LHCP2021
7-12 June
Online

ResearchAbility:
Do we really need a more inclusive environment in research?

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on behalf of the ResearchAbility Task Force
Marie Curie Alumni Association

MARIE CURIE ALUMNI

ResearchAbility

Definitions of Disability: Medical vs. social model

Medical Model

Social Model

Is housebound

Needs help and carers

Confined to a wheelchair

Has fits

The problem is the Disabled person

Can't walk

Is sick Looking for a cure

Can't get up steps Can't walk

Can't see or hear

Badly designed buildings

Poor job prospects

Stairs not ramps No lifts

Isolated families

The problem is the disabling world

Special schools

Inaccessible transport No parking places

Few sign language interpreters

Discrimination

Source: InclusionLondon

Inclusion and Diversity

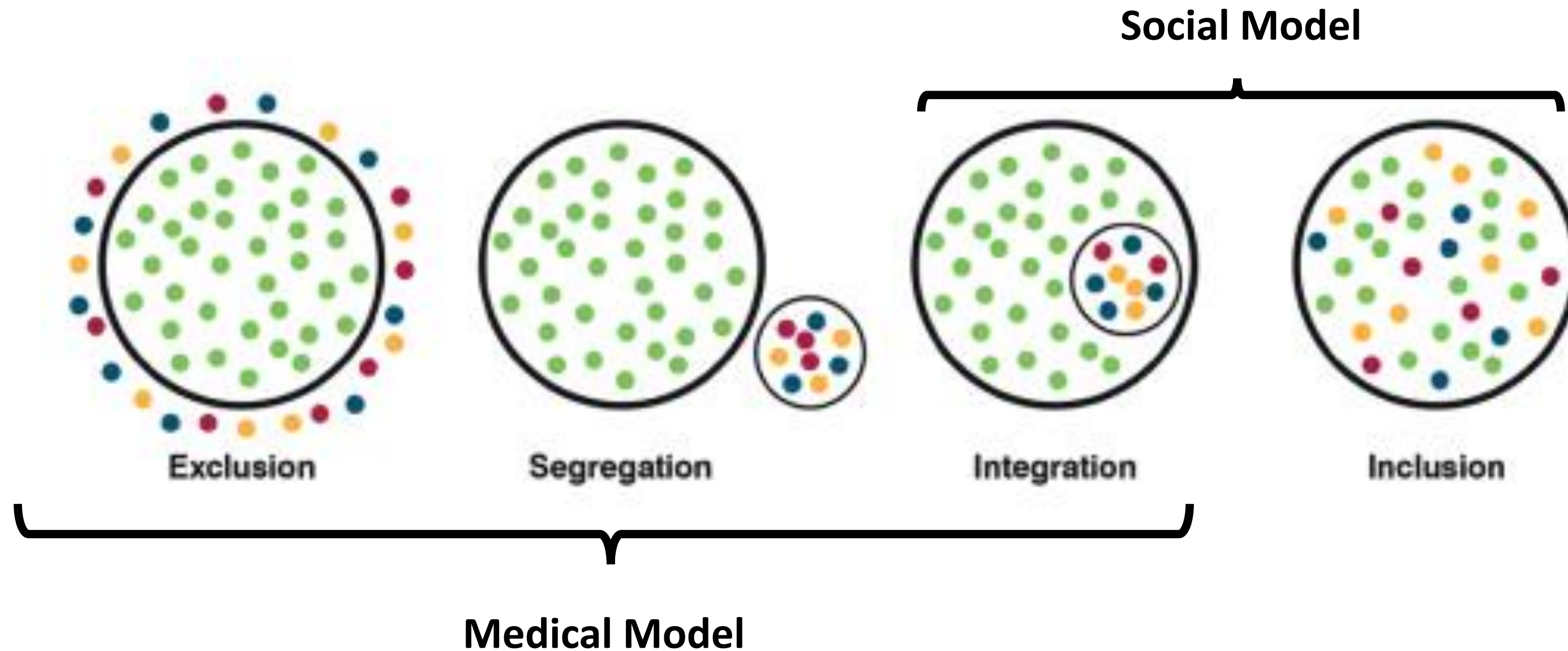Exclusion   Segregation   Integration   Inclusion
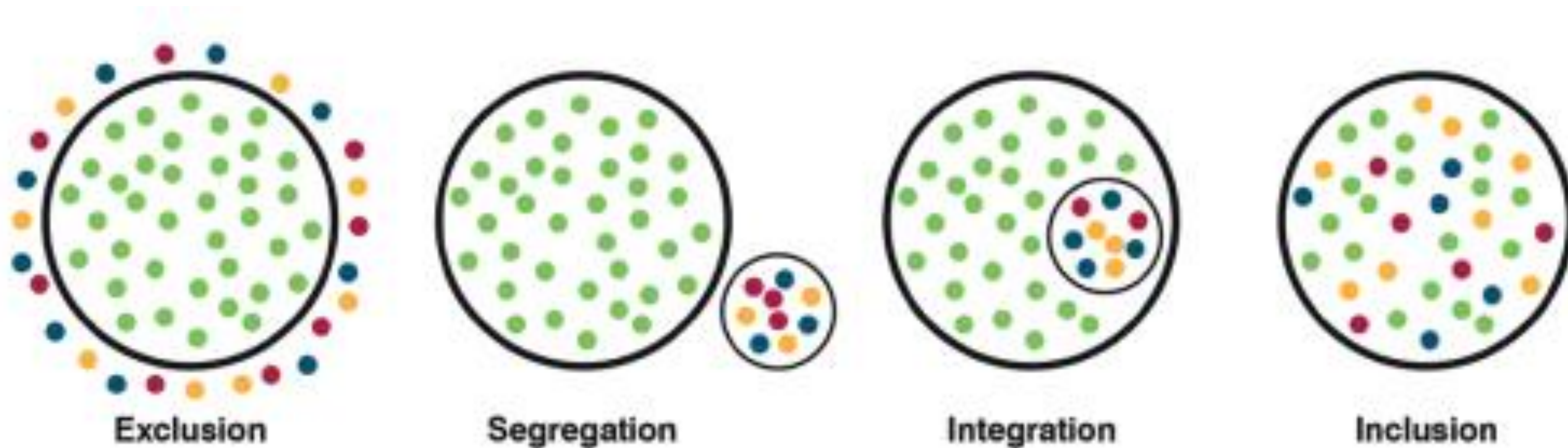
Source: City of Sidney (Disability) Action Plan 2017-2021

