### **MEMO**

**RE:** Options for Establishing a Disability Studies

Association of Ireland.

TO: National Institute for Intellectual Disability (Trinity

College Dublin), Disability Studies Centre (University College Dublin), Professor Roy McConkey (University

of Ulster).

FROM: Centre for Disability Law and Policy (NUIG).

**Date:** 16 **November**, 2011.

## **Purpose of Memo**

The purpose of this memo is to explore options for the establishment of a Disability Studies Association in Ireland or a similar body (North and South).

The study of disability has grown exponentially in Ireland (North and South) in the last two decades in part due to pioneers such as Professor Patricia Noon-Walsh in UCD. There is scarcely an institution of higher learning in Ireland without a researcher on disability. Most disciplines are represented – but not connected. Some of the teachers/researchers conduct their work in isolation. A network of some sort would allow them to emerge and step up their engagement and impact both at national level and internationally.

In order to explore the options some background research was conducted to see how such associations have been established elsewhere.

Building on this comparative survey the memo sets out the options concerning the possible functions, purpose, organizational structure and membership of some form of Irish association.

We would like to acknowledge and warmly thank Professor Rannveing Traustadottir (Nordic Network on Disability Research), Professor Mark Priestly (Leeds University Disability Studies Centre), Professor Dan Goodly (Manchester Metropolitan University), Professor Jennifer Harris (University of Dundee) and Professor Bob Sapey (Lancaster University) for invaluable assistance and guidance. All errors are ours.

The main researcher on this memo was Rosin Fitzpatrick to whom we are most grateful.

- 1. A Survey of Existing Disability Studies Associations.
- 2. Non-Disability Studies Associations in Ireland that may Provide a Model.
- 3. The Common Features in Disability Studies Associations.
- 4. Options for the Future with respect to the establishment of a Disability Studies Association of Ireland.
- 5. For Consultation & Decision.

### 1. Survey of Existing Disability Studies Associations.

A survey of existing regional and national disability studies associations and research networks was undertaken in preparation of this options paper.

The most useful comparators for a possible Irish Disability Studies Association were as follows: the UK Disability Studies Association, the Nordic Network on Disability Research, the Canadian Disability Studies Association and the US Society for Disability Studies. A brief introduction to each of these organisations is provided below, to give context for potential discussions in the Irish context.

**UK Disability Studies Association** <a href="http://www.disabilitystudies.net/">http://www.disabilitystudies.net/</a>
The UK Disability Studies Association was formed around a core group of those involved in the editing of the journal Disability & Society and focused on a newsletter and a national conference.

With the growth of disability studies in Britain and its internationalisation it came more to focus on a bi-annual conference. Then Lancaster University rather took on the role of conference host and this continues.

There is a website but there is no longer any actual 'association' that one could really point to. The website refers on to the Lancaster Centre for Disability Research, the Leeds Centre for Disability Studies, the Dundee Interdisciplinary Disability Research Institute and the Manchester Metropolitan Research Institute for Health and Social Change. Mark Priestley of Leeds University and Dan Goodly of Manchester Metropolitan University, Jennifer Harris of University of Dundee and Bob Sapey of Lancaster University are our contacts.

Lancaster University Centre for Disability Research hosts a biennial international disability studies conference. These conferences to date have been held in 2003, 2004, 2006, 2008, 2010. Information on the conferences is available at <a href="http://www.lancs.ac.uk/fass/events/disabilityconference/">http://www.lancs.ac.uk/fass/events/disabilityconference/</a>.

Nordic Network on Disability Research <a href="http://www.nndr.no/eng">http://www.nndr.no/eng</a>
NNDR is a multidisciplinary network of disability researchers interested in cultural, societal and environmental dimensions of disability and marginalization. The purpose of NNDR is to advance research and development in the field of disability.

It combines the Danish, Finnish, Icelandic, Norwegian and Swedish Networks on Disability Research. Bodil Ravneberg of the Norwegian Network on Disability Research is our contact.

