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Interim Report 1

Disabled Intimacies – sexual and reproductive citizenship of disabled women in Portugal

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Interim Report 1:

(Timespan: April 2012 – March 2013)

1 - Summary of the work undertaken

Literature review (April – June 2013)

The first task of the project took place between April and August (2012). We gathered a substantial amount of articles, book chapters and books, with a particular focus on disability studies, gender studies (addressing disability-related issues), and feminist disability studies. Readings also included electronic documents. Most of the books were purchased and became available to users of the public Library of the Centre for Social Studies (CES). After in-depth reading of these materials, a first theoretical chapter was written, critically engaging with the three theoretical models of disability - biomedical model, social model and biopsychosocial model –, in relation to feminist disability studies and crip theory. The research team met on 27th July (2012) to discuss theoretical issues of the chapter and to outline possible contributions from each colleague to this first draft.

The research team carries out reading and updating bibliographic sources, parallel to progress in relation to other tasks. A second chapter on sexuality and motherhood/ reproduction issues in relation to disabled women is in preparation.

Organizing the opening colloquium

The first event organized within this research was the colloquium "Cities Without Walls - contributions from academia in the field of disability." During this event, guest speakers (technicians, researchers and activists) discussed changes in disability policies in Portugal, sharing examples of good practices within and outside the academic environment, and suggested what can - and should - be implemented in order to overcome discriminatory practices within the academy. The objective of this seminar was twofold: to share knowledge in the field of studies and policies about disability, and to promote new and unequivocal commitments to avoid disabling practices in future academic events. This event took place in CES, Coimbra, 23/04/2012.

Meetings with consultants (June 2012)

Two meetings with the project consultants Prof. Margrit Shildrick (Linköping University, Sweden) and Prof. Rosemarie Garland-Thomson (Emory University, Atlanta, U.S.) took place during the 'Sensualising Deformity: Communication and Construction of Monstrous Embodiment' Conference, held at the University of Edinburgh, between 15 and 16 June 2012. These meetings resulted in sharing information, including bibliographical materials and suggestions, theoretical input and setting out future collaboration within the project.

BNIM training and preparation of fieldwork materials (July-September 2012)

The research team received intensive training in Biographic Narrative Interpretive Method (BNIM) for 5 days. After the training, the team held a meeting to discuss the training and to plan future steps – fieldwork and panel analysis. Data collection tools were also prepared to perform the fieldwork.

Website (September 2012)

During September 2012 we launched the project website, as planned: http://www.ces.uc.pt/projectos/intimidade. This website has been regularly updated. In an effort to make more contacts, reach a greater number of people, and maximize opportunities, a page on Facebook was also created: <u>https://www.facebook.com/intimidadedeficiencia</u>.

Meetings with partnership organizations (September 2012)

It was also in September that took place, in Lisbon, two meetings with the Portuguese Association of Disabled People (APD) and the Union of Women and Alternative Response (UMAR). These meetings were held to formally introduce the project to these two partner institutions and to outline strategies of articulation and participation in the activities of the project.

BNIM interviews (Strand 1 + strand 2) (September 2012 - January 2013)

In October (2012) the team began doing the BNIM interviews all over the country. Up until now (March 2013), 21 BNIM interviews with disabled women were conducted.

BNIM analytic panels (October 2012 – March 2013)

Four interviews were selected to become more in-depth case studies, subject to BNIM analysis methodology. In January (2013), the team started the group panel analysis, with the participation of both the team and invited researchers. These meetings aimed at the interpretation of the transcribed, anonymized interviews. Each interview was analyzed in two panels during three hours. Eight panels were done for four interviews, three of which related to the Sexuality Strand and one to the Reproduction/Motherhood Strand.

Theoretical training

The fellow researcher Ana Lúcia Santos participated in the training course Out of Order: Disability, Danger and Desire, organized by the Unit of Gender Studies in collaboration with InterGender, in Linköping University, Sweden. Among the team of trainers was Professor Margrit Shildrick, consultant of the project. Through a postmodernist and interdisciplinary lens, the course drawn on philosophy, literature, history, social science, feminist theory, crip theory and queer studies to gather new ways of thinking about the body in all its forms. The three approaches presented by the course leaders (Margrit Shildrick, Robert McRuer, Jens Rydström) offered a plural vision to critical disability studies which can then be applied to various areas of knowledge. This course took place in Sweden, between 3 and 5/12/2012.