Human variation paradigm
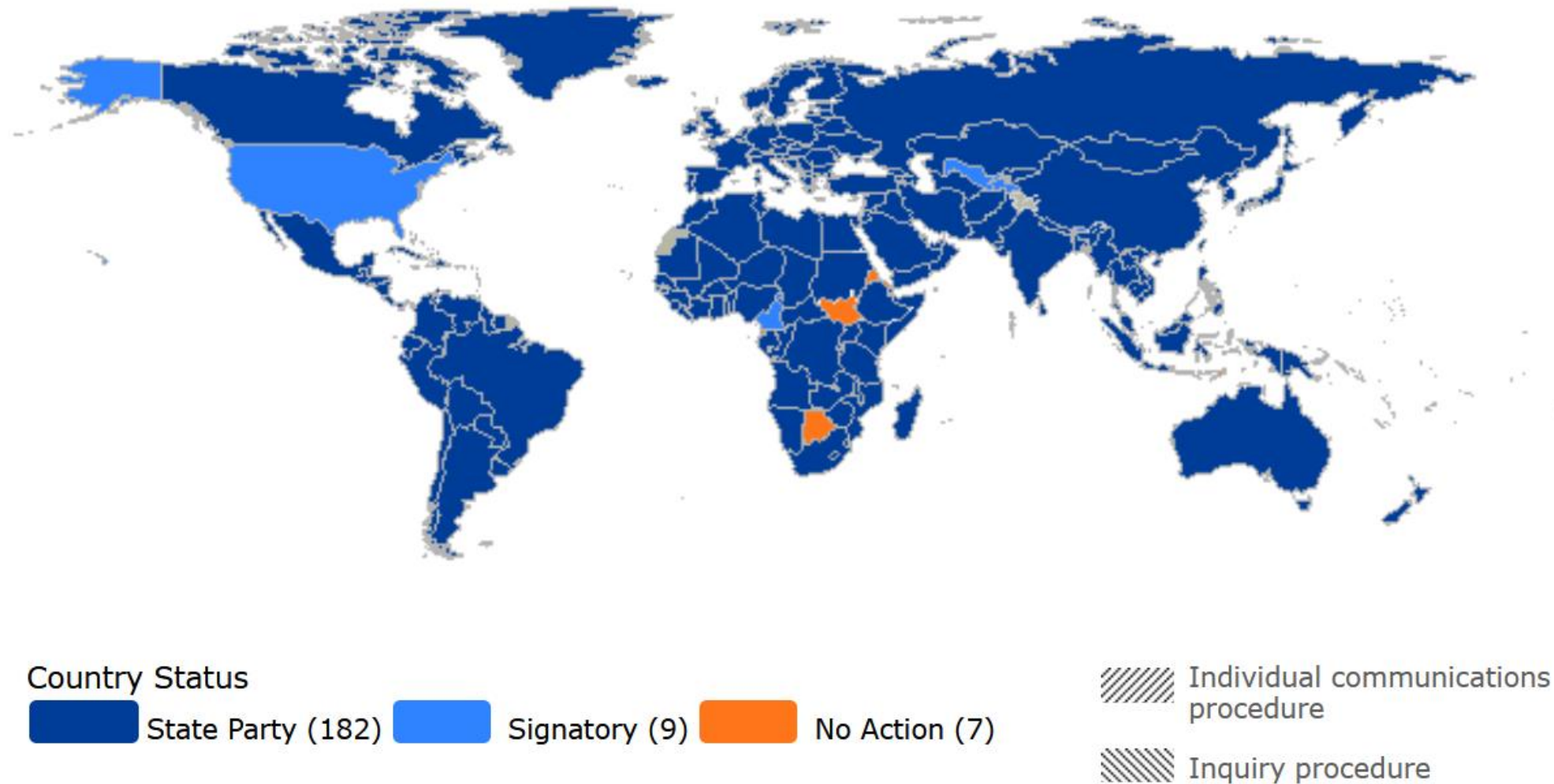"Difference is not an exception, not a monstrosity, but something that happens in the natural course of things"