The NNDR is governed by statues that were proposed, discussed, amended, and approved at the founding meeting of NNDR 1997, revised in 1998 and 2003 and again in 2007. These are available at <a href="http://www.nndr.no/eng/Statutes">http://www.nndr.no/eng/Statutes</a>.

Membership is open to persons who work in research and/or development in the field of disability, as well as others interested in such research. The Board is elected for two years and consists of: President, Treasurer and three other members – the five board members must represent the five Nordic countries. The Associate Board members are also elected for two years and consist of a NNDR webmaster, NNDR editor and five substitute board members who must also represent the five Nordic countries. The NNDR has hosted biennial conferences since 1993. The Board decides which country will have responsibility for each conference. The conference committee shall have a contractual agreement with the Board. They also publish the Scandinavian Journal of Disability Research. The Editor is appointed by the Board, an appointment presented to the General Assembly as a point of information. The Editor appoints consulting editors in collaboration with the Board.

There is no financial information available to us. Members do pay annual dues as decided by General Assembly. Also a conference fee is charged for NNDR conferences.

Canadian Disability Studies Association-Association Canadienne des Études sur L'Incapacité. <a href="http://www.cdsa-acei.ca/english.html">http://www.cdsa-acei.ca/english.html</a>
The CSDSA/ACEI is a multi-disciplinary, non-profit organization that promotes the exploration of disability through research, publications, artistic production, teaching, and general development. A key value of the CDSA-ACEI is to bring Canadian perspectives into the global scholarship that is currently growing regarding disability issues and disability rights. Dawna Lee Rum ball, the Secretary-Treasurer and Nancy Viva Davis, the President-elect, on the Executive Board are our contacts.

The CDSA/ACEI is governed by the CDSA Bylaws (<a href="http://www.cdsa-acei.ca/english.pdf">http://www.cdsa-acei.ca/english.pdf</a>). Membership in CDSA/ACEI is open to anyone interested in promoting the purposes and principles of the association. The CSDA/ACEI Executive Board is elected annually and consists of: President, President-elect, Past President, Secretary/Treasurer, Publications Officer, Newsletter Editor, Student Representative, Social Media Coordinator, Bilingual Coordinator, Conference Coordinator, Vice Conference Coordinator, Canadian Centre on Disability Studies Liason Officer.

The CDSA/ACEI have held annual conferences since 2004. At the AGM the General Assembly nominate a conference coordinator to create a conference committee to oraganise their annual conferences. They also publish the Canadian Journal of Disability Studies. From the General Assembly, three members will serve for two years on the Publications Committee to oversee the development and publication of a peer-reviewed journal. The first issue will be published in September 2011.

The CDSA-ACEI presents a Tanis Doe Award for Canadian Disability Study and Culture. It was first awarded in 2009, and is named for the activist and professor, Tanis Doe, who passed away in 2004. This award honours an individual who dares to "speak the unspeakable" in advancing the study and culture of disability, and who has enriched through research, teaching, or activism, the lives of Canadians with disabilities.

They produce financial reports annually (<a href="http://www.cdsa-acei.ca/about.html">http://www.cdsa-acei.ca/about.html</a>). They support themselves financially through:

- 1. Annual Membership Dues from Members: Faculty and Professional (\$60), Other Waged (\$30) and Student, Unwaged or Retired (\$20).
- 2. Annual Conference outgoings and incomings roughly equal themselves out.

#### Society for Disability Studies, USA http://disstudies.org/

The SDS is a scholarly organization that is dedicated to the cause of promoting the disability studies as an academic discipline. Through research, artistic production, teaching and activism, the SDS seeks to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to advocate for social change. Our contact is Joan Ostrove, Secretary on the Board of Directors.

