me....

- I am married to Tim, we have 4 adult children
- Farmer/Home Maker
- Columnist in Irish Country Living Mag, IFJ
- Teacher in Our lady of Good Counsel School, Ballincollig, Co Cork (Special school)
- Served as a Board Director of Inclusion Ireland
- Served on the Advisory Group of NDA
- Served on the Advisory Group of NCSE
- Currently Board Director of Cope Foundation

- Chairperson of Quality, Safety and Governance Committee.
- Chairperson of the 'Informing Families Project' Cork Region.
- Member of the HSE Transforming Lives Committee.
- I hold a degree in Disability Studies Facilitating Inclusion



**Advocate for the rights of people with disabilities.**



# **My personal story**

1985 Julie is born

1986 Julie is diagnosed with Cerebral Palsy

I quit full time work

1988 Diarmuid is born with Down syndrome

1989 Philip is born

1991 Colm is born

**Life happens and we cope!**

# What does Governance mean?

- Legislation, Financial Functioning, Health and Safety.
- Who's responsible – Government
- Have we Good Legislation?
- Disability Act 2005, EPSEN Act 2004
- Assisted Decision Making Bill
- UN Convention
- Difficult climate for the HSE

# What do Individuals want Governance to Deliver?

- My words: Individuals need to be supported to lead ordinary lives
- Diarmuid's words: My own home, a job and not just any job. "I want to be an actor in Hollywood!"  
I want to have an amazing life!



# What do Families want Governance to Deliver?

- A happy life for their son/daughter, brother/sister, aunt or uncle with a guarantee of safety and good health care.
- Do Families think about Governance?  
No!  
Too busy, Trust the Provider.

# Climate of Suspicion

- In our recent past **trust was broken!**
- Lack of accountability
- All of it has hurt.
- Result is more control

So what has this meant for Voluntary Organisations' Boards and Governance?



# Board Reality in 2018

- It has torn the hearts out of them
- It has made the public suspicious
- It has drawn down Governance on top of Governance!
- It has rendered it practically impossible to function in a person centred way
- It has killed off “Blue Sky Thinking.”

# Is this Culture sustainable?

Permission  
to hire  
extra staff

Permission  
to create a  
new  
service

Chief Executive Report

Audited Accounts

Quality, Safety and Governance

HIQA Reports

## Service Level Agreement

Permission  
to create a  
new post

Waiting Lists

Procurement

Risk Management

Permission  
to buy a  
house

Critical Incidents

Financial Statements

# Risk Management

The bodies and systems that Voluntary Orgs are accountable to include:

HIQA- Health Info and Quality Authority

NIMS - National Incident Management,

HSE Safeguarding & Protection Team,

Gardai – Criminal Justice Withholding of Information Act 2012 re Children and Vulnerable Adults,

Tusla - Child and Family Agency

CORU - Regulating Professionals

Trust in Care - Guidelines for Employees

HSA - Health and Safety Authority.

# We have reached a cross roads

- **We are suffering because of history**
- **We are drowning in red tape**
- **We need to breathe**
- **We need to innovate**
- **We need to be trusted**
- **We need to deliver for the people we support**



# Change the Culture

- Trust each other
- We need to be able to respond
- We need to be able to borrow money
- We need to be able resolve decisions locally with the people who know us
- Governance must not control us
- Understand Policy
- Value Policy
- Inter Agency Collaboration

# What should we be discussing?

- Real service provision in how we enhance peoples everyday lives
- Opportunities to upskill ourselves
- Bringing self advocates onto our boards
- Communicating in an accessible way
- Benchmarking how many lives we've made more ordinary since the meeting before .....
- Time for Blue Sky Thinking

# Community Must Step Up

- An Education Programme is required
- To facilitate opportunities of employment
- To foster inclusion in community activities
- To provide worthwhile educational opportunities
- A caring society has to be enabled
- Think of how communities responded in 2003

# **We need to rebuild trust**

- Better communication
- Attention to Governance without overkill
- By continuing to place the person needing the support at the centre
- By implementing policy
- By enacting and improving legislation
- By allowing time for “blue sky thinking!”