(Stiker, 1999/1997, p. 12)

Inclusion and Diversity

Social Model

Medical Model

Exclusion   Segregation   Integration   Inclusion

International Legal Framework:
UN Convention on the Rights of Persons with Disabilities

World

Europe

Country Status
State Party (182)   Signatory (9)   No Action (7)

Individual communications procedure

Inquiry procedure

Source: UN OHCHR

UN Convention on the Rights of Persons with Disabilities
- **disability is an evolving concept**
- disability **results** from the **interaction between persons with impairments** and attitudinal and environmental **barriers**
- that hinders their full and effective participation in society on an equal basis with others.

Legal Framework: Terminological Confusion

The case of accessibility:

- Accessibility as a principle for human rights

- Accessibility as a human right per se

- Accessibility as a human right for persons with disabilities

- Accessibility as a pre-condition for human rights

Difficulties in the implementation of effective laws and regulations

National Legal Framework: not homogeneous

Three main groups:

1. Non-discrimination model with common law plans (UK, Sweden)

2. Mix in between the two models (Portugal, Neatherlands)

3. Social protection model with quotas and protected work sector (Germany, France, Italy)

RIGHTS OF PERSONS WITH DISABILITIES

2016:
Council of **Europe** adopted **Strategy** on the Rights of Persons with **Disabilities** 2017-2023

Example of a problem: the legal recognition of disability is not transferrable to another country, possibly lost when being in mobility

Excellence: Is it enough? Dangerous narratives

J. A. Fleming

Dorothy Hodgkin

Stephen Hawking

Temple Grandin

"The 'super crip' narrative, a character centered story telling of how a person overcame disability, often by heroic means. […] disability is a tragedy to be 'overcome' by heroic individual efforts" (Maconi 2020).