Founded in 1982 as the Section for the Study of Chronic Illness, Impairment, and Disability (SSCIID), the organization was renamed the Society for Disability Studies in 1986. SDS are governed by By-Laws. The Society for Disability Studies welcomes members from all countries of the world. There are four levels of membership: Life-Time membership, Organisational membership, Professional membership and student/low-income membership. SDS also runs an online discussion forum for its members.

The SDS Board of Directors is elected annually by the SDS's membership. The Board Officers consist of thirteen directors, including: President, Vice-President, Treasurers and Interim-Secretary. There are also SDS Board Directors, an SDS Executive Officer and DSQ Editor. There are also seven standing committees. SDS hosts an annual international conference. <a href="http://afdo.org.au/node/4">http://afdo.org.au/node/4</a>. SDS also publishes the Disability Studies Quarterly exclusively online. <a href="http://disstudies.org/dsq/">http://disstudies.org/dsq/</a>. SDS has also set out guidelines for programs that describe themselves as "disability studies". <a href="http://disstudies.org/guidelines-for-disability-studies-programs/">http://disstudies.org/guidelines-for-disability-studies-programs/</a>. In an effort to ensure that outstanding scholarship is recognized, SDS has established two awards to honor individuals who have shown dedication to Disability studies. These are the: Senior Scholar Award and the Irving K. Zola Award for Emerging Scholars in Disability Studies.

They do not publish their financial annual reports. However the Directors are responsible for maintaining adequate finances for the Society's operation. Also members pay membership dues, which range from \$1000 to \$30.

## 2. Some Non-Disability Associations in Ireland that May Provide a Model.

In addition to the disability-specific associations and networks described above, a number of Irish non-disability related academic or research associations were chosen as comparative examples which might prove useful. The examples highlighted here are the Social Research Ireland Association, the Irish Society of Comparative Law and the Children's Research Network. This is not intended to represent an exhaustive list of academic associations in Ireland but to provide examples of the various approaches that could be taken.

#### **Social Research Association Ireland**

#### http://www.the-sra.org.uk/sra\_ireland.htm

The Social Research Association Ireland plays a unique role as an organisation open to social research practitioners and trainees from all sectors, as well as others with an interest in social research. SRA has a unique contribution to make to the professional development of social research in Ireland. The SRA provides a forum for people working in a diverse range of settings and in different subject specialties, to form wider contacts, exchange views and information, and pursue issues of common concern.

The SRA has been registered as a charity since May 1st 2008. Their Memorandum and Articles have been submitted to Companies House and the Charity Commission for approval and registration.

According to it's Memorandum and Articles, SRA has open membership where annual subscription fees must be paid. Members are entitles to vote at an AGM and an EGM.

The trustees and offices of Chair, Vice-Chair, Honorary Secretary and Honorary Treasurer are elected at the AGM.

The purpose of the Board of Trustees is to lead, direct, monitor and control the a ctivities of the Social Research Association (SRA) so that its mission and objectives can be achieved; and to formulate corporate strategy, These officer posts shall each normally be held for a period of two years but members must seek renomination in the normal way for subsequent terms. The trustees and Company Directors manage the Charity, property and funds. A copy of the Charity's latest available statement of account must be supplied within two months to any

Trustee or member, or to any other person who makes a written request and pays the Charity's reasonable costs

There is no financial information available on their website. However membership costs £84.00 per year for full-time workers, £52.50 for part-time workers and retired, and £25.00 for unwaged and full time student members.

## Irish Society of Comparative Law www.iscl.ie

The Irish Society of Comparative Law (ISCL) was established in June 2008. ISCL's purpose is to encourage the comparative study of law and legal systems and to seek affiliation with individuals and organisations with complementary aims. We are recognised by the International Academy of Comparative Law.

ISCL is governed by it's Constitution, which is available at: <a href="http://www.iscl.ie/constitution.html">http://www.iscl.ie/constitution.html</a>. Its membership is open to those interested in Irish and comparative law. There are four categories: individuals, institutions, students and honorary membership. Executive business is conducted by our Executive Council. The Executive Council is made up of the following officers: President, Vice President and Secretary. Members at General Meetings elect the Council for three year terms. They will appoint a treasurer and individuals for an Advisory Board. The Officers also select individuals for a National Committee representing the Republic of Ireland in the International Academy of Comparative Law.

