

Executive Summary of DOCTRID Research Strategy

This DOCTRID Research Strategy outlines the mission of the DOCTRID Research Institute (Daughters of Charity-Technology, Research into Disability Research Institute). The DOCTRID RI is a collaborative international institute committed to research excellence into Intellectual Disabilities (ID), autism and cognitive impairment. It was established as a research programme under the RESPECT and Daughters of Charity (DoC) Board in October 2010 and is made up of the DOCTRID Research Board (DRB), stakeholders and funders¹. The DOCTRID Research Institute is overseen by the DOCTRID Research Board (DRB) which was established in 2011 with the aim of providing accountability and proper governance, oversight of good practice and due diligence in the operations of the RI. The objective of the DRB is to make informed decisions which will serve the long term interests of the DOCTRID RI and its stakeholders. The DRB will identify, promote and manage new collaborative initiatives with existing and new national/international key partners from academia, the private sector and Service providers.

The aims of the DOCTRID Research Institute are

- To enlarge the DOCTRID RI with more excellent research organisations and to create a critical mass of scientists, engineers and service providers.
- To oversee the successful management of existing research programmes; the ASSISTID Marie-Curie COFUND and the Michigan State University-DOCTRID programme (Hegarty Fellows)
- To serve as a centre of research excellence in conducting evidence-based research to inform policy and practice throughout the organisation to improve services, care and outcomes for the individuals served at the Daughters of Charity Service and other State-subsidised Intellectual Disability and Autism services in Ireland.
- To support the partnership between the universities and DoC service through the acquisition of funding for sustainable research programmes, fellowships and the development of assistive technologies.
- To enable the professional service training of fellows in the Care Service Centres of the DoC, its special schools and employment training centres, and in the DoC Community Housing projects (SmartHomes and Intelligent Design) for people with disability.
- To bring together the critical mass of scientists, engineers, behavioural therapists, psychologists, rehabilitation therapists and people with ID and autism, their families and carers to conduct interdisciplinary and inclusive research to improve services, care and standards of living for people with ID and Autism via evidence-based practices and assistive technologies.

- To ensure research and training carried out under the remit of the DOCTRID RI will include a wide array of disciplines relating to ID, autism and cognitive impairment including Applied Behaviour Analysis and Autism, Augmentative and alternative communication, Assistive technologies and innovative learning, Intellectual disability research Ethics and rehabilitation, Intellectual disability policy and law, multimedia and ICT development, rehabilitation and counselling in employment for intellectual disability and best practice in service provision.

Additional Notes from Prof. Mary McCarron

DOCTRID: Building an Inclusive Research Agenda with People with Intellectual Disabilities.

Given the investment of RESPECT, the sponsorship by the Daughters of Charity and the historic absence of input from people with intellectual disabilities (ID) themselves and their families from the design and delivery of research affecting their lives, there is a responsibility that DOCTRID be a leader in building an inclusive research agenda addressing the critical needs of people with ID.

Building an Inclusive Research Model

Immediately there should be a commitment to include a family member and a person with ID as members of any research advisory and administrative committee and their roles should be both equal to other members and there should be commitment to sufficient orientation and to sharing needed information in an accessible manner so that they may play full decision-making and guidance roles.

The first cohort of DOCTRID fellows should be engaged in developing a series of focus groups with people with ID, with family members and with staff at all levels within the Daughters of Charity and other ID services stakeholders to develop better understanding of the most critical issues, the desired research and interventions and ways in which people with ID, families and staff may be included in planned projects. This process will include training for Fellows on conducting such focus groups emphasizing inclusive and respectful language, soliciting and exploring opinions, and participating/guiding techniques that avoid leading and directing discussions.

A one day consensus conference should then be organized including DOCTRID key researchers, Daughters of Charity and RESPECT administrators, DOCTRID Fellows, and interested and willing self-advocates for their fellow people with ID, families and staff at all levels identified through the focus groups process.

From this conference DOCTRID guidelines for inclusive research will be developed, a planned set of project developed and preliminary research teams identified that include people with ID, families and staff as well as DOCTRID fellows and academic researchers.

Fellows, therefore, as part of their post-doctoral training, will become expert in inclusive research approaches and the opportunity for such training will be a defining aspect of DOCTRID.

Although the focus group and consensus conference process may identify different or other priorities, three areas may be a starting point for the discussions. Regardless, once an agreed set of studies is identified, in recruiting future Fellows they will be asked to match their interests to and commit to a specific project.

Promoting Healthy and Fulfilling Lives

For the general population there are a range of evidence-based interventions that are intended to improve health and make lives more fulfilling and enjoyable. People with ID rarely participate. Yet, it is well established that people with ID have greater levels of health problems, have more sedentary lifestyles, participate less in physical activities, have poorer diets and are less able to access healthcare and health screenings. Even health promotion activities targeted at people with ID are rarely utilized. There is a need for research and technology based solutions to help increase the identification of such health and quality of life concerns, linkage and support to health promotion programs and identification of adaptations to programs (while remaining consistent with evidence for efficacy) to better include people with ID in mainstream offerings. Input at all levels of projects from people with ID, families and staff will increase relevance and success.

Building Inclusion and Participation

Movement to community setting or living with family does not necessarily mean that people with ID are members of their communities and participate in ways similar to the general population, even though that is the stated intention of community living. Transportation, awareness, access and acceptance barriers often mean people with ID lead isolated lives. In addition, there is evidence that people with ID are less likely to use mobile and smart phones, the internet and social media tools meaning virtual as well as actual isolation. Interventions and related research and technology tools are needed to address all of these barriers particularly the development of accessible travel, mapping, cueing, medication reminder, and social calendar apps, touch screen solutions, dedicated web pages, inclusive yet secure virtual communities/blogs/social media, monitoring systems and tools and technology supported environmental modifications.

Managing and reducing additional disability in dementia and other chronic illness

Persons with lifelong disabilities who have enjoyed some level of self-determination and self-management often see that independence threatened when dementia, arthritis, osteoporosis, and other age-related chronic conditions occur. Adaptive equipment and technology supports are often seen as occurring in earlier years to build capacity for self-management and independence but may need to be revisited in older years and will often need to be different kinds of solutions more

responsive to the unique challenges of additional disability and designed to maintain rather than add to function and/or to compensate when continuance of prior activities and solutions pose too much difficulty. Interventions and related research and technology tools are needed to address monitoring needs, communication and memory supports, medication and treatments management, brain training and stimulatory activity, adaptive furniture, and technology supported environmental modifications.

In all three areas some of these interventions and the related technologies may be already be available or are being tested in the general population. However, there is a need to test for effectiveness and to consider and test adaptations for people with ID. In addition, efforts to develop unique solutions for people with ID may have offer suggestions for improvements that will also benefit the general population. Regardless the prime consideration for DOCTRID will be to better the lives of people with ID.

¹ Partners are Dublin City University (DCU), National University of Ireland Maynooth (NUIM), National University of Ireland Galway (NUIG), Trinity College Dublin (TCD), University College Dublin (UCD), University College Cork (UCC), University of Limerick (UL), the Royal College of Surgeons in Ireland (RCSI), Institute of Technology Tralee (ITT), Dublin Institute of Technology (DIT), Queen's University Belfast (QUB), Ulster University (UU), Michigan State University, University of Massachusetts Medical School and the Intellectual Disability Services of the Daughters of Charity, and other Services providing care and education to people with autism or intellectual disability as appropriate