Some data from the UK

W. Joice and A. Tetlow (2021), Disability STEM data for students and academic staff in higher education 2007/08 to 2018/19. Executive Summary.

Conducted by JISC on behalf of the Royal Society.

Some data from the UK: Students 1

The percentage of STEM entrants with a known disability is rising year on year at both first degree and postgraduate level.

The percentage of STEM first degree entrants with a known disability has increased from 7.5 per cent (12,585) in 2007/08 to 15.5 per cent (33,530) in 2018/19.

At postgraduate level, the percentage of STEM entrants with a known disability has increased from 6.1 per cent (3,400) in 2007/08 to 12.5 per cent(12,585) in 2018/19.

Much of this growth can be attributed to the large rise in the number of STEM students reporting either a mental health condition or a specific learning difficulty.

Source: Text quoted from Royal Society Report

Some data from the UK: Students 2

The percentage of entrants with a known disability is lower for students studying STEM subjects than non-STEM at both first degree and postgraduate level.

Despite the rise in numbers with certain disabilities, those STEM students who are blind or deaf (or have a serious visual/hearing impairment) have not increased as a percentage of all STEM students over this period.

STEM first degree students with a known disability are continuing into postgraduate level study in roughly the same proportion. There does not appear to be a drop-off.

Some variation in the subject areas for STEM entrants with a known disability: In 2018/19 17.8 per cent for Biological sciences compared with 10.9 per cent for Medicine and dentistry subjects.

Some data from the UK: Students 3

There is little difference in the non-completion rate between those with a known disability and those without for STEM first degree students.

For postgraduate STEM students the gap is wider–those with a known disability are more likely to leave with no award compared to those with no known disability.

Some data from the UK: Staff 1

The percentage of STEM academic staff with a known disability has increased from 2.0 per cent (1,645) in 2007/08 to 3.8 per cent (4,465) in 2018/19.

The percentage of academic staff with a known disability is lower for staff working in STEM than non-STEM.

There is variation in the subject areas that STEM academic staff with a known disability work in.

In 2018/19 5.3 per cent of STEM academic staff working in Subjects allied to medicine have a known disability vs 2.7 per cent in Agriculture & related subjects.

Some data from the UK: Staff 2

STEM academic staff with a known disability are more likely to have a contract that is teaching only compared to STEM academic staff with no known disability.

STEM academic staff with a known disability are less represented in more senior contract levels.

They are less likely to hold a senior position than STEM academic staff with no known disability

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The ResearchAbility Initiative

- Born in 2018 as a multi-association initiative by initiative of Alexandra Nothnagel.

- Researchers with disabilities & research about disability

- Since 2019: a subgroup of the Task Force "Diversity & Inclusivity", within the Genders, Equity, Diversity and Inclusion Working Group of the Marie Curie Alumni Association

MISSION: Support careers of students and researchers with disabilities and assist making their professional environment accessible.

ResearchAbility's Four Pillars

Inclusive research system with equitable chances for persons with disabilities.

Foster Individual Support

Educate ecosystem Disability, Inclusion, Equity, Accessibility

Research & Expertise

Networking & Policy Making

Nothing about us without us

ResearchAbility Core Team

1. MCAA
- Carlo Antonini – Material Sciences
- Gian Maria Greco – Accessibility Studies
- Murat Gunes – Physics
- Alexandra Nothnagel – Biochemistry/Access. Expert – Initiator of the initiative

2. La fédé 100% Handinamique
- Abdelkhalek Bouchikhi, ICT
- Chems Hacini - Architecture
- Felix Hartmann – Engineering
- Khalil Ibrahim Hamzaoui - ICT
- Madina Karsakpayeva, UN volunteer for inclusive work

External supporters/collaborators
- MCAA GEDI Task Force "Diversity & Inclusivity"
- MCAA Communication Working Group
- Benoît Blossier, CNRS researcher
- Ludovic Petitdemange, researcher at CNRS

