

## **Supported Decision Making for People who Communicate Differently**

**hosted by the Centre for Disability & Policy (CDLP) NUI Galway on the**

**20<sup>th</sup> June 2017 at 7.00 – 9.00pm.**

**This event will be held in the G018 Theatre, ILAS Building, North  
Campus, National University of Ireland, Galway**

**Speaker: Dr. Jo Watson, Deakin University, Australia**

This seminar is aimed at all people who support people who communicate differently or informally including people supported, family members and professionals who work in support services especially speech and language therapists

Dr. Jo Watson is a Speech Pathologist, lecturer and researcher with over 25 years experience in the disability sector as a clinician, trainer, support worker, and family member from Deakin University in Australia. She has supported and been supported by people with disability for many decades. Jo's interests are focused on developing techniques to discover the will and preference of those she believes are rarely heard, people with severe cognitive disability who communicate informally. Jo believes these people are some of the most disempowered people on the planet, and the discovery of their will and preference are essential for them to achieve genuine social inclusion. Jo has lived and worked in Australia, China and the United States and is very excited to be in Galway for the first time.

Jo Watson's 2016 PhD thesis was entitled "The right to supported decision-making for people rarely heard" her work is pioneering on new methods of informal communication to identify will and preference for people who communicate differently. Prof. Gerard Quinn says: "The myth system of autonomy is one thing - it is the operation system that needs to change. It's time to get real - and there is no better person than Jo to show us how to do this."

The abstract of her thesis summarises this work as:

*The adoption of and entry into force of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) represents an important step towards promoting, protecting and ensuring human rights for people with disability (United Nations., 2006). Article 12 of the Convention, requires that legal capacity should not be defined based on cognitive disability. It mandates that all people with disability be recognized before the law*

*on an equal basis with others and importantly be supported to exercise that legal capacity. In so doing, it challenges the use of substitute decision-making. Substitute decision-making allows others to make decisions for someone else. In response to the UNCRPD, supported decision-making is emerging as an alternative paradigm to be employed in lieu of substitute decision-making, consistent with signatory nations' obligations under Article 12 of the UNCRPD.*

*Australia ratified the Convention in 2008. Since this time, tension has existed around the relevance and application of Article 12 for those who communicate informally, and sometimes unintentionally: people with severe or profound intellectual disability. Due to the interdependent nature of their lives, autonomous decision-making is obviously challenging for this group. However, if signatory nations to the UNCRPD are to live up to their obligations under Article 12 attention needs to be paid to how best to support this population to have their preferences heard and reflected in the decisions that are made about their lives. This is the central focus of this thesis.*

*This study used an interpretative, multiple case study design. Five people with severe or profound intellectual disability and their circle of support participated in a supported decision-making approach, targeting a range of life decisions. Interview, focus group, questionnaire and observation data were collected and analysed.*

*A primary aim of this study was to characterize supported decision-making for people with severe or profound intellectual disabilities. Addressing this aim, supported decision-making was characterized for this group in terms of the existence of two distinct but interdependent roles. Drawing from the study's data, the thesis describes the roles played by (a) the person with a disability (supported), and (b) the circle of support (supporters) in the supported decision-making process. The role of the person with a disability in this dynamic is their expression of preference, and the role of supporter is to respond to this expression of preference by acknowledging, interpreting and acting on this expression in some way.*

*Within this decision-making dynamic, supporter responsiveness, as opposed to focus people's expression of preference, is the component that is amenable to change through structured practice guidance, making the enablement of responsiveness a crucial strategy for supporting decision-making. This focus is consistent with the social model of disability, where the onus of enhancing decision-making capability should not rest with the person with a disability, but with the environment of which they are a part.*

*A secondary aim of the study was to identify and discuss factors that underlie supporter responsiveness and therefore supported decision-making for people with severe or profound intellectual disability. Five themes and ten sub themes, characterizing supporter responsiveness within the context of supported decision-making for people with severe or profound intellectual disability were identified. These themes are explored in this thesis.*

*The thesis furthers understanding of what supported decision-making looks like specifically for people with severe or profound intellectual disability. These findings give a focus for practice and policy efforts for ensuring people with severe and profound disability receive appropriate support in decision-making, a clear obligation of Australia under the UNCRPD.*

**Keywords:** *supported decision-making, severe and profound intellectual disability, UNCRPD, complex communication needs.*

This event will be recorded and made available on the CDLP website afterwards.