

# 科技部補助專題研究計畫成果報告 期末報告

## 發展與評估智障者性健康方案(第3年)

計畫類別：個別型計畫  
計畫編號：NSC 101-2410-H-010-003-SS3  
執行期間：103年08月01日至104年07月31日  
執行單位：國立陽明大學衛生福利研究所

計畫主持人：周月清  
共同主持人：林純真、蒲正筠、盧孳艷  
計畫參與人員：碩士級-專任助理人員：蔡欣潔

報告附件：出席國際會議研究心得報告及發表論文

處理方式：

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中華民國 104 年 10 月 30 日

中文摘要：結合實務工作者、智障者本人及家長，就智障者、父母及服務工作者發展三套「性健康」介入方案，以介入研究典範、解放學研究（邀智障青年規劃擔任介入講師），三年期三階段—方案發展、初次評估、主要評估與推廣使用。此「性健康」強調智障者性健康權利、親密關係、婚姻、生育、成人父母權利等，回應CRPD第23條。

第一年：就青年、家長、工作者收集資料，含訪談、過去研究發現與文件、政策法案，發展智障者性健康相關三套介入方案。前測及執行此新介入方案，以準實驗設計前後測兩組團體量性及訪談智障者、父母及工作者質性方法從事初次方案評估（pilot test）。實驗組為南部日照中心，比較組為同性質南部兩間日照中心。量性：實驗組青年36名，家長12名，工作者38名；比較組青年22名，家長19名，工作者27名。質性：訪談實驗組青年8名，家長1名，工作者5名。

第二年：第一年評估後，收集量性與質性資料，修正方案，修正後新介入方案擴大樣本進行main field test。參與者增加社區居住的智障者、父母、工作者。實驗組者：持續對第一年青年及家長進行第二次介入，針對第一年比較組者一間照護服務中心介入與評估，邀請中部社區居住住民、家長及工作者。比較組：第一年為比較組一間日照中心，中部兩間社區居住中心。量性：實驗組青年63名，家長15名，工作者45名；比較組青年24名，家長2名，工作者24名。質性：訪談實驗組9名青年、3名家長，3名工作者，工作者焦點團體。

第三年：再修正介入方案，舉辦成果發表會；第一、二年為實驗組，繼續第三年介入。提供兩年修正介入方案給第一、二年比較組青年、家長、工作者。量性：實驗組青年33名，家長32名，工作者99名。質性訪問8名青年、7名家長，7名工作者，工作者焦點團體。

量性評估工具青年：性態度量表與性知識量表簡明版（ASK Tool）、智障者生活品質量表（POS）；青年一對一親自訪問。家長及工作人員使用（ASQ-ID）量表，家長和工作者自填或訪談。質性資料以深度訪談與焦點團體進行。

量化資料發現：智青三年介入性知識逐年顯著提高，第三年比第一、二年顯著高。性態度三年期間沒顯著差異。生活品質第二、三年顯著比第一年高。只參加第二年介入者，性知識與性態度顯著提高。父母介入組整體性態度顯著提高，相對的比較組沒有。工作人員介入整體性態度顯著提高。質化資料發現：青年、工作者對介入使用的圖片、模型、練習戴保險套印象深刻，對青年擔任講師，結婚青年來分享，有鼓舞作用。家長、工作者認為此介入提供其針對青年性健康權有所認識，包括針對聯合國CRPD對此重視。實務工作者期待使用此介入方案。

中文關鍵詞：智能障礙、性健康、介入研究、方案發展、方案評估

英文摘要：Background: Based on intervention research paradigm, three intervention programs for adults with ID, their parents and service workers were developed, implemented, evaluated and disseminated to promote sexual health rights for adults with ID. Methods: A non-equivalent pre/post test groups

design and the standardized questionnaires were used to collect quantitative data for the effectiveness of evaluation of the intervention; in-depth interview and focus groups were conducted to collect qualitative data. The 1st year of the pilot test had been completed at one daycare center in Tainan area, 2nd year of the main-field test based on the revised intervention was extended to the residential care centers in Taichung in addition to the daycare centers. The 3rd year, the intervention continued to be provided to the daycare center that had been involved in the 1st and 2nd year. The revised intervention was provided in the daycare center who had been as the comparative group in the 1st and 2nd year. In total, 48, 85 and 139 adults, 12, 12 and 31 parents and 38, 47 and 99 service workers involved in the experimental group (EG) in the first, second and third year respectively; and 22 and 35 adults, 14 and 8 parents and 27 and 26 service workers in the comparative group (CG) in the first and second year respectively. Results: Quantitative findings revealed that the adults involved in the EG for three years whose sexual knowledge were improved in particular in the 3rd year. Overall quality of life among these adults was promoted after the intervention in the 1st year. The adults involved in the intervention in the 2nd year whose sexual knowledge and attitudes were improved after the intervention. The quantitative data revealed that after the intervention the sexual attitudes were strongly increased among both the parents and service workers. In stead, the scores of sexual attitudes among the parents who were as the CG did not see significant difference between the pre- and post-test. According to the qualitative data from the EG, the adults and the service workers replied that they were very impressive for the pictures, props of penis and vagina use, the practice of using condom, and the adults including the married couple as the instructors. Both service workers and parents responded that the intervention was useful for them to recognize the sexual rights of the adults.

英文關鍵詞： intellectual disability, sexual health, intervention research, pilot test, main-field test

## 發展與評估智障者性健康方案（期末報告）

### (Developing and evaluating intervention programs for promoting sexual health in adults with intellectual disabilities –Final report)

執行單位：國立陽明大學 衛生福利研究所

計畫編號：NSC 101-2410-H-010 -003 -SS3(2012/08/01~2015/07/31)

計畫主持人：周月清

共同主持人：盧華艷、林純真、蒲正筠

研究人員：林幸君、李婉萍、尤佩蓉

研究助理：蔡欣潔

連絡方式：[choucyc@ym.edu.tw](mailto:choucyc@ym.edu.tw) ; (02)2826-7182

本計畫除繳交成果報告外，另含下列出國報告，共 1 份：

移地研究心得報告

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中 華 民 國 105 年 10 月 30 日

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<sup>1</sup>擬於 2015 年 5 月出席 NNDR(Nordic Network of Disability Research) 北歐障礙研究國際會議國際會議。

# 發展與評估智障者性健康方案(期末報告)

## 一、中文摘要

**關鍵詞：**智能障礙、性健康、介入研究、方案發展、方案評估

本研究結合社工社福、護理、特教、民間機構及實務工作者、智障者本人及其家長，針對智障者、父母及服務工作者發展三套介入方案，以介入研究典範(intervention research paradigm; Thomas & Rothman, 1994; Reid, 1987; Richman, 2010; Rothman, 2014)、解放學研究(emancipatory research)(邀請智障者青年參與規劃及擔任介入時之講師)，三年期三階段進行—方案發展、方案初次評估(pilot test)、主要評估(main-field test)與推廣使用。此「性健康」含性行為、懷孕、生育、結紮、節育、性侵害、性病、HIV/AIDS 預防及健康管理等，尤其強調智障者的性健康權利，包括親密關係發展、婚姻、生育、成人父母權利等，以回應 CRPD 第 23 條。

**第一年**分別就三者(青年、家長、工作者)收集資料，含訪談、分析過去研究發現與文件、相關政策法案、解放學研究運用，發展 generalizations, practice guidelines 等與智障者性健康相關之三套介入方案；亦進行初次方案評估前測及執行此新介入方案，以準實驗設計前後測兩組團體量性及訪談智障者、父母及工作者質性方法等從事初次方案評估(pilot test)。實驗組為南部某一日間照顧服務中心，比較組為屬同性質南部兩間日間照顧服務中心。

**第二年**，目的在針對第一年評估之後，收集量性與質性資料，修正介入方案，依據修正後新的介入方案擴大樣本進行 main field test。研究參與者增加使用居住服務者(社區居住)的智障者、父母、工作者。參與之介入實驗組者有三：一為持續針對第一年者(使用日間服務者)青年及家長繼續進行第二次介入及評估(工作者未參與)，二為針對第一年比較組者之一間照顧服務中心介入與評估，三為邀請中部社區居住住民、家長及工作者。比較組有二：第一年亦為比較組之一間日間照顧中心，同為中部兩間社區居住中心。

**第三年**，目的在再次修正介入方案，並舉辦此介入方案宣導成果發表會，同時也提供此介入方案給比較組的青年、家長及工作者，以及針對第一年、第二年皆為實驗組之服務中心，繼續第三年介入。同時也提供此經由兩年修正之介入方案給第一、第二年為比較組的青年、家長、工作者。

量性評估工具針對青年：性態度量表與性知識量表簡明版(ASK Tool)、智障者生活品質量表(POS)；青年為一對一親自訪問。家長及工作人員使用(ASQ-ID)量表，發放問卷由家長和工作者自填，家長必要時，由研究團隊成員以訪問方式完成。

### 完成工作：

- (一) 第一年(2012.8-2013.7)：(1) 於 2013 年 4 月共進行第一年介入及收集之量化與質性資料。(2) 第一年實驗組青年共 36 名，家長 12 名，工作者 38 名，完成前測與後測；比較組青年共 22 名，家長 19 名，工作者 27 名，完成前測與後測量性資料。(3) 針對實驗組，共訪談青年 8 名，家長 1 名，工作者 5 名之質性資料。(4) 研究成果發表於 2014 年七月 14 日 Vienna IASSID 國際會議。
- (二) 第二年(2013.8-2014.7)：(1) 追蹤測量實驗組青年，修正第一年之介入方案。(2) 於 2014 年三、四月共分別進行南、中部服務單位(南部兩

個日間服務單位、中部一個社區居住服務單位)三梯次介入，針對三組參與者(青年、家長、工作者)。第二年實驗組青年共63名，家長15名，工作者45名，完成前測與後測；比較組青年共24名，家長2名，工作者24名。(3)針對實驗組，介入後進行深入訪談與焦點團體訪談(智障者、家長、工作者)，完成訪問9名青年、3名家長，3名工作者，以及一場工作人員(6人)對青年上介入課程後回饋之質性資料。(4)研究成果發表於2015年5月挪威Bergen NNDR國際會議。

- (三) 第三年(2014.8-2015.7): (1) 追蹤測量實驗組青年，再次修正方案。(2)於2015年3月27日，舉辦成果發表會，與會者包括34單位71位青年、家長、實務工作者參與。(3)於2015年3月20-22針對第一年、第二年比較組，提供介入作為回饋，包括青年、家長及工作者，並開放各單位學習。(4)於2015年5月繼續第一年、第二年皆為實驗組單位進行第三年介入。(5)於2015年7月完成實驗組青年追蹤第三次測量量性資料。(6)第三年實驗組青年共33名，家長32名，工作者99名，完成前測與後測。針對實驗組，介入後進行深入訪談與焦點團體訪談(智障者、家長、工作者)，完成訪問8名青年、7名家長，7名工作者，以及一場工作人員(人)對青年上介入課程後的回饋之質性資料。

## 結果：

(一) 分析實驗組量化資料發現：

- (1) 智青三年介入: 針對介入三年各一次之青年 (3 interventions, once a year): 共測量九次。
- (a) 性知識: 逐年顯著提高，尤其第三年比第一、二年顯著高。
  - (b) 性態度: 三年期間沒有顯著差異。
  - (c) 生活品質: 第二、三年顯著比第一年高。
- (2) 針對智青第二年介入(n=19): 只參加第二年介入者，其性知識與性態度顯著提高。
- (3) 針對智青第三年介入 (n=6): 第一、二年為比較組，第三年接受介入，性知識與性態度，皆未顯著提高，但生活品質卻顯著下降。
- (4) 針對父母的介入: 介入組(n=53)的整體性態度顯著提高 (p=.000)，相對的比較組(n=14)則沒有。
- (5) 針對工作人員的介入: 介入組(n=145)的整體性態度顯著提高 (p=.000)，相對的比較組(n=24)則顯著下降。

(二) 分析實驗組質化資料發現: 青年、工作者對介入使用的圖片、模型、練習戴保險套印象深刻，也對青年參與擔任講師，包括結婚青年來分享，有鼓舞作用。家長、工作者認為有此介入，提供其針對青年性健康權有所認識，包括針對聯合國CRPD對此之重視。實務工作者期待使用此介入方案。

## 二、英文摘要

### **Developing and evaluating intervention programs for promoting sexual health in adults with intellectual disabilities (3rd year)**

#### **Abstract**

**Key words:** intellectual disability, sexual health, intervention research, pilot test, main-field test

**Background:** In order to promote sexual health care and rights in persons with ID, based on intervention research (IR) paradigm (Thomas & Rothman, 1994; Reid, 1987; Richman, 2010; Rothman, 2014), the intervention programs for adults with ID, their parents and service workers were developed, implemented, evaluated and disseminated. This three-year study were conducted into following stages: program innovation, implementation, pilot test, main-field test and dissemination through an interdisciplinary collaboration including social welfare/social work, nursing, public health, special educators and senior practitioners.

**Methods:** A non-equivalent pre/post test groups design was used for these “pilot – test” and “main-field test” (advanced developed) and both quantitative and qualitative data from the participants were collected. The standardized questionnaires (Sexual knowledge and attitudes/ASK and the ASQ) were used to collect quantitative data for the effectiveness of evaluation of the intervention. In order to modify the intervention, in-depth interview and focus groups were conducted to collect data related to the intervention among the participants (service workers, parents and adults with ID) in the experimental group including three service units.

The 1<sup>st</sup> year of the pilot test had been completed at one daycare center in Tainan area, second year of the main-field test based on the revised intervention was extended to the residential care centers in Taichung in addition to daycare centers. The third year, the intervention continued to be provided to the daycare center that had been involved in the first and second year. Additionally, the revised intervention was provided in the daycare center in which had been as the comparative group in the first and second year. Between march of 2013 and July of 2015, in total, 48, 85 and 139 adults, 12, 12 and 31 parents and 38, 47 and 99 service workers involved in the experimental group in the first, second and third year respectively; and 22 and 35 adults, 14 and 8 parents and 27 and 26 service workers in the comparative group in

the first and second year respectively.

**Results:** The quantitative findings revealed that the adults involved in the experimental group for three years whose sexual knowledge were improved in particular in the third year. Additionally, the overall quality of life among these adults was promoted after the intervention in the first year. However, their sexual attitudes did not find significant difference between the tests of three years. The adults involved in the intervention in the second year whose sexual knowledge and attitudes were improved after the intervention. The adults who had been as the comparative group in the first year and second year did not show any significant change for their sexual knowledge and attitudes after the intervention in the third year. In contrast, their quality of life was decreased.

The quantitative data revealed that after the intervention the sexual attitudes were strongly increased among both the parents and service workers. In stead, the scores of sexual attitudes among the parents who were as the comparative group did not see significant difference between the pre- and post-test. Surprisingly the service workers who participated in the comparative group even showed significantly decreased in their sexual attitudes.

According to the qualitative data from the experimental group, the adults and the service workers replied that they were very impressive for the pictures, props of penis and vagina use, the practice of using condom, and the adults including the married couple as the instructors. Both service workers and parents responded that the intervention was useful for them to recognize the sexual rights of the adults.

**Conclusions:** Both quantitative and qualitative results show that the intervention caused positive impact on the participants in terms of their sexual knowledge, attitudes and wellbeing. In particular, the results of the intervention disclose the issue, the sexual rights and needs among this group of adults, even it is still under the debate in the society.

## **Introduction**

Sexual and reproductive health is certainly central to a person's health and quality of life, particularly for a woman; it has been increasingly used as a public health concept in the past decade (Edwards, 2004; Sandfort & Ehrhardt, 2004; The Women's Sexual Health Foundation, 2010; WHO, 2004). In Taiwan, social and health issues and the unique care needs of people with intellectual disabilities (ID) are typically ignored by policy-makers and health/social care services (Chou et al., 2008a, 2008b; Chou et al., 2010). An infrastructure that promotes the well-being of persons with ID is needed especially health including sexual and reproductive health (Ailey et al., 2003; Bambara & Brantlinger, 2002; Blanchett & Wolfe, 2002; Cuskelly & Gilmore, 2007; Doyle, 2008; Galea et al., 2004; Lesseliers & Van Hove, 2002; Lunsy & Konstantareas, 1998; McCabe, 1999; Servais, 2006) and women with disabilities in particular (Bernert & Ogletree, 2013; Eastgate, van Driel, Lennox, & Scheermeyer, 2011; Fitzgerald & Withers, 2013; Lunsy, Straiko, & Armstrong, 2003; McCarthy, 2014; United Nations General Assembly Committee B., 2005; Walsh et al., 2001; Walsh, 2002). In terms of policy and planning, separating this group from the wider population is unrealistic in the context of providing health services for people with ID.

According to the Convention on the Rights of Persons with Disabilities/CPRD (United Nations, 2006), states should protect the rights of those with disabilities, provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes (Article 25). Although Taiwan is not a signatory to this Convention, in order to make efforts to comply with the Convention, Taiwan issued the CRPD Implementation Act in 2014.

Based on the Taiwan Genetic Health Law introduced in 1984, anyone diagnosed with a genetic disease or mental disabilities may choose to be sterilized, or their legal guardians may submit their case to Eugenic Health Committee for review (Article 10). When one receives genetic health measures under the Act, the government may reduce, exempt or subsidize expenses (Article 16). That is, persons with ID and women with ID in particular may choose sterilization implemented by health-care providers under this law.

Sexual health is an important policy and intervention issue related to any person's well being (Sandfort & Ehrhardt, 2004; WHO, 2004), including those who have ID (Kyrkou & Margaret, 2005) and their carers such as parents and those providing social and health care services (Janicki et al., 2002; Servais, 2006). However, insufficient attention including intervention programs has been paid to the knowledge, attitudes, unique experiences and support needs of this group including their parents and service workers who are working with people with ID in Taiwan.

This study utilized an **Intervention Research paradigm** particularly suited for conducting research in an environment which is different from much basic research (Rothman, 1984; Thomas, 1984; Richman, 2010). The particular advantage of IR is to innovate intervention in particular settings/service users and it allows to construct, test **(pilot-test and main field test) and modify (and re-modify)** or the intervention program; thus to develop a service model rather than the generation of knowledge (Fraser et al., 2009; Thomas & Rothman, 1994; Reid, 1987).

### **Aims of this study**

The primary concern of this study was to develop the intervention programs to promote sexual health care and well being in people with ID and as well as to evaluate (including outcome and process evaluation) whether these intervention programs are effective and efficient. The intervention programs were provided to adults with ID (including men and women with ID), parents and service workers; the intervention components were the issues related to adults with ID's sexual health, knowledge and rights concerns. This study was conducted for three years and two times of tests (pilot test first and then main field test) and modifications after the tests had been conducted. The aims of **this three-year study** were as follows.

1. **1<sup>st</sup> year: intervention innovation, pre-test of Pilot Test and intervention implementation**
  - a. to collect field practice (data was based on the interviews from people with ID, parents and service workers including senior practitioners) and integrate the literature reviews (including current findings conducted by Chou & Lu, 2011-2012, NSC100-2314-B-010-062);

- b. to innovate three intervention programs related to sexual health and well-being in people with ID and one for people with ID, one for the parents and another one for the service workers;
  - c. to carry on main-field test before the intervention (pre-test); and
  - d. to implement the innovative intervention programs for three groups (adults with ID, parents and service workers).
- 2. 2<sup>nd</sup> year: Post-test of Pilot Test, intervention modification, pre-test of Main-field Test and modified intervention implementation**
- a. to evaluate the innovative intervention programs (post -test);
  - b. to modify the intervention programs;
  - c. to carry on pilot test before the modified intervention (2<sup>nd</sup> one) (pre-test) with bigger samples; and
  - d. to implement the modified intervention.
- 3. 3<sup>rd</sup> year: Post-test of Main-field Test, intervention re-modification and dissemination**
- a. to carry the evaluation after the intervention (post-test of Main-field Test);
  - b. to refine the intervention programs again from 2<sup>nd</sup> year;
  - c. to carry the third year of the intervention for the same group; and
  - d. to disseminate the final version of the intervention programs for use national wide.

**Significance of the study (Skipped)**

**Literature Review (Skipped)**

**1. Taiwan literature review**

**2. International literature review**

*2.1. WHO's Definition of sexual health*

*2.2. Sexual health model from Robinson et al.*

*2.3. Sexual health care in people with ID and women with ID*

*2.4. The parents and service workers' attitudes towards people with ID's sexuality*

**2.5. Intervention programs of sexual health to promote people with ID's sexual health and wellbeing**

**2.6. Components of the intervention programs**

**3. Intervention research**

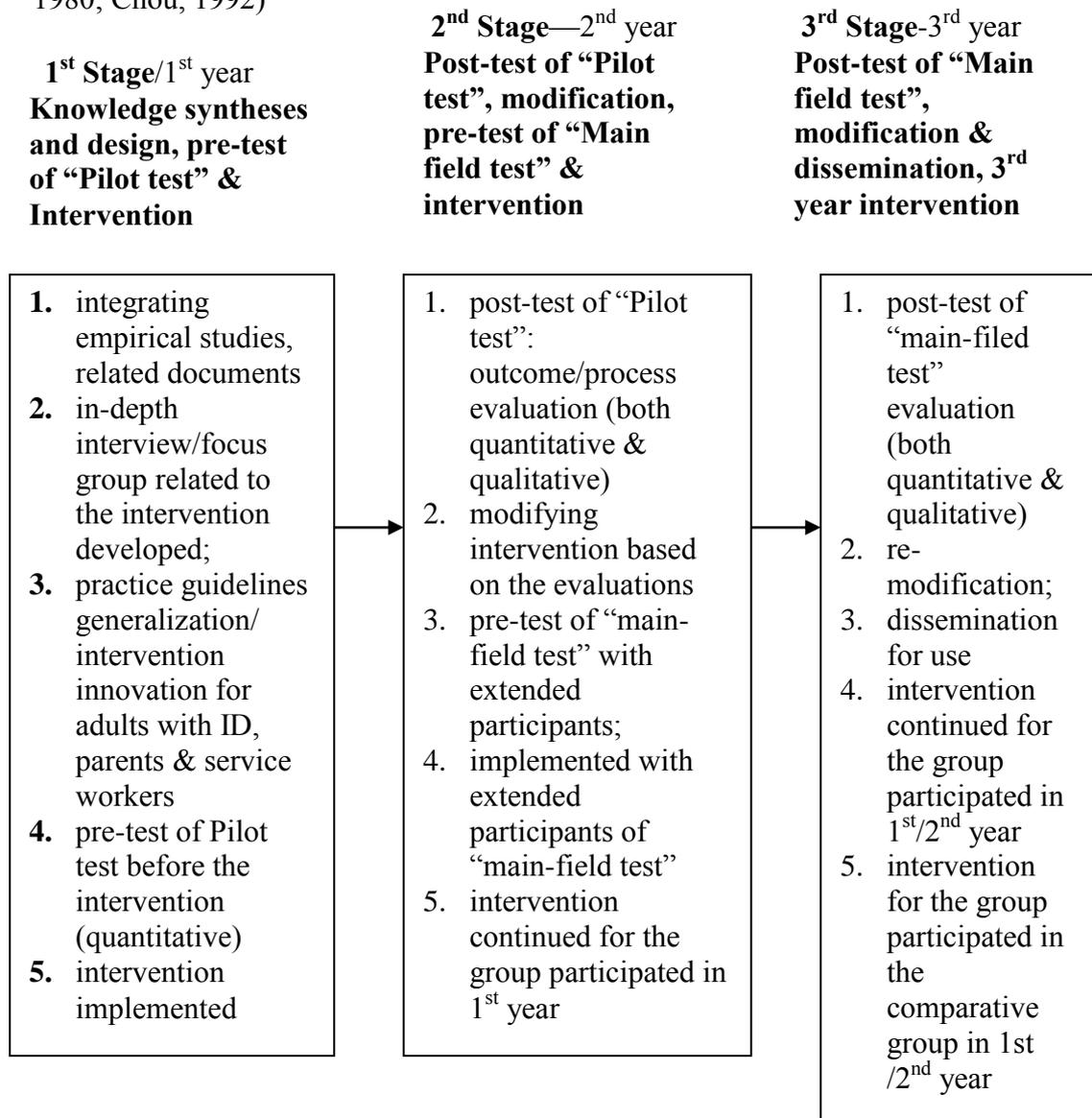
**3.1. Pilot test**

**3.2. Advanced development test**

**Methods**

The intervention programs were developed and the processes were followed as figure 2.

**Figure 2: Research paradigm and process in three years/three stages (Rothman, 1980; Chou, 1992)**



In order to provide more effective intervention for meeting the needs of sexual health care among people with ID, the intervention and practice guidelines were developed based on consensus findings which emerged from literature review and practice wisdoms (e.g., from the adults with ID, their parents and service workers' experiences). A pilot test was carried on to test whether the intervention package was applicable for adults with ID, parents and service workers. After the evaluation of the pilot test, the intervention package was refined. Continuing the pilot test, the second and third year of current study aim to carry on a "main-field test" to have second time modification and evaluation with extended samples in order to disseminate an accountable intervention.

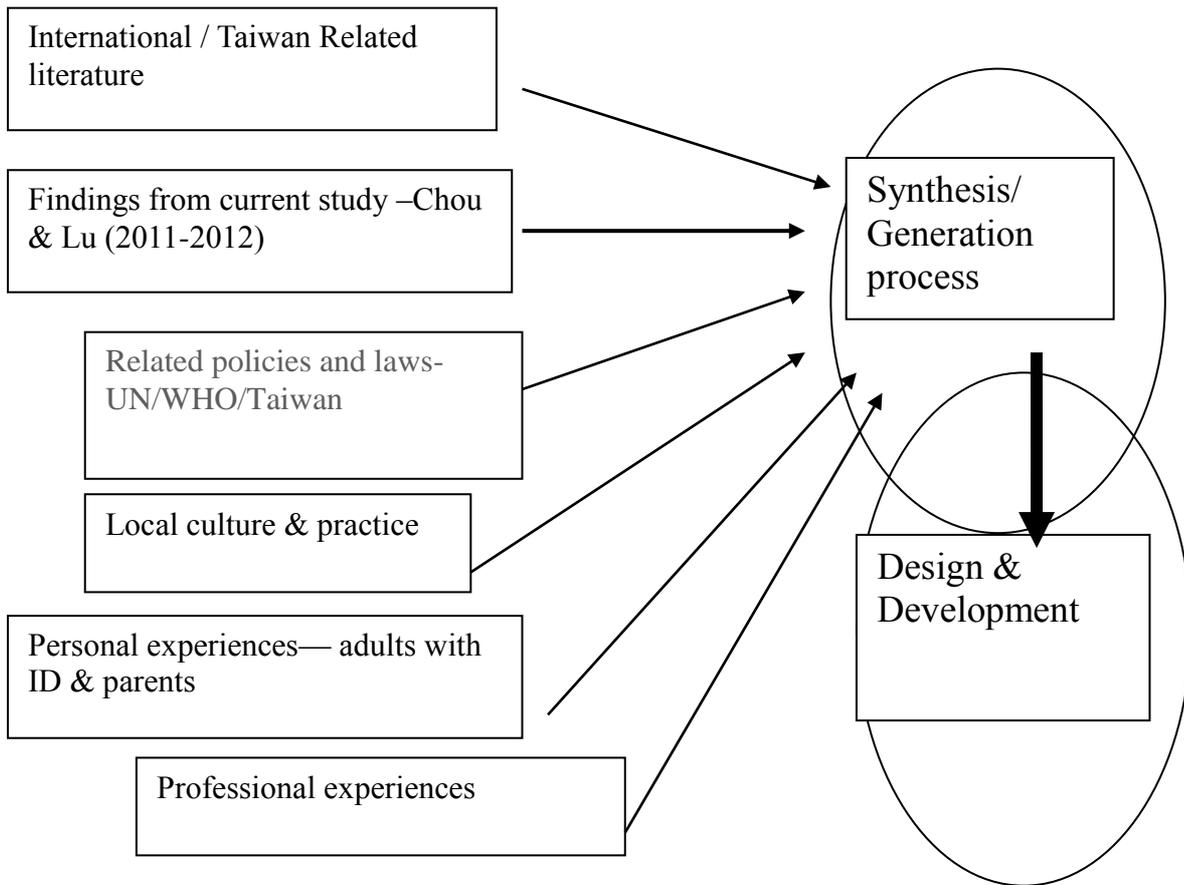
The first year study focuses on the knowledge syntheses and intervention development related to sexual health and well being promotion to people with ID provided for adults with ID, their parents and service workers based on the IR (Intervention research) paradigm (Reid, 1987, 1995; Rothman, 1980, 1995; Thomas, 1987) (as shown in Figure 2). As well as, the pre-test of pilot test and the innovative intervention were carried on.

## **1. knowledge synthesis**

### **1.1 Sources for intervention design:**

First of all, sources of knowledge included related documents, international and Taiwan literature review (including the findings from Chou and Lu's study, 2011-2012), related international documents (UN/WHO), sexual health related education packages, and Taiwan policies and laws, local culture and practices (as shown in Figure 3). The practices and specific concerns about the intervention design were collected through the interviews with people with ID, the parents and service workers. The individual interviews and focus groups were used to collect data. All these knowledge and practices were synthesized and integrated.

Figure 3: Knowledge and Practice Synthesis and Intervention Development



### 1.2. Participants for collecting practice wisdom

The senior practitioners working at the three NGOs were invited working with this study. They helped to invite the services users (adults with ID), the parents and the service workers to be interviewed individually and/or in the focus groups in order to collect their practice wisdom related to the intervention design. There were five adults with ID (3 women and 2 men), five parents and five service workers invited involved in the both individual interviews and focus groups.

## 2. Intervention development

Based on the knowledge and practice syntheses, the consistent findings, practice guidelines and intervention programs for people with ID, the parents and the service workers related to sexual health and rights issues to people with ID were generalized and innovated respectively (for detail see the Manual of the intervention).

### 3.1. Research design

First of all, the quantitative approach focused on the outcome evaluation of the intervention. Thus, a **non-equivalent groups design** (as shown in Figure 4) was used to evaluate the outcome of the intervention programs whether the knowledge and attitudes to sexual health related to people with ID changed among adults with ID, their parents and service workers after they receive the intervention, as the experimental group. Adults with ID, their parents and service workers as the comparative group were recruited from the same background of these three groups to compare whether there is a difference between the two groups after the intervention. Additionally, the adults with ID's quality of life before and after the intervention and between the two groups (experimental and comparative group) were measured to assess whether there was a positive effect for adults with ID resulted from the intervention.

Furthermore, **Multiple-group Time Series Design (Figure 5)** was also used to collect quantitative data for the adults with ID.

**Figure 4: non-equivalent control group design** (Rubin & Babbie, 2008)

O1	X	O2	Experimental Group
O3		O4	Comparative Group

Note: X: intervention; O1 and O3: pre-test; O2 and O4: post-test.

**Figure 5: Non-equivalent Multiple-group Time Series Design** in three years for participants with ID (Shadish, Cook, & Campbell, 2002)

	Year 1/Pilot test				Year 2/Advanced develop./main field test				Year 3/ Further Advanced develop.			
G1	T1	X1	T2	T3	T4	X2	T5	T6	T7	X3	T8	T9
G2	T1			T3	T4	X2	T5	T6				
G3	T1			T3	T4			T6	T7	X3	T8	T9
G4					T4	X2	T5	T6				

G5					T4			T6				
----	--	--	--	--	----	--	--	----	--	--	--	--

Note: G: group; X1: intervention in Pilot test; X2: intervention in advanced/main-field test; X3: intervention in further advanced;  
T1: pre-test of pilot test; T2 posttest of pilot test; and T3: follow up of pilot test; T4, T5 and T6: pretest, posttest and follow up of the advanced development/main-field test respectively in 2<sup>nd</sup> year; T7, T8 and T9: pretest, posttest and follow up of the further advanced development respectively in 3<sup>rd</sup> year.

Research questions of the quantitative evaluations: (1) are adults with ID’s attitudes to sexual health, sexual knowledge and quality of life improved after receiving the intervention? (2) is there a significant difference of the scores of the adults with ID’s attitudes to sexual health, sexual knowledge and quality of life between the two groups, the adults who receive the intervention and the adults who do not? (3) is there a significant improvement in the scores of the attitudes to sexual health related to people with ID among parents after receiving the intervention while comparing with the scores before the intervention received? (4) is there a significant difference of scores of the attitudes to sexual health related to people with ID among the parents from the two groups, the experimental and comparative groups? (5) is there a significant improvement in the scores of the attitudes to sexual health related to people with ID among service workers after receiving the intervention while comparing with the scores before the intervention received? (6) is there a significant difference of scores of the attitudes to sexual health related to people with ID among service workers from the two groups, the experimental and comparative groups?

**3.1.1. Independent variable (intervention) --The intervention package**

The independent variable is the intervention package which was the innovated in the first year and revised in the 2<sup>nd</sup> and 3<sup>rd</sup> year, as described previous. There were three intervention packages for adults with ID, the parents and the service workers respectively.

**3.1.2. Dependent variables.**

The intervention package innovated in the first year aims to promote positive attitudes to sexual health in people with ID among adults with ID, the parents and the service workers. Two more dependent variables, that are adults with ID’s sexual knowledge and quality of life, were evaluated as well as the outcomes of the

intervention among adults with ID.

Three different groups of participants (i.e., the adults with ID, the parents and the service workers) were evaluated individually.

***The adults with ID.*** The adults with ID's sexual knowledge and attitudes were measured by the Assessment of Sexual Knowledge Tool (ASK Tool) (Centre for Developmental Disability Health Victoria, 2011). The adults with ID's quality of life will be measured by the Personal Outcomes Scale (POS): A Scale to Assess an Individual's Quality of Life -Chinese version (Chang, 2010).

***The parents and the service workers.*** Both parents and service workers' attitudes to sexual health will be measured by the Attitudes to Sexuality Questionnaire—Individuals with an Intellectual Disability (ASQ-ID) (Cuskelly & Gilmore, 2007).

### ***3.1.3. The Instruments (Skip)***

The **Assessment of Sexual Knowledge Tool (ASK Tool)** has been tested by Galea et al. (2004) with high reliability and validity. The Assessment of Sexual Knowledge (ASK) is a new test that aims to assess the sexual knowledge and attitudes of people with ID. There are four components to this assessment tool: Knowledge, Attitudes, Quick Knowledge Quiz and A Problematic Socio-Sexual Behaviours Checklist. The ASK has been designed so that each part can be used independently or in conjunction with another. In this study the Quick Knowledge Quiz (25 items) and Attitudes (40 items) were utilized (Centre for Developmental Disability Health Victoria, 2011).

The Attitudes to Sexuality Questionnaire—Individuals with an Intellectual Disability (ASQ-ID) was developed by Cuskelly and Gilmore (2007) and Cuskelly and Bryde (2004) and is based on the four indicators: sexual rights (13 items), parenting (7 items), non-reproductive sexual behaviour (5 items), self-control (3 items); this makes up a total of 28 items that are answered by the participant using a 6-point Likert Scale (1=disagree very much, 6=agree very much). The higher scores indicate more positive or accepting attitudes. The reliability has been reported previously by Cuskelly and Gilmore (2007) with Cronbach's alpha coefficients that range from 0.67 to 0.93 for the four domains. The ASQ-ID was developed initially in English and was translated into Chinese by the present authors and two bilingual practitioners; in addition, it was back translated to allow full comparison of the

Chinese and the English original version. The use of this ASQ-ID scale has been agreed by the Authour, Dr. M. Cuskelly.

**The Personal Outcomes Scale (POS)** is a scale to assess an individual's quality of life among people with ID. It has a Chinese version (Chang, 2010) and it can be purchased from the Taiwan Community Living Consortium. The POS was developed by van Loon et al. (2008) and made up of 48 items that represents eight domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional, physical, and material well-beings. Each domain has six indicators related to people with ID's QoL (Schalock et al., 2005; Chou et al., 2007). The POS is measured by two ways: (1) self report-- based on the individual interviewee's own self report; and (2) direct observation--the observation from the persons who know the individual interviewee at least for three months such as the interviewee's parents, relatives or staff working with the individual interviewee. For example, the question is asked based on interviewee's self report: "Can you eat and get up from bed, use toilet and dress up by your own?"; the questions is observed by the person who know the interviewee: "Do you think the individual can carry on his/her daily life activities, such as eat, get up from bed, use toilet, and dress up?" A 3-point Likert Scale is used to scale the response dimensions for both sets of questions: (a) self report: in general I can do it individually (3), I need some help (2), I can not do it individually (1); and (b) observation: in general he/she can do it individually (3), somehow help needed (2), can not do it individually (1) (van Loon et al., 2008). A higher score indicates a better QOL for both "self report" and "observation". In this study, only the adult subjective QOL (e.g., self report) was measured.

### **3.2. Settings and participants for three years**

The pilot test is for testing and modifying the intervention instead of generalization. Adults with ID, parents and service workers were recruited from three daycare centres (G1, G2, G3) in Tainan area as experimental group and comparative group. These daycare centers all managed by NGOs. After the intervention was modified, named the advanced developed intervention, the participants were extended to the residential services settings in another city (G4 and G5), Taichung, including the adults with ID, parents and service workers. The participants (adults with ID and parents, except service workers) of the experimental group of the first year remained

in the experimental group and one of the comparative groups became the participants of the experimental group and another comparative group also remained as the comparative group. The participants of the adults, parents and service workers from the experimental group who participated in year 1 and year 2 (G1) continued to be involved in the experimental group; and the participants of the daycare center (G3) who participated in year 1 and year 2 as the comparative group were invited as the recipients of the intervention in year 3.

The numbers and characteristics of the participants including adults with ID, parents and service workers of the experimental and comparative groups in three years were as shown in Table 1-1 to Table 3-2.

Table 1-1. Participants with ID and Settings of the Experimental and Comparative Groups

	Pilot test-1 <sup>st</sup> year		Main-field/advanced develop.-2 <sup>nd</sup> year		advanced develop.-3rd year	
	X1(N)	Data analyses (N)	X2 (N)	Data Analyses (N)	X3 (N)	Data Analyses (N)
G1	48	36	51	33	61	27
G2		14	14	14		
G3		8		6	84	6
G4			20	19		
G5				17		
Total	48	58	85	89	139	33
Total Involved	73		108		145	

Note: X1: 1<sup>st</sup> year intervention (2 adults with ID; one mother); X2: 2<sup>nd</sup> year intervention (one couple with ID); X3: 3<sup>rd</sup> year intervention (2 adults with ID; one married couple with ID)

**Table 1-2. Characteristics of the Participants with ID in the Groups**

Characteristics		G1 (n=33)	G2 (n=11)	G3 (n=7)	G4 (n=19)	G5 (n=17)	Z <sup>a</sup> /X <sup>2</sup>
Mean age	Mean (SD)	27.1 (6.5)	30.73 (8.2)	30.7 (6.2)	31.7 (5.9)	28.7 (6.5)	7.4
	Range	19-41	21-43	23-41	21-42	20-43	
Gender N(%)	Men	22 (66.7)	6 (54.5)	7 (100.0)	6 (31.6)	3 (17.6)	21.8 <sup>***</sup>
	Women	11 (33.3)	5 (45.5)	0	13 (68.4)	14 (82.4)	
Level of disability N(%)	Mild / moderate	21 (63.6)	10 (90.9)	4 (57.1)	14 (73.7)		
	Severe/ profound	12 (36.4)	1 (9.1)	3 (42.9)	5 (26.3)	17 (100.0)	11.9 <sup>*</sup>

Note: The numbers of the participants analyzed were only for those who answered the questionnaires.

<sup>a</sup> Kruskal-Wallis one-way analysis of variance by ranks

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

**Table 2-1. Parents and Settings of the Experimental and Comparative Groups**

	Pilot test-1 <sup>st</sup> year		advanced develop.-2 <sup>nd</sup> year		advanced develop.-3 <sup>rd</sup> year	
	X1(N)	Data analyses (N)	X2 (N)	Data Analyses (N)	X3 (N)	Data Analyses (N)
G1	12	12	7	5	8	8
G2		9	5	5		
G3		5		0	23	23
G4			7	6		
G5				2		
Total	12	31	12	18	31	31
Total Involved	31		21		31	

Note: X1: 1<sup>st</sup> year intervention (2 adults with ID; one mother); X2: 2<sup>nd</sup> year intervention (one couple with ID); X3: 3<sup>rd</sup> year intervention (2 adults with ID)

**Table 2-2.** Characteristics of all the Parents in the Groups (實驗組和比較組)

Characteristics		Overall (n=78)	Exp. G. (n=57)	Comp. G. (n=21)	Z <sup>a</sup> /X <sup>2</sup>
Mean age	Mean (SD)	56.49 (8.88)	57.42 (7.63)	53.85 (11.56)	-1.70 (.088)
	Range	26-75	36-75	26-75	
Gender N(%)	Men	24(30.8)	14(24.6)	10(47.6)	3.83 (.05)
	Women	54(69.2)	43(75.4)	11(52.4)	
Education-years (all groups)	Mean(SD)	11.48 (4.64)	11.84 (4.60)	10.39 (4.71)	-1.12 (.26)
	Range	0-23	0-23	0-16	
Religion N(%)	Dao/fock	29(27.2)	21(36.8)	8(38.1)	4.90 (.18)
	Buddhism	37(47.4)	30(52.6)	7(33.3)	
	Christian	5(6.4)	2(3.5)	3(14.3)	
	none	7(9.0)	4(7.0)	3(14.3)	
Marital status N(%) (with partner)	married/co -hab	62 (79.5)	48(84.2)	14(66.7)	2.90 (.09)
	Single/div orce/wido w	16(20.5)	9(15.8)	7(33.3)	
Family income (only for parents) NT\$	<40000	36 (50.0)	26(50)	10(50.0)	.72 (.70)
	40001- 70000	22(30.6)	17(32.7)	5(25.0)	
	≥70001	14(19.4)	9(17.3)	5(25.0)	

Note: For parents: Experimental groups : Year 1 G 1+ Year 2 G 1+G2 +G4 + Year 3 G1+G3 ; Comparative group: Year 1 G2 + G3 + Year 2 G 5.

The numbers of the participants analyzed were only for those who answered the questionnaires.

<sup>a</sup> **Mann–Whitney U test**

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

Table 3-1. Service workers and Settings of the Experimental and Comparative Groups

	Pilot test-1 <sup>st</sup> year		advanced develop.- 2 <sup>nd</sup> year		advanced develop.-3rd year	
	X1(N)	Data analyses (N)	X2 (N)	Data Analyses (N)	X3(N)	Data Analyses (N)
G1	38	38	0		43	43
G2		13	31	30		
G3		14		13	60	60
G4			16	15		
G5				11		
Total	38	65	47	69	99	99
Total Involved	65		71		99	

Note: X1: 1<sup>st</sup> year intervention (2 adults with ID; one mother); X2: 2<sup>nd</sup> year intervention; X3: 3<sup>rd</sup> year intervention

**Table 3-2.** Characteristics of the service workers in the Groups

Characteristics		Overall (n=201)	Exp. G. (n=164)	Comp. G. (n=37)	Z <sup>a</sup> /X <sup>2</sup>
Mean age	Mean (SD)	37.57 (10.20)	36.92 (9.85)	40.32 (11.30)	-1.70 (.09)
	Range	22-62	22-62	23-62	
Gender N(%)	Men	28(13.9)	21(12.8)	7(18.9)	-9.41(.33)
	Women	173 (86.1)	143 (87.2)	30 (81.1)	
Education-years (all groups)	Mean(SD)	15.86 (1.70)	15.93 (1.73)	15.55 (1.55)	-.92 (.36)
	Range	7-28	7-28	12-18	
Religion N(%)	Dao/fock	80(39.8)	67(40.9)	13(35.1)	3.51(.48)
	Buddhism	31(15.4)	23(14.0)	8(21.6)	
	Christian	36(17.9)	29(17.7)	7(18.9)	
	none	45(22.4)	36(22.0)	9(24.3)	
	Else	9(4.5)	9(5.5)	0(0.0)	
Marital status N(%) (with partner)	married/co-hab	87(43.3)	71(43.3)	16(56.8)	.000(.99)
	Single/divorce/widow	114(56.7)	93(56.7)	21(43.2)	
Working experiences (years) with ID	Mean(SD)	7.7(7.03)	7.81(6.8)	7.26(7.99)	-1.42 (.16)
	Range	0-33	0-33	0-26	

Note: Experimental group: Year 1 G1+ Year 2 G2 + G4 + Year 3 G1+ G3; Comparative Group: Year 1 G2 + G3+ Year 2 G3 + G5. The numbers of the participants analyzed were only for those who answered the questionnaires.

<sup>a</sup> Mann–Whitney U test

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

### 3.3. Procedures

First, phone calls to the managers of the service units about agreeing to participation including helping to have adults with ID and their parents involved were made. Then the emails to each manager of the service units that includes an official document from the affiliation of the research team of the present study were followed. A list of adults with ID, their parents and the service workers using services and working willing to be involved in each service unit were developed with help from an appointed staff member from each setting and this staff member became the main contact person of the study. The research assistant of the project kept contacts the appointed staff member from each service unit to make sure who (adults with ID's legal guardians, parents and service workers) were willing to be involved in our study.

For the experimental group, the full-time research assistant and trained interviewers conducted face-to-**face interview** with the adults with ID before and after the intervention at the service units. The questionnaires for the parents and service workers were distributed and completed by the parents and service workers before and after the intervention. Some of the parents were interviewed by the research team members before and after the intervention if it was necessary.

For the comparative group, the research assistant and trained interviewers conducted face-to-**face interview** with the adults with ID at the service units. The interview data about adults with ID's parents were completed through the help of the service workers of the units. The service workers' data were collected when the interviewers conducted the interview with adults with ID at the settings. For example, the appointed staff at each service unit helped the research assistant to distribute the questionnaires to the staff of the service units who participated in the study. Once the service workers complete the self-administrated questionnaires, they submitted the questionnaires to the research assistant. All questionnaire packs, which contained a written informed consent form, were signed by the participants; and for the adults with ID were signed by their legal guardians. These covered all adults with ID and the parents and service workers who were willing to participate.

### 3.4. Data analysis quantitative evaluation

The dataset was analyzed using the Statistical Package for Social Sciences

(SPSS), Version 20.0 (SPSS Inc., Chicago, IL USA). Within the group, a Friedman's Test (Non-Parametric Repeated Measures Comparisons) was used initially to test whether there were significant differences among the numbers of time points (e. g., T1 to T9 for adults in G1) and then the Wilcoxon Matched Pairs Signed-rank Tests were conducted as a *post hoc* test to measure if a main effect of the intervention (T1 vs. T2, T1 vs. T3, T2 vs. T3 and etc.) was found for the participants within the group (Table 3). Due to the differences of the characteristic data and also the pretests among the participants from five groups, the Mann Whitney U-test (Non-Parametric Repeated Measures Comparisons) was used to measure if there is significant difference between the difference and difference in different groups, under the first year, second year and two years follow up. It means that, for example, the Mann Whitney U-test was used to compare the result of T3 -T1 (T3 minus T1) of Group 1 and the result of T3-T1 of Group 2 in the first year and to compare the result of T6 – T1 of Group 1 and the result of T6-T1 of Group 2 for the two years follow up and etc. An alpha level of 0.05 is used in all analyses.

### ***3.5. Qualitative interviews after the intervention: participants, data collection and analysis***

In order to collect data related to what the extent of the impact of the intervention that might not be measured by the standardized questionnaires, in-depth interview and focus group were conducted after the intervention of three years.

As shown in the Table 4, the participants of the in-depth interview were only recruited from the experimental groups that included the adults with ID, parents, service workers and also the research team members including four adults with ID as our research team members.

The semi-structured interviews were used and conducted by the principal investigators (PI) and the full-time research assistant between April of 2013 and July of 2015. The development of the interview guides was based on the purposes of the pilot test and advanced development (Fraser & Galinsky, 2010; Thomos & Rothman,1994).

The research questions of the qualitative design in the pilot test were such as:

1. whether the intervention package is suitable to use by the trainers/practitioners?

2. whether the intervention package is suitable for the target groups (adults with ID, parents and service workers)?
3. what do the parts need to be modified?
4. whether the instruments in the quantitative and qualitative evaluation are suitable to use?

In order to re-modify and disseminate the intervention to the participants national wide, the **semi-structure questionnaires** and **focus group** were conducted to collect qualitative data from the experimental group in the year 2 and 3. As the pilot test, the evaluations for three packages (i.e., for adults with ID, the parents and service workers) will be carried on individually.

The research questions of the qualitative design in the year 2 were such as:

1. whether the intervention package is accountable for the participants?
2. which parts are necessary to re-modify in order to be used widely?

The research questions of the qualitative study in the year 3 were such as:

1. what were the impacts of three interventions on the adults, parents and service workers in the three years respectively?
2. Are there necessary for the interventions that had been lasted for three years for the adults, parents and service workers? Yes/no and why?

The qualitative data also aimed to collect data in relation to the effect of the intervention and strength and weakness for later revision use, as presented in the Appendix. The interviews were delivered in Mandarin or Taiwanese based on the language use of the interviewees and tape-recorded and later transcribed and translated into English and double-checked by all authors.

The transcripts were coded and analyzed using interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009) by the research team. First, the PI and one of co-PIs independently reviewed the transcripts at length to identify an initial set of themes. As themes emerged, the two researchers compared and reconciled discrepancies to ensure quality control of coding. They then brought their findings to the whole research team, including the research assistants, for further discussion. Themes that were found by the whole team were retained. The remaining possible themes were evaluated by all researchers to determine whether evidence was

sufficient to warrant the inclusion of each theme. Themes were retained only if all researchers were able to reach a consensus on their validity. These themes were then listed under appropriate headings.

Table 4: Participants of experimental groups in-depth interview and focus group in the pilot test and advanced development

		1 <sup>st</sup> year (04/2013)	2 <sup>nd</sup> year (March 2014- Jan 2015)	3 <sup>rd</sup> year (March –May 2015)
In-depth interview (n=participants)				
G1	Adults	10 <sup>a</sup>	6 <sup>c</sup>	6
	parents	2 <sup>b</sup>	1	3
	workers	8	5	2
G2	Adults		5	
	parents		1	
	workers		2	
G3	Adults			4
	parents			4
	workers			7
G4	Adults		2	
	parents		2	
	workers		4	
Total	Adults	10	11	
	parents	2	4	
	workers	6	11	
Focus group (n=times)				
workers		2	1	1
Team members		3	3	

<sup>a</sup> Two instructors with ID; <sup>b</sup> one mother instructor; <sup>c</sup> one married couple with ID as the instructors

#### 4. Users, parents and practitioners of the intervention and training new practitioners of the intervention

The practitioners of this study were three research team members including the PI (from social welfare and social work background) and two Co-PIs (one from health and nursing background and another from special education background). We also invite 6 adults with ID (2 adults with ID in first year and one married couple in the 2<sup>nd</sup> and 3<sup>rd</sup> year respectively) and two mothers (one in first year and one in 3<sup>rd</sup> year) involved as the instructors of the intervention. In the 3<sup>rd</sup> year, we also invited the

practitioners from the participated settings to observed, learned and practiced as the instructors of the intervention.

## **5. Re-modification and dissemination**

Three interventions for the adults with ID, parents and service workers respectively had been modified after 1<sup>st</sup> and 2<sup>nd</sup> year interventions. Three intervention package in the 3<sup>rd</sup> year for the participants of the experimental groups had been revised twice and became the version as the accountable programs in which were disseminated to the users, parents, practitioners and researchers in Taiwan. Thus there was a seminar organized by the research team and sponsored by the Taiwan Community Living Consortium in Taipei City and the related individuals and NGOs were invited to participate. The participants including the adults with ID, parents and service workers and managers who had been involved in this study were invited to present their experiences of participation and also the impact on these individual adults, parents, service workers and the service sectors. The details of the Dissemination seminar were attached in Appendix 1.

## **6. Research ethics**

The current study had been approved by the Research Ethical Board of the National Taiwan University (approve number: 201207HS007). All the participants were informed by both oral and document (an Informed Consent Form was used and approved by the REB of the NTU) before the interviews conducted.

## **Results—**

### **1. Quantitative outcome evaluation among the participants**

#### **1.1. Mean effect on the outcomes among adults with ID for three years**

**Table 5-1.** Characteristics of the Participants with ID in the two groups (G1 and G3) Groups

Characteristics		G1 <sup>a</sup> (n=27)	G3 <sup>b</sup> (n=6)	Z <sup>c</sup> /X <sup>2</sup>
Mean age	Mean (SD)	28.00 (6.55)	30.5 (6.35)	-1.41(.16)
	Range	19-41	23-41	
Gender N(%)	Men	19 (70.4)	6 (100.0)	2.35(.13)
	Women	8 (29.6)	0	
Level of disability N(%)	Mild / moderate	16 (59.3)	3 (50.0)	.17(.68)
	Severe/profound	121(40.7)	3(50.0)	

<sup>a</sup>: G 1: in the year 1, n=33; in the year 3, n=26: one adult passed away, 6 adults did not use the service anymore; 1 adult applied for leave due to family member passed away; <sup>b</sup> G3: in the year 1, n=7; in the year 3, n=6: 1 adult not use the service

<sup>c</sup> Mann Whitney U-test

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

Table 5-2: Mean effect on the outcomes for the intervention within the group (G1) among adults with ID for three years (n=26)

G1	M(SD)									Z <sup>a</sup> (p-Value)	Post hoc <sup>b</sup>
	First year			Second year			Third year				
	T1	T2	T3	T4	T5	T6	T7	T8	T9		
ASK knowledge	25.82 (6.01)	28.87 (5.81)	28.45 (6.90)	28.12 (7.72)	28.04 (8.67)	30.20 (8.88)	29.85 (7.94)	30.96 (7.05)	30.64 (8.24)	26.57** (.001)	T6>T1* T7>T1* T8>T1** T9>T1* T6>T3* T8>T3* T6>T4* T7>T4* T8>T4** T9>T4* T6>T5* T7>T5* T8>T5** T9>T5*
ASK attitudes	57.62 (2.56)	56.61 (2.87)	55.54 (3.98)	55.89 (3.38)	57.54 (3.65)	57.43 (3.50)	56.85 (2.96)	57.77 (4.39)	57.40 (3.64)	9.56 (.30)	
POS overall (self report)	105.81 (9.42)	104.27 (8.72)	103.77 (10.25)	113.65 (8.19)	113.81 (6.82)	113.19 (8.80)	113.46 (7.14)	115.85 (7.13)	112.00 (7.89)	36.56*** (.000)	T4>T1*** T5>T1*** T6>T1*** T7>T1*** T8>T1*** T9>T1** T4>T2* T5>T2**

												T6>T2** T7>T2** T8>T2** T9>T2** T4>T3*** T5>T3*** T6>T3*** T7>T3*** T8>T3*** T9>T3*** T8>T7* T9<T8**
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Note: G1=intervention group for three years; T1, T4, T7=pretest; T2, T5, T8 =post-test; T3, T6, T9=Follow-up test

<sup>a</sup>Based on Friedman’s repeated measures.

<sup>b</sup>Based on Wilcoxon matched pairs signed-rank test.

<sup>c</sup> Two participants drop out (not use the service any more).

\*  $p<0.05$ ; \*\*  $p<0.01$ ; \*\*\*  $p<0.001$ .

Table 5-3: Mean effect on the outcomes for the intervention within the group (G3) among adults with ID in 3rd year (n=6)

G3	M(SD)									Z <sup>a</sup> (p-Value)	Post hoc <sub>b</sub>
	First year			Second year			Third year				
	T1	T2	T3	T4	T5	T6	T7	T8	T9		
ASK knowledge	21.33 (8.08)		29.33 (5.78)	23.67 (6.38)		24.67 (4.50)	27.67 (4.50)	26.33 (7.50)	23.83 (7.39)	4.74 (.58)	
ASK attitudes	56.67 (2.25)		53.50 (3.08)	53.50 (2.51)		56.50 (2.12)	56.33 (3.78)	57.67 (3.01)	53.67 (1.97)	7.59 (.27)	
POS overall (self report)	117.83 (5.53)		114.33 (8.87)	114.00 (12.10)		106.33 (7.29)	107.50 (11.71)	110.67 (6.19)	107.00 (7.32)	15.35* (.02)	T6<T1* T7<T1* T8<T1* T9<T1* T7<T4*

Note: G3=as comparative group in the 1<sup>st</sup> and 2<sup>nd</sup> year; receiving intervention only in the 3<sup>rd</sup> year; T1, T4, T7=pretest; T2, T5, T8 =post-test; T3, T6, T9=Follow-up test

<sup>a</sup>Based on Friedman’s repeated measures.

<sup>b</sup>Based on Wilcoxon matched pairs signed-rank test.

<sup>c</sup> Two participants drop out (not use the service any more).

\*  $p<0.05$ ; \*\*  $p<0.01$ ; \*\*\*  $p<0.001$ .

## 1.2. Mean effect on the outcomes for the intervention within the group among adults with ID for two years

The Freidman’s Repeated Measures for more than three tests and the Wilcoxon

Matched Pairs Signed-rank Test as a *post hoc* test were used to compare the sexual knowledge and attitudes, and overall quality of life after the intervention within the group, as shown in Table 6. Quantitative data showed that there was a significant increase in the scores of Sexual Knowledge after the involvement in the program, in particular for the second year intervention, among the participants from two experimental groups (Group 1 and Group 4) ( $P < .05$ ,  $P < .01$ ); improvement in the scores of sexual attitudes was found only among the participants from one of the experimental groups (Group 4) ( $P < .05$ ). The scores for QoL in the experimental group who had been involved in the programs for two years (Group 1) ( $P < .001$ ,  $P < .01$ ) were found to be significantly improved in the second year. The participants of the comparative groups (Group 2 and Group 3) ( $P < .05$ ) also showed significant changes of QoL between the tests within two years. However, no experimental group showed significantly improved in all three respects (sexual knowledge, sexual attitudes and overall QoL).

The quantitative findings, based on the analyses within each group, suggested that the intervention, particularly for the revised intervention in the second year, might be more likely to be effective in sexual knowledge than sexual attitudes. Specially, the intervention caused positive impact on quality of life was only presented in the experimental group whose participants had been involved in the intervention for two years.

Table 6. Mean Effect on the Outcomes for the Intervention within the Group among Participants with ID for Two Years

	M(SD)						Z <sup>a</sup>	Post hoc <sup>b</sup>
group	First year			Second year				
	T1	T2	T3	T4	T5	T6		
ASK knowledge								
G1 N=33	26.5 (5.9)	29.5 (5.9)	28.6 (6.7)	28.1 (7.9)	28.6 (8.5)	29.8 (8.5)	13.96*	T2>T1* T6>T1* T6>T3* T6>T4*
G2 N= 11	38.5 (3.6)		34.4 (8.5)	34.1 (8.2)	35.7 (8.0)	34.1 (8.8)	4.84	
G3 N= 7	22.5 (7.0)		29.3 (5.8)	23.4 (5.9)		23.7 (4.8)	4.71	
G4 N= 19				29.3 (7.2)	34.5 (5.4)	32.4 (7.3)	11.91**	T5>T4** T6>T4*
G5 N= 17				31.9 (8.0)		31.4 (7.4)	.29	
ASK attitudes								
G1 N=33	58.2 (2.7)	56.9 (3.0)	56.0 (3.9)	56.0 (3.2)	57.6 (3.5)	58.1 (3.7)	5.82	
G2 N= 11	59.6 (2.4)		54.7 (3.5)	56.0 (3.7)	57.3 (3.1)	59.5 (4.2)	8.24	
G3 N= 7	56.7 (2.3)		53.1 (3.0)	54.00 (3.5)		56.5 (2.1)	2.68	
G4 N= 19				57.3 (3.8)	59.7 (2.7)	58.6 (3.6)	9.85**	T5>T4*
G5 N= 17				57.0 (4.0)		58.8 (2.4)	.40	
POS overall (self report)								
G1 N=33	106.8 (10.2)	106.8 (10.4)	104.2 (9.9)	113.9 (8.1)	114.2 (7.0)	112.9 (8.6)	30.49**	T4>T1*** T5>T1*** T6>T1*** T4>T2** T5>T2** T6>T2** T4>T3*** T5>T3*** T6>T3***
G2 N= 11	118.2 (9.0)		116.5 (8.7)	106.8 (6.1)	109.1 (7.2)	113.0 (9.8)	18.21**	T1>T4** T1>T5* T3>T4** T3>T5* T3>T6* T6>T4*
G3 N= 7	118.7 (5.6)		115.6 (8.7)	115.4 (11.7)		107.0 (6.9)	8.39*	T1>T4*
G4 N= 19				117.2 (7.8)	117.8 (6.0)	115.8 (5.4)	2.51	
G5 N= 17				113.8 (8.3)		119.1 (8.8)	3.27	

<sup>a</sup>Based on Friedman's repeated measures.

<sup>b</sup>Based on Wilcoxon matched pairs signed-rank test.

<sup>c</sup> Two participants drop out (not use the service any more).

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$ .

### **1.3. Comparison of quantitative outcomes between the experimental and comparative groups**

As shown in Table 7, we did not find the significant difference of sexual knowledge among the participants between the experimental groups and comparative groups in the first year (Group 1 vs Group 2, Group 1 vs Group 3) and second year (Group 4 vs Group 5) including the participants between two years' involvement and without involvement or only second year involvement in the intervention (Group 1 vs Group 2 and Group 1 vs Group 3).

With regard to sexual attitudes, Table 5 showed the significant difference between Group 1 and G3 for the first year and also for the two years follow up. However, first, no significant differences of pretests and follow up tests within the Group 1 and Group 3 in two years as presented in Table 4. Second, the scores of sexual attitudes among the participants of Group 1 and Group 3 all decreased in the first year; the scores of second year had been increased but they were still lower than the pretest of first year.

Comparing the participants' quality of life, we found the significant difference between Group 1 vs Group 2 and Group 1 vs Group 3 in the second year follow up (Table 5). According to the mean scores of quality of life among the participants as shown in Table 4, it suggests that the participants of Group 1 whose quality of life had been increased significantly in the second year while comparing with the participants from Group 2 and Group 3.

Based on the analyses between five groups, difference in difference, the findings suggest that, despite of sexual knowledge and attitudes, the intervention might be effective for quality of life among the participants who had been involved in the

intervention for two years while comparing with the participants from comparative groups.

Table 7. The Changes of the Experimental Groups vs Comparative Groups

First year (T1 –T3) Exp. G=G1 Comp. G=G2 and G3	$Z^a$ ( <i>p</i> -Value)	Second year (T4-T6) Exp. G=G1, G2, G4 Comp. G=G3 and G5	$Z^a$ ( <i>p</i> -Value)
<b>ASK knowledge</b>			
G1(T3-T1) vs G2(T3-T1)	-.62(.53)		
G1(T3-T1)vs G3(T3-T1)	-.61(.54)		
G1(T6-T1) vs G2(T6-T1)			-.61(.54)
G1(T6-T1) vs G3(T6-T1)			-.45(.65)
		G4(T6-T4) vs G5 (T6-T4)	-1.89(.06)
<b>ASK Attitudes</b>			
G1(T3-T1) vs G2(T3-T1)	-.01(.99)		
G1(T3-T1) vs G3(T3-T1)	-2.99(.003)		
G1(T6-T1) vs G2(T6-T1)			-1.06(.29)
G1(T6-T1) vs G3(T6-T1)			-3.38(.001)
		G4(T6-T4) vs G5(T6-T4)	-.41(.68)
<b>POS overall</b>			
G1(T3-T1) vs G2(T3-T1)	-.85(.39)		
G1(T3-T1) vs G3(T3-T1)	-.26(.79)		
G1(T6-T1) vs G2(T6-T1)			-3.00(.003)
G1(T6-T1) vs G3(T6-T1)			-4.01(.000)
		G4 (T6-T4) vs G5(T6-T4)	-2.4(.02)

<sup>a</sup>Based on Mann Whitney U-test.

\**p*<0.05; \*\**p*<0.01; \*\*\**p*<0.001.

#### 1.4. Quantitative outcome for parents –within group and between groups

Table 8: The pretest and post test of the ASQ among parents in the experimental group

	M(SD)		$Z^a$
	1. Pretest	2. Post test	
Factor 1 Sexual rights (N=55)	48.16(6.54)	51.98(11.15)	-3.11 (.002)
Factor 2 Parenting (N=54)	17.95(6.59)	20.24(6.72)	-2.84 (.005)
Factor 3 Non- reproductive sexual behavior (N=54)	21.27(4.74)	24.02(3.72)	-4.60 (.000)
Factor 4 Self-control (N=55)	10.32(3.01)	11.31(3.02)	-1.77 (.077)
ASQ overall (N=53)	97.77(13.49)	107.77(16.07)	-4.62 (.000)

<sup>a</sup> Wilcoxon matched pairs signed-rank test

\*  $p < .05$ . \*\*  $p < .01$ .

Table 9: The pretest and post test of the ASQ among parents in the comparative group

	M(SD)		$Z^a$
	1. Pretest	2. Post test	
Factor 1 Sexual rights (N=16)	48.94(5.83)	50.56(6.33)	-3.93(.69)
Factor 2 Parenting (N=15)	18.37(6.74)	21.81(7.92)	-1.51(.13)
Factor 3 Non- reproductive sexual behavior (N=18)	21.20(3.27)	22.16(3.67)	-1.70(.09)
Factor 4 Self-control (N=16)	10.68(2.41)	10.83(3.19)	-0.56(.57)
ASQ overall (N=14)	99.65(11.69)	106.56(16.55)	-1.45(.15)

<sup>a</sup> Wilcoxon matched pairs signed-rank test

\*  $p < .05$ . \*\*  $p < .01$ .

Table 10: Comparison of the pretest in ASQ between the parents in two groups

		M(SD)		
		GE: Exp. Group	GC: Comp. Group	Z <sup>a</sup>
Factor 1 Sexual rights GE, N=55 GC, N=16	Pre-test (T1)	48.16(6.54)	48.94(5.83)	-.26(.80)
	Post-test (T2)	51.98(11.15)	50.56(6.33)	-.55(.58)
	GE (T2-T1) vs GC(T2-T1)			-1.71(.09)
Factor 2 Parenting GE, N=54 GC, N=15	Pre-test (T1)	17.95(6.59)	18.37(6.74)	-3.84(.70)
	Post-test (T2)	20.24(6.72)	21.81(7.92)	-.67(.51)
	GE (T2-T1) vs GC(T2-T1)			-.47(.64)
Factor 3 Non-reproductive sexual behavior GE, N=54 GC, N=18	Pre-test (T1)	21.27(4.74)	21.20(3.27)	-.47(.63)
	Post-test (T2)	24.02(3.72)	22.16(3.67)	-1.74(.08)
	GE (T2-T1) vs GC(T2-T1)			-1.34(.18)
Factor 4 Self-control GE, N=55 GC, N=16	Pre-test (T1)	10.32(3.01)	10.68(2.41)	-.62(.54)
	Post-test (T2)	11.31(3.02)	10.83(3.19)	-1.04(.30)
	GE (T2-T1) vs GC(T2-T1)			-.44(.66)
ASQ overall GE, N=53 GC, N=14	Pre-test (T1)	97.77(13.49)	99.65(11.69)	-.50(.62)
	Post-test (T2)	107.77(16.07)	106.56(16.55)	-.38(.70)
	GE (T2-T1) vs GC(T2-T1)			-.90(.37)

<sup>a</sup> Mann-Whitney *U* test

\*  $p < .05$ . \*\*  $p < .01$ .

### 1.5. Quantitative outcome for service workers: within group and between groups

Table 11: The pretest and post test of the ASQ among **workers** in the experimental group

	M(SD)		$Z^a$
	1. Pretest	2. Post test	
Factor 1 Sexual rights (n=158)	56.11(5.75)	57.41(6.06)	-3.97(.000)
Factor 2 Parenting (n=158)	27.83(7.47)	29.34(8.30)	-4.28(.000)
Factor 3 Non-reproductive sexual behavior (n=158)	25.99(3.46)	26.85(3.20)	-4.98(.000)
Factor 4 Self-control (n=160)	12.4(2.8)	13.25(3.19)	-3.99(.000)
ASQ overall (n=145)	122.55(14.8)	127.23(17.16)	-5.43(.000)

<sup>a</sup> Wilcoxon matched pairs signed-rank test  
 $p < .05$ . \*\*  $p < .01$ .

Table 11: The pretest and post test of the ASQ among workers in the comparative group

	M(SD)		$Z^a$
	1. Pretest	2. Post test	
Factor 1 Sexual rights (n=26)	55.54(5.38)	39.96(11.55)	-4.38(.000)
Factor 2 Parenting (n=26)	27.53(6.80)	28.58(5.07)	-0.27(.978)
Factor 3 Non-reproductive sexual behavior (n=27)	25.73(3.37)	25.37(3.75)	-1.27(.204)
Factor 4 Self-control (n=25)	13.14(2.68)	13.12(2.46)	-2.06(.040)
ASQ overall (n=24)	121.51(12.91)	107.64(14.57)	-4.17(.000)

<sup>a</sup> Wilcoxon matched pairs signed-rank test  
 $p < .05$ . \*\*  $p < .01$ .

Table 12: Comparison of the pretest in ASQ between the workers in two groups

		M(SD)		
		GE: Exp	GC: Comp	$Z^a$
Factor 1 Sexual rights GE, N=158 GC,N=26	Pre-test (T1)	56.11(5.75)	55.54(5.38)	-.62(.54)
	Post-test (T2)	57.41(6.06)	39.96(11.55)	-6.40(.000)
	GE (T2-T1) vs GC(T2-T1)			-7.37(.000)
Factor 2 Parenting GE, N=158 GC,N=26	Pre-test (T1)	27.83(7.47)	27.53(6.80)	-.07(.94)
	Post-test (T2)	29.34(8.30)	28.58(5.07)	-.83(.41)
	GE (T2-T1) vs GC(T2-T1)			-1.68(.09)
Factor 3 Non-reproductive sexual behavior GE, N=158 GC,N=27	Pre-test (T1)	25.99(3.46)	25.73(3.37)	-.79(.43)
	Post-test (T2)	26.85(3.20)	25.37(3.75)	-2.18(.03)
	GE (T2-T1) vs GC(T2-T1)			-3.10(.002)
Factor 4 Self-control GE, N=160 GC,N=25	Pre-test (T1)	12.4(2.80)	13.14(2.68)	-1.65(.099)
	Post-test (T2)	13.25(3.19)	13.12(2.46)	-.52(.61)
	GE (T2-T1) vs GC(T2-T1)			-3.30(.001)
ASQ overall GE, N=145 GC,N=24	Pre-test (T1)	122.55(14.80)	121.51(12.92)	-.31(.76)
	Post-test (T2)	127.23(17.16)	107.64(14.57)	-4.94(.000)
	GE (T2-T1) vs GC(T2-T1)			-6.73(.000)

<sup>a</sup> Mann-Whitney  $U$  test

\*  $p < .05$ . \*\*  $p < .01$ .

## 2. Qualitative outcome evaluation among the participants

### *Qualitative findings from the adults involved in the intervention*

Table 13-1: Participants of in-depth interview: Adults, parents and workers in three years

		1 <sup>st</sup> year (2013.4)	2 <sup>nd</sup> year (2014.3. 2015.1)	3 <sup>rd</sup> year (2015.3-2015.5)
		X1: G1: Instructors: 2 adults, 1 mother	X2: G1: Instructors: one married couple	X3: G1: one married couple G3: 3 adults; 2 practitioners & 1 mother: observers
G1	Adults	10 (2 instructor with ID)	4(one couple with ID)	6
	parents	2 (mother instructor)	1 (instructor mother)	3
	workers	8 (2 workers working with instructor with ID)	5	2
G2	Adults		5	
	parents		1	
	workers		2	
G3	Adults			4 (3 instructor from LW)
	parents			4 (1 mother observer)
	workers			7 (2 observer from DL)
G4	Adults		2	
	parents		2	
	workers		4	
Total	Adults	10	11	10
	parents	2	4	7
	workers	6	11	9

Table 13-2: Participants of the focus groups after the interventions

	1 <sup>st</sup> year (2013.4-2014.1)	2 <sup>nd</sup> year (2014.3-2014.5)	3 <sup>rd</sup> year (2015.3-2015.7)
1	A Daycare Center: 7 workers	A Daycare Center: 6 workers	2 daycare centers: 13 +2 (observers from DL)
2	A Daycare center: 4 workers	Research Team members I	One daycare center: 10+2 (observers from ZF)
3	Research Team members I	Research Team members II	
4	Research Team members II	Research Team members III	
5	Research Team members III		
Total	5	4	2

Within three years we interviewed adults from the experimental groups (G1, G2, G3 and G4) respectively and almost all adults interviewed replied that they liked the intervention and they additionally suggested that such an intervention could continue. Regarding five young adults with ID and two married couples with ID who were invited in the first/third year and second/third year respectively as the instructors; the participants gave positive feedback.

***Shy to see the penis and vagina props and condom but most impressive.***

Majority of them shared that the most impressive part of the intervention was to see the penis and vagina props, made by plastic, and learn how to use condom and some of them also mentioned they had never seen condom and practiced. Chong (M, 30 yrs old) shared he had never seen the props and condom. Ping (F, 43 yrs old) responded she was shy when she saw those props; and Nue (F, 25yrs old) answered she felt a bit shy for using condom and felt luckily it was fake penis for the practice. Wun (F, 35) also shared she did not feel comfortable during the practice of condom use; but she liked the part related to developing intimacy relationship. For example, when they were asked which parts of the program they had learned or which parts they like most, they replied as below.

Kou (M, 38, G1): *the teaching material, little bird (prop of Penis). ...sexual intercourse.*

Shung (F, 32, G1): *I feel a bit uncomfortable (When she saw the penis props).*

Haw (M, 21, G2): *Teaching us how to use condom. ...I have never learned, but I want to experience.*

Tin (M, 24, G2): *I have never seen (condom) . ...First time, I saw the penis props.*

Yu (M, 21, G4): *that condom, ...those pictures help us to understand the differences between boys and girls.*

Chun (M, 34, G4): *It was not bad, use condom, ... I saw it first time.*

For the female participants who had been second time, second year, involved in this intervention did not feel shy to see those pictures or feel shy to share who she likes, Shung (F, 32) was one of the examples. Both Shung and Yi (F, 32) appreciate one married couple with ID coming as the instructor in the second year.

***Qualitative findings from the service workers working with the adults involved in the intervention***

***Giving a chance to the adults recognizing their sexual rights.*** Seven service workers from G1 in the first year interviewed all positively recognized that this intervention was valuable for the adults. First, they agreed the intervention was good for their service users to give them a chance to acknowledge their sexual rights. Sing (F, supervisor) is the supervisor for adult users in A Daycare Center (G1) for 11 years and she shared *“Involvement in this intervention is good for the service users; it is kind of challenge for them and they could advocate for their sexual rights and for their love.”*

***Intervention material, the practice of condom use and two adults being the instructors appreciated.*** The service workers also replied that the most impressive parts of the intervention were the pictures, intervention material (e.g., vagina and penis props) and the practice of condom use including the content of sexual knowledge such as masturbation, sexual intercourse, and etc. They appreciated that the service users could have opportunity to practice and to speak out what they concerned and to give their feedback. As well as having two adults with ID joined to be the instructors of the research team members was good, not only these two adults were empowered through the participation but also the participants were given a positive learning sample that who could be like these two adults being an instructor

one day.

*“I must say your teaching material was really good. For example the props of vagina and penis were impressive. Also giving condom to the service users to practice was really good.” (Zuei, working with the adults for 10 years)*

*“I have heard the service users talking each other; they were very impressed by the practice of using condom and the pictures. ...It is good I have to say. So the service users could recognize more. ...the part inviting the two adults with ID as the instructors was good too.” (Liang, M, working with the adults for 3 years)*

***Less shy and more openly about the sexual issues.*** After the intervention, the service workers shared that the participants were less shy and more openly talk about their needs, developing an intimacy relationship or hoping to have a marriage than earlier.

*“One of the service users with hearing disability has shared with me that she is planning to make a boy friend and get married. ...this is a kind of empowerment because of joining the intervention” (Zuei)*

*“Before their involvement of this intervention, they were shy or they have never discussed each other about their sexual needs or how to develop intimacy relationships. Now they start to discuss about it and they are not as shy as before; they also came to ask me how to do.” (Liang)*

***Effect of the intervention not only on the adults but also the service workers and parents.*** Second year we interviewed the manager, supervisor and service workers including focus group with the service workers from Group 1 in which the adults with ID have been involved in the intervention for two years. The manager of A Daycare center, Group 1, was interviewed and replied that she positively supports this intervention in which causes positive changes on sexual attitudes not only among the service users but also the service workers and the parents. For example, the

intervention promotes all of them to face sexual needs and rights of their service users but not to ignore. She shared this intervention emphasized on awareness and rights of sexual needs and used practical material, e.g., pictures, props of penis and vagina, and practice how to use condom. Thus the service users learn to be brave to show who they adore; and the service workers and parents learn to be open to support these adults' sexual needs and rights.

*“Sexual education is part of our programs for adult users, but your intervention did give us different perspective of it. ...our staff have been shocked by your intervention. ...see those photos, our service users were learning how to use condom that were very interesting. ...now, our staff are trying to work with the parents who can be supportive in terms of sexual rights for their adult children. Being these adults' service workers and parents, we should support them but not to avoid their needs.”* (Lee, manager, Group 1)

***Adults changed and become more relaxed; staff changed too, become supportive.*** Sing, the supervisor of the daycare center, also gave positive feedback to our two years intervention working with the adults with ID at their Daycare Center. She appreciated those pictures and practice for use condom and now their staff learn to use the real pictures for their sexual education programs—“your intervention gave us enormous impact; it causes us a great change”. She replied after the second-year intervention which focused on rights for intimacy relationship including having a married couple with ID coming for share and giving encouragement to the service users. Now they feel relaxed and open to share who they like each other; the staff show support and discuss with them. She summarized three positive impacts of the intervention on their staff: teaching materials, staff's own sexual attitudes, attitudes towards these adults' sexual needs and rights, and how to communicate with the parents who can accept and respect their adult children' sexual needs and rights. She had shared as below when she was interviewed again.

*“For these two years, our service users learn to be brave to express their needs and who they like. ...our staff learn how to support and give them opportunities to have a date and also learn how to communicate with the parents including the attitudes. For sure some staff in the beginning felt shy to see those pictures (e.g., masturbation, intercourse), but now they feel nature when they see these sorts of pictures. ...we have no idea whether some service users with ID involved in the intervention follow or not; it does not matter because they had rights to be involved too. ...after the intervention, we support our service users to go to toilet for masturbation. After that, these users’ emotion becomes more stable and psychologically healthy; and they do not need to lie to us anymore.”* (Sing, F, supervisor)

Some other service workers from Group 1 also shared at the focus groups. For example, Fung (F, frontline worker) described: “the intervention of first year was very important, that now the service users did not feel guilty when they do masturbation. And those pictures are good to give them correct way for doing masturbation.” Zai (F, frontline worker) shared that: “this time I feel I am much better to talk about sexual issues”.

***Married couple giving adults hope for pursuing intimacy relationships.*** One service worker who has been with the service users with ID for two years shared that after the intervention in first year, the adults learn how to find a person who like and plan to build up partner friendship; continuing after the second year intervention, the adults developed more expectations having intimacy relationships. Additionally the married couple, as the instructors, gave them hope and positive idea to plan their future intimacy relationships.

Specially, the married couple with ID came to be instructors with the adults received positive feedback from the manager, supervisor and also service workers too. They all agreed that this couple gave a successful example, encouragement and hope, being married, to their service users. The service workers replied that this couple did

not talk or share so much, it does not matter whether they can use languages well or not.

***Adults becoming happier, motivated for activities involved.*** Liang (service worker, Group 1) shared: *“after the first year intervention, the adults start to have some good feelings and to have closer relationships each other, sending cards or gifts. Second year, they became brave to express who they like. We did not stop and we try to tell them how to plan if they are going to have a date. For example, Wun (F) and Huei (M) now express how they adore each other. ... In general, their rights in this perspective were promoted, ...sometimes they would talk one another who they like, ...now such kind of topics are getting more and more, ...they learn how to show their concern to the person they adore, e.g., writing letters. ...they become happier to come to the service center, to be more motivated for activities they involved and to have more positive interaction one another. ...Earlier we, as service workers, felt shy to talk about the sexual issues; now our attitudes have been changed, becoming open and supportive.”*

***Feel relaxed, would not be prohibited or blame any more.*** The participants of Group 4 were the users of residential services; besides, we also provided intervention for the service workers working with the residents with ID and the residents’ parents at the same period of time. The service workers of Group 4 replied that the intervention gave them new idea about sexual rights and needs for adults with ID. Before the involvement in the intervention, they were used to consider what the parents’ think instead of paying attention to their service users what they need in sexual issues. One of the service workers responded that it was first time for her to be involved in such a kind of intervention, watching two movies and then following small group discussion with the colleagues. She shared: “He (the residents with ID

was also involved in the intervention) now feels nature and tells me he is going to toilet. ... I just tell him to keep clean and try to support. They (the residents) now feel relaxed because they know they would not be prohibited or blamed as earlier.”

***My worry had not been happened; instead, adults, parents and service workers all changed.*** The front line manager of residential services of Group 4 shared: “In the beginning when you invited our service users involved as the experimental group, I had been worried that the users might learned some sexual behavior in which they did not know earlier. For example, unlike male users, female users did not show their needs for masturbation. Then the intervention might motivate them to do so; afterwards, it would give us more work. After the intervention, my worriers were not happened at all. After the involvement, the adults who need to have intensive support learn to find suitable place for doing masturbation and it was useful for them to have emotion calmed down. For those adults being more independent become more brave to express what she or he likes and say no to whom she or he does not like. ...For parents now they recognize their adult children’s sexual needs and rights for having intimacy relationships. ...For workers now they use correct way to communicate with the residents including language use and support and respect the users’ sexual rights.”

#### ***Qualitative findings from two team members with ID***

Fen ( female, 32) and Ren ( male, 34) were involved in this project from the beginning of the intervention developed; they had been interviewed in the focus group with other young people with ID. Both Ren and Fen were happy as one of the instructors and research team members to be involved in first year at the A daycare Center (Group 1) and they all shared that they learned much from the issues related to sexual health. Not only both of them were involved in the intervention as one of the

team members, but also they were involved in the team meeting after the intervention.

In the second year, one married couple with ID were invited as the instructors and as the members of the research team at the A Daycare center (Group 1). This couple has married for 3 years; Hong was 37 and worked at the gas station and Ling was 32 and worked at 7-11 shop when working with us. After they married, the couple lived with Hong's original family. After the intervention, we interviewed both of them including Hong's mother whom the couple living with.

***Learned much from the issues related to sexual health.*** First, Ren replied that he had never been taught as impressively and as practically as the contents of this intervention before, in particular the pictures showing masturbation and sexual intercourse, and the practice of using condom. He had good time with the participated adults from the service center during 5 hours of the intervention and he appreciated all the male participants who were very actively and openly involved in the program and who knew sexual knowledge a lot and bravely shared each other. Fen replied the payment for being an instructor was big for her and she did not care even having no payment and she also felt very good that every person was equal and like friends in the research team. After her participation in this project, she felt she wanted to try to get married with her boyfriend who is also the service user at the same service unit. Below were what they shared when they asked whether they had something changed after the intervention and also their feedback to their participation as an instructor of the intervention.

*Ren: I feel I am more brave to speak out and getting more attentive in making girlfriend. ...After this project, I have different perspective in sexual issues. ...In the beginning I was a bit nervous; gradually I was getting used to. ... I feel more confident of myself. Being an instructor was different, you talk and keep talking in front of all people, and you need to concentrate and talk clearly as well, not only like a member sitting there. I'd like to try to be*

*an instructor next time.*

*Fen: Yes, I know much now. For example, I know those men and women have. I also took the photos of the props of penis and vagina and also shared with the service workers at my workplace. ... I also discussed with my boyfriend about marriage. ...Before taking part in this project, I did not think I could be able to take care of myself and I have been afraid to leave the service center. Now I feel it is a challenge for me and I want to try to get married. We (with her boyfriend) can move out after we marry. We need to find a work first and then save money. ...It was fun and a kind of experience. ...Next time I will be better because for me it is rarely to talk in front of many people. Today I learned a lot, very much knowledge that I did not know earlier. ... In the beginning I saw those pictures I was nervous. In the end, I do not feel scared.*

***Not bad, I like to try next time.*** Hong and Ling, the married couple, and Hong's mother were interviewed after the intervention about what they had experienced as the instructors and were involved in the intervention at the A Daycare Center.

*Interviewer: What do you (Hong) feel when you were working with us as the instructor?*

*Hong (M, 37): I feel not bad.*

*Interviewer: Which parts did you like most?*

*Hong: All were fine.*

*Interviewer: Did you feel you learn something from this involvement?*

*Hong: Maybe talk with them (the participants with ID at the A Daycare Center).*

*Interviewer: Do you feel your relationships with Ling changed after this involvement?*

*Hong: yes, ...hugging each other.*

*Interviewer: Will you (Ling) like to be the instructor next time?*

*Ling: I think so.*

*Interviewer: Do you think Hong has become kind to you after the involvement?*

*Ling (F, 32): Yes. ...Hugging and kissing.*

*Interviewer: Do you (Hong's mother) feel the relationships between Hong and Ling changed after their involvement of our project?*

*Hong's mom: It was good for them to be involved. ...I have asked them about it after they came back, they told me they shared their lives with those young people. ...It is good they can learn more, ...it is good for mental health too.*

## **Discussion**

### **The impact of the intervention**

The most important of this intervention is to initiate the talks about sexual rights issues for adults with ID even it is under a debate in the society. First, in terms of our innovative intervention, not only the service users but also the service workers and two team research members with ID and one married couple with ID appreciated and were impressive by our current intervention based on the qualitative data in this study. We did not use the term “sexual education” to name the intervention that we had developed and implemented among the adults with ID. In stead, promoting positive attitudes toward sexual health issues and awareness of sexual rights among this group of people was the main concern of this intervention. As mentioned as previous, the terms “sexual health” and “sexual rights” had never been used or discussed among people with ID in Taiwan except our current intervention. In contrast, sexual education is almost included and provided for the adult users with ID in the education and welfare service units in Taiwan. However, the issues such as masturbation, sexual intercourse, rights of gay and lesbian relations including use of condom were not included in such kind of sexual education programs. Moreover, the service workers might worry that the knowledge related to masturbation, sexual intercourse or gay and lesbian relations might motivate these individuals therefore having such desire in

particular for those people with higher level of care needs. For example, before our intervention, we had discussed with one supervisor working with residential care service for adults with ID and she did not agree such issues (i.e., masturbation, sexual intercourse and gay/lesbian relations) could be included in the intervention for the participants with ID. She said "...if he has no idea about masturbation or no such sexual needs, or has no idea about gay or lesbian, and then you let them know about it and he might go to do it. Actually they are just friends, after you teach them and then they may go to try. So for those young people with higher care needs, this kind of intervention might cause troubles. ...For us when we provide the services or we have group activities, we need to consider many conditions that might be happened to any individual member of the group. So I will suggest this kind of intervention needs to be more careful and meet the need of every individual case's special condition." Another service worker working at an institution for service users with ID and interviewed and replied "When we know any service user is doing masturbation, we try to keep his attention away, in stead we encourage him to do more exercise." Based on our qualitative findings in which we interviewed with the service workers and supervisors from Group 1 and 4 who had been involved in the intervention that we provided for service workers, their attitudes had been changed and became supportive to the adults with ID if they want to do masturbation. It implies that the intervention not only provided for the adults with ID but also for the service workers as well.

A Daycare Center (Group 1) is organized by a NGO which is organized by Catholic church and the manager had been worried whether the intervention would cause some impacts which was against the Catholic rituals, such as sexual intercourse without marriage. However, after the two years intervention, the feedback from the service users with ID, the service workers, the supervisor and the manager all

appreciated this intervention and now they had been expecting to be involved for the third year intervention. To sum up, from the service users' perspective, their life coming to the service center had been changed to be livelier than before. For example, masturbation would not be prohibited but supported and viewed as nature but not as deviant behavior. They became brave to express whom they adore and to learn how to show their concerns to whom they like. They are more motivated to join the activities and try to be the same group with whom they like. The topics between the service users are increasing and their emotions become more stable than earlier. The married couple with ID came to share in the second year had given an encouraging example for the service users who now have an expectation that they could be possible to have a family of their own in future. "They are happier when they come to service center" as shared by the supervisor. The changes among the service workers and the center, sexual issues could be discussed openly and the sexual needs among the service users are not ignored as early as told by parents; instead, the service workers now have been trying to communicate with the parents actively.

### **Service workers and parents also need to be involved in the intervention**

Majority of the adults' family never had discussed sexual issues with them. Even the adults hoped to have intimacy relationships or to have marriage, they need to have the agreement from their parents/family first. Before we worked with A Daycare center (Group 1) whose service users were involved in our intervention, we had been rejected by couple of service centers where we invited their service users taking part in this project. The reason they rejected is that the pictures and themes related to masturbation and sexual intercourse could not be accepted by the parents of the adults with ID. However, the manager and service workers of A Daycare Center accepted

our invitation and helped to have the service users' parents/families informed consent to be able to take part in this project and therefore the service users of A Daycare Center became the participants of the intervention since the first year. Based on the findings of this study and as discussed as above, the service users gained opportunity to be aware of sexual health issues including sexual rights because of their participation in the intervention. On the contrary, for those service users whose managers or providers rejected our invitation lose such an opportunity. Doubtlessly it suggested that rights of parenting and non-productive sexual behaviors among these adults with ID is still under controlled by the service workers in particular their parents. Furthermore, it implies that who are the managers and providers is related to the service users whose well being would be like, as discussed as above, sexual health is an issue of well being, this has been approved by both quantitative and qualitative findings of this study, e.g., the findings from participants of Group 1. Additionally, it means that the intervention promoting sexual rights and sexual health in this group of people cannot only focuses on these adults but also their service workers and parents.

### **The changes among female adults**

In the first year, the intervention showed those pictures related to masturbation and sexual intercourse, props of penis and vagina and condom for practice, the participants including the service workers coming with the service users with ID were shocked in particular some of female users even screening and saying that was disgusting. All in all, based on our interviews, male participants with ID and service workers gave positive feedback except female users. In the second year, female participants with ID from Group 1 showed nature instead of shocked or uncomfortable when seeing the props or practicing condom in the first year

intervention. Similar to previous both Western and Taiwanese studies(Chou et al., 2015; Bernert & Ogletree, 2013; Eastgate, van Driel, Lennox, & Scheermeyer, 2011; Fitzgerald & Withers, 2013; McCarthy, 2014), women with ID were more likely to have negative attitudes to non-reproductive sexual behavior than their male counterparts. Our findings also echo previous findings (Jahoda & Pownall, 2014; Rushbrooke, Murray, & Townsend, 2014) that men and women with ID both men and women with ID had very limited opportunities to develop romantic relationships and a healthy sexual identity.

### **Users included and empowered**

According to the qualitative data and comparison between three experimental groups (Group 1, 2 and 4) for two years, we found consistent findings that the participants with ID who were involved in first year showed most impressive for the penis and vagina props and also the condom practice. Instead, for the participants who had been involved for two years felt more impressive to the married couple with ID who came to share with them during the intervention. It worth to point out that inviting the adults with ID as instructors of the intervention was not only to empower these instructors but also to empower the participants.

### **Quantitative vs qualitative method in terms of intervention evaluation**

According to the quantitative data within the two experimental groups (Group 1, Group 4), we found that the positive changes on sexual knowledge, sexual attitudes and quality of life were more likely to show intermediate changes than to present long-term effectiveness with regard to the outcome of the intervention among the participants with ID. Based on the two years' quantitative data, including the

comparisons within and between the groups, related to changes of sexual knowledge, sexual attitudes and quality of life among the adults with ID who had been involved in the intervention from experimental groups (Group 1, 2 and 4), the results did not show clear effects of the intervention. However, the level of quality of life among the participants with ID from Group 1, who had been involved in the intervention for two years, had been increased in the second year according the comparisons within the group 1 and the comparison with group 2 and 3.

It is necessary to point out, in contrast, that the qualitative data collected from both participants with ID and service workers revealed that the intervention did cause the participants' positive changes of their sexual knowledge and attitudes to their sexual needs. First, it suggests that the mixed methods used for the outcome evaluation in such intervention research and conducted for this group of people is warranted. Furthermore, it also implies that using qualitative approach is rather than the standardized questionnaires for collecting data related to the impact of the intervention. Third, the standardized questionnaires might not be suitable to collect data from the participants with ID, although the ASK Tool which was designed for this group of people. Gilgun (2004) and her colleagues (Gilgun and Sands, 2012) have argued that qualitative approach is more suitable for program evaluation as our study showed that qualitative study might be more suitable than the quantitative one for collection data among this group of people in particular.

### ***The strengths of this intervention***

In general our first strength is that this intervention was the first and innovative one to advocate the rights of masturbation and intimacy relationships for this group of adults

in the society. Second, in terms of the intervention, the use of the pictures printed in the manual of ASK tool that we purchased from the Centre for Developmental Disability Health Victoria (2011) in which showing the nude bodies of men and