Some Actions: MSCA Special Needs Allowance

Support and advise MSCA regarding Special Needs Allowance

Foster Individual Support

MSCA Special Needs ALLOWANCE @MSCActions

Interview of the team in September 2019 :
- List of accommodations
- Part of the fellowship's allowance + contract
- Fellow asks, not institute

Cut-off	Number of submitted proposals	Country of applicants
First cut-off 2019	10	Bulgaria, France, Ireland, Italy, Sweden and the UK
Second cut-off 2019	14	Belgium, France, Germany, Ireland, Spain, the UK and Iceland
First cut-off 2020	5	Ireland, Spain and the UK
Second cut-off 2020	11	Belgium, Switzerland, France, Ireland, Italy, the Netherlands and the UK

researchAbility

Some Actions: Publications, Workshops and Conferences

- MCAA Blog and Newsletters

- Conference sessions within MCAA

- Awareness workshops

- Annual conference

- Chapter events 2019, France

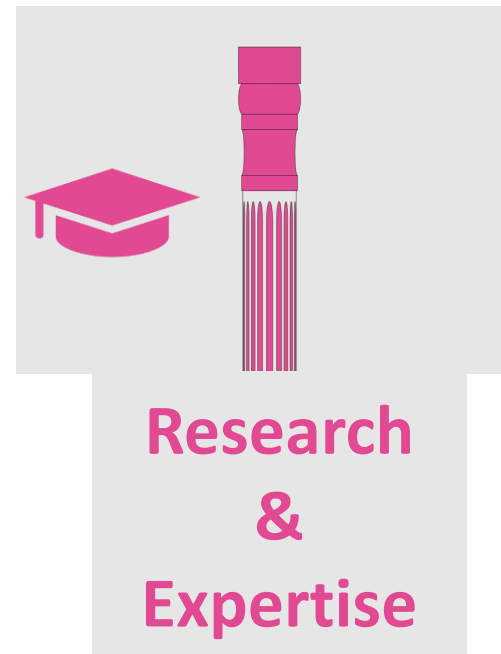- Accessibility guidelines for annual meetings

Educate ecosystem
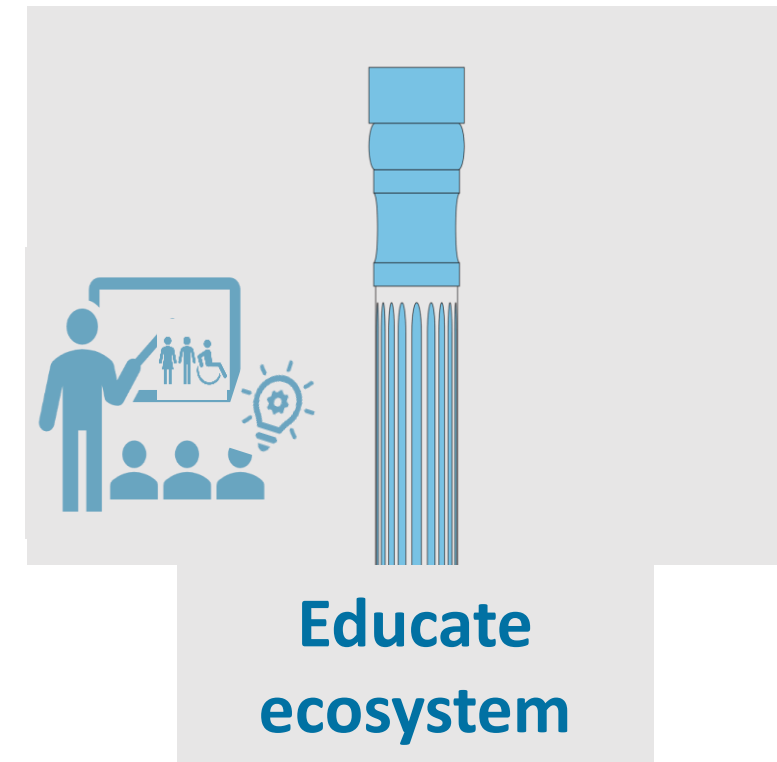
Some Actions: Research projects