ISCL hold a conference along with their AGM. It was last held in 2010 in Belfast. <a href="http://www.iscl.ie/events.html">http://www.iscl.ie/events.html</a>.

There is no financial information available on their website. However members due pay membership dues, which is €50/£45 and free for students.

#### **Children's Research Network**

http://www.childrensresearchnetwork.org/

The Network has been formed out of two pre-existing networks and brings together a wide range of professionals with an interest in research on child and family issues across the island of Ireland.

The Network seeks to: build bridges between researchers in different sectors of this research community to create a network and focus on developing structures and mechanisms to promote the sharing of information, joint learning, joint working and the promotion of better understanding across the different sectors. It also links more experienced and early career researchers and create opportunities for researchers to raise awareness of relevant issues. For its

members it develops a range of membership services that support researchers in this field to build better technical skills and provide training and other supports. The Network publishes a newsletter of activities and events.

Executive Committee which is made up of a chair, secretary, treasurer, communications officer, activities officer and membership officer. There is also the founding Steering Group includes researchers from academia, government, voluntary and independent sectors.

Membership of the Network is open to any person with a bona fide involvement in child or youth or social research including research policy professional working with an institution or organization, independent research policy professionals, students and retired/Emeritus researchers.

The Network receives funding from Atlantic Philanthropies. Also the members pay membership dues, which range from €10 for unwaged and students to €25.00 for full-time employed.

# 3. Some Common Features of Disability Studies Associations.

Through the research into the various comparative associations all over the world, common themes began to clearly emerge under similar various headings.

#### Overall Purpose.

The common features of the general purpose of the society include: developing a network, fostering research, inspiring further interest in disability studies and encouraging co-operation and collaboration.

These are the common threads that link the comparative associations.

#### **Providing Expanded Networking Opportunities.**

A prevailing feature associations is the creation of a network of individual members, community groups and organisations and other academic organizations.

The associations provide a forum for members to meet, present and discuss research and ideas. They also allow for the exchanging of ideas and opinions of individuals and academics working in the different fields of disability.

For example, the Nordic Network of Disability Research has a threefold network function:

- to promote establishment of a network for Nordic researchers in the field of disability;
- to promote development of national networks in each of the Nordic countries;
- to promote international contacts with individuals and organisations having similar interests.

The main meeting place for the comparable networks and associations across the world are annual or biennial conferences.

The Nordic Network of Disability Research, UK Disability Studies Association, Society for Disability Studies and the Canadian Disability Studies Association-Association Canadienne des Études sur L'Incapacité all run conferences to enable researchers to present and discuss their results from research on disability. Such conferences enhance the understanding of disability, promote greater awareness of disability research and contribute to positive social change. It also promotes the contacts for national and international collaboration.

#### **Promoting Pan-Disability Research.**

The research element features strongly in all the comparative associations.

The Canadian Disability Studies Association-Association Canadienne des Études sur L'Incapacité maintains a "firm commitment to supporting research and scholarship which is fully inclusive of and informed by the perspectives of people with disabilities".

The Nordic Network of Disability Research states that it's "purpose and intention is to promote and advance research and development in the field of disability".

The associations support research and related activities to promote new concepts and ideas and to advocate the research's efficient use to improve the lives of those with disabilities and enable opportunities for their full participation within their community. They provide a co-coordinated and an extensive approach to support research and related activities within the area of disability. This work will lead to developing innovative practices in the fields of disability.

Many comparable associations on a global level publicize their members' research through publishing an academic journal. For example, Nordic Network for Disability Research publishes the Scandinavian Journal of Disability Research; the Canadian Disability Studies Association-Association Canadienne des Études sur L'Incapacité publish the Canadian Journal of Disability Studies and the Society for Disability Studies publishes the Disability Studies Quarterly.