Disseminations of results (October 2012 – March 2013)

The participation, by invitation, in academic and civil society initiatives enabled some early dissemination of the theoretical principles that guide this research project. We highlight the following initiatives:

"Turn the prejudice inside out: contributions of feminist disability studies" presented by Ana Lucia Santos at the VI Conference on Stuttering, held at the Institute of Accounting and Administration of Coimbra, 20/10/2012.

"Biomedical power in processes of disabling: cultural and political challenges from the social model", presented by Fernando Fontes and Ana Cristina Santos in Luso-Brazilian Meeting on Involvement and Listening of the citizens health, CES-Coimbra, 08/11/2012.

Several conference papers were prepared and presented in national (4) and International (1) scientific meetings. Please refer to Indicators (point 4 below).

The dissemination of the work in progress has also been made through the website and Facebook page.

2. Deviations from the approved proposal

All planned activities were carried out. There was however a slight delay in the interview process. During the period that comprises this interim report (April 2012 to March 2013), 21 interviews were conducted, of a planned total of 30. The team and partner associations have faced some difficulties in contacting disabled women who are mothers and available to participate in the study. For that reason, there are 9 interviews missing and they all refer to the Reproduction/Motherhood Strand. The team is making additional efforts in order to quickly fill this partial delay in the completion of fieldwork.

It was also not possible to meet in person with the consultant Gill Valentine, despite electronic contacts.

We have also added two persons to the team of consultants: Prue Chamberlayne and Tom Wengraf. This addendum was due to the need for specific training in biographical method BNIM (Biographic Narrative Interpretive Method), which was developed by these two persons, and due to the need to maintain their involvement in the project throughout the process of data collection and analysis, as well as interpretation (if necessary).

Although not originally planned in the application form, we point out as a positive deviation from the plan having organized the colloquium "Cities Without Walls - contributions of academia in the area of disability", held at the Centre for Social Studies in April 2012.

Another additional activity was the participation of the fellow researcher Ana Lúcia Santos in the Out of Order: Disability, Danger and Desire training, organized by the Unit of Gender Studies, Linköping University, Sweden, in December 2012.

3. Publications

Published - Santos, Ana Cristina (2012), "Disclosed and willing: towards a queer public sociology", Social Movement Studies, (special issue: Ethics of Research on Activism), 11(2), 1-14.

Published - Santos, Ana Cristina (2012), "Academia, Activism and Sexuality: Reflections on a Queer Public Sociology" in Portuguese Association of Sociology (ed.), *Society, Crisis and Reconfigurations. Minutes of the VII Congress of Sociology*. Lisbon: Portuguese Association of Sociology, 1-14.

Published - Santos, Ana Lúcia (2012), "Robert McRuer, Anna Mollow (eds.) (2012), Sex and Disability", *Revista Crítica de Ciências Sociais*, 97, 155-157.

Conference papers:

"Policies of disability in Portugal - a sociological approach," Cities Without Walls - contributions of academia in the area of disability, presented by Fernando Fontes, 23/04/2012.

"Gender Studies in Portugal: dilemmas and potentials", presented by Ana Cristina Santos at the Inaugural Conference of the Centre for Interdisciplinary Gender Studies (CIEG), Institute of Social and Political Sciences, Technical University of Lisbon, 24-25/05/2012;

"Academia, Activism and Sexuality: Reflections on a Queer Public Sociology", presented by Ana Cristina Santos at the Portuguese Congress of Sociology, in Porto, 19-22/06/2012;

"Secret Agents? Scientists, activists and Queer Public Sociology ", presented by Ana Cristina Santos at the Congress of the Brazilian Association of Studies of Homoculture, in Salvador da Bahia, 1-3/08/2012;

"Turn the prejudice inside out: contributions of feminist disability studies", presented by Ana Lúcia Santos in the VI Conference on Stuttering, held at the Institute of Accounting and Administration of Coimbra, 20/10/2012;

"Biomedical power in processes of disabling: cultural and political challenges from the social model", presented by Fernando Fontes and Ana Cristina Santos in Luso-Brazilian Involvement and Listening on the citizens health, CES-Coimbra, 08/11/2012.

4. Achieved indicators

2 national papers; 1 international paper

Note: This Interim Report was submitted to the Foundation for Science and Technology in April 2013. It refers to the timespan: April 2012-March 2013.