Search funding, foster collaborations & visibility of research about compensatory tools, accessibility & inclusion

Proposal of a COST ACTION

Proposal submission: October 2021

Research & Expertise

cost
EUROPEAN COOPERATION
IN SCIENCE AND TECHNOLOGY

Information and Communication
Technologies (ICT)

**Join now and become a main proposer!**

Some Actions: Research projects

**Building a community of disability advocates
and mainstreamers
within and beyond the MCAA.**

Since 2018: collaborating with a La fédée 100% Handinamique

2020: Request of a disability strategy for French multi-year research

programming law "LPPR"

Alternative Report to inform the UN Committee about how the UN CRPD is

respected in France, chapter on research society (with La fédée 100%

Handinamique).

**Networking
&
Policy Making**
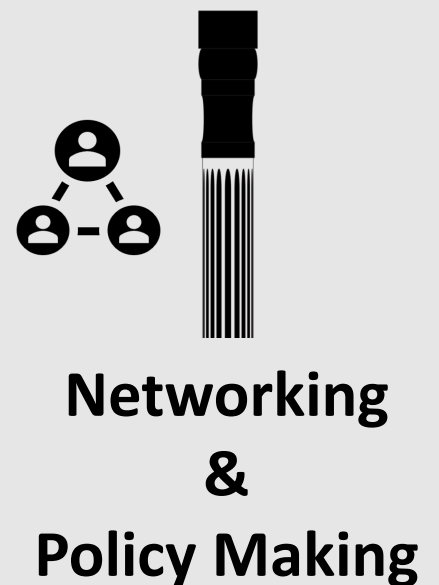
Different experiences

Internal survey: All 4 researchers are in the same country while declaring different disabilities at different career stages.

PhD/Early Stage Researcher

PostDoc

Assistant Professor

Professor/Groupe Leader

"I was told that in MSCA there is no place for researchers with disabilities that risk to affect the efficiency (no 4th year funding for no-one) as this is not compatible with excellence& usage of public funds. All further career support stopped, no PhD, no publication."

"During my studies not even the medical department for medical emergencies had a ramp and they explained the historically protected building could not be adapted for my needs. I had to fight to get access for the accessibility of my courses."

"I guess I am spoilt. My institutions did everything for me to adapt work environment after the work accident that caused my disability, even adapting a historically protected building. Everyone supported me, from team to direction."

"When I finally got the administrative recognition for my evolutive disease impairing my vision opening rights as a worker with disability to, the HR of my research institution explained me to rather choose an early retirement instead of accommodations. And this although I published at a competitive level with the team I led.»

Some issues: MSCA Special Needs Lump Sum

MSCA Special Needs Lump Sum changes for Horizon Europe

Recommendations:

- Part of the fellowship contract (allowance)

- Discuss when & to whom to disclose the disability: disability manager?

- Additional time ESR/PhD funding and durations : > 3 years

- Remote working

- Conditions for grant candidatures (extended time 🗌 as maternity leave)

Some issues: Factors to be addressed

Which factors could influence the inclusion of a researcher with disability ?

Acquired during the career or lifelong?

- Financial aspects

- Adaptive technologies and compensation

- Personal investment and excellence of work

- It is comprehensive and supportive hierarchy and collegues

- Laws

- Regulations, including at the level of the single institutions

Some issues: Factors to be addressed

The heterogenous national laws and definitions and cultures about disability recognition need to be addressed to guarantee equitable access to the dispositive

access to regular and special medical services in the host countries sometimes needed in mother tongue or in local language for recognition (e.g. language barrier for psychologists)

Priorities for Future Actions

EDUCATION
about inclusion and
diversity management

Supporting
SELF-DETERMINATION
and
SELF-IDENTIFICATION
for Researchers

POLICY MAKING
at European
and national level

Promotion of adoption of
ACCESS SERVICES
in education and research

Thank You!

Any questions or needs?

Interested in joining the initiative?

Contact us: researchability.eu@gmail.com