#### Broadening inter-disciplinary interest in Disability Studies.

A purpose of the comparative associations to inspire and stimulate further interest in disability studies and research is a key theme that connects the

associations. The Society for Disability Studies (SDS) seeks to promote greater awareness of the experiences of disabled people, and to advocate for social change.

#### **Expanding International Contacts.**

The promotion of co-operation and collaboration component can be seen in all the comparable associations.

The Nordic Network of Disability Research encourages national and international exchange and collaboration. The associations develop extensive links and connections to the broader disability and research community on a global level. This facilitates a sharing of information and resources with associations and networks working in the areas of disability studies in other countries.

# 4. Options for the future with respect to the establishment of an Irish Association.

#### a. No formal association but a meeting point.

There would be no formal structured association but a meeting point would be created for those who are interested in advancing disability research and development.

As in the UK, the meeting point could take the form of an annual or biennial meeting of members or an annual or biennial conference. A biennial conference can bring members together to present, discuss and critique research on various areas of disability studies. This option is similar to the UK Disability Studies Association which runs a biennial conference as a meeting point for those interested in disability studies.

#### Advantages:

An advantage of this option is that there is a smaller amount of work required. Also all efforts of organisers can be focused on organizing the meeting point which can lead to a successful conference or meeting.

#### Disadvantages:

This option would be a smaller organisation which has less potential of creating a strong network and enabling national and international cooperation. It is also less likely to fulfill the research function of an association as there is less opportunity to discuss the creation of joint research projects within the association.

#### b. Disability Research Network.

This would involve a network of individuals and academic institutions interested and involved in disability research (similar to the Nordic Network of Disability Research). It is reported that one of the main reasons the Nordic Network was not styled a Disability Studies Association' was to avoid confusion with the British Association.

The network would promote and encourage it members to participate in research into different fields of disability studies, including law and policy.

#### Advantages:

An advantage of this form of association is that the emphasis on research would lead to a more focused research association. This would likely lead to increased research within disability studies as well as providing a forum for researchers to discuss their projects and ideas.

#### Disadvantages:

A disadvantage of this research network is that is would exclude a large membership base due to its specific focus on research – and might draw its membership more from academia than from users and commissioners of disability-related research. This exclusion would mean that the network would be a very academic association, rather than encouraging those who are early-career researchers, students, people with disabilities themselves and others with an interest in disability studies to become

#### c. Disability Studies Association

This would involve a formal association that encompasses all the above common features of other comparative associations. It would follow in the successful footsteps of the Nordic Network of Disability Research, the Canadian Disability Studies Association-Association Canadienne des Études sur L'Incapacité and the Society for Disability Studies.

The Association would focus on encouraging new research and ideas, developing a network and promoting national and international collaboration. It would have clear priorities such as using academic studies to impact on policy and practice, becoming a tool for easing people out of silo-thinking, ensuring the inclusion of people with disabilities in research and equipping advocates for social change. As with the comparative associations, it could hold an annual or biennial conference and perhaps in the future publish a journal.

The Association would ensure that it is inclusive of persons with disabilities through out its membership and governance.

#### Advantages:

An advantage of this association is that its focus is very broad ranging and it would be an excellent tool in promoting, creating awareness and inspiring interest in disability studies. Another advantage is that a strongly connected multi-disciplinary network could be created on the island of Ireland. Also this form of association would enable a larger membership group to participate, as it not narrowly defined as an academic or student association.

#### Disadvantages:

A disadvantage, however, would be the workload that goes with this type of association. There would be a Board of Directors who would have to focus on developing the association – and at least in the set up phase, these would likely be drawn from the partners to this memo.

### 5. For Consultation & Decision.

- 1. Whether to proceed to set up an association?
- 2. What kind of association?
- 2. What its core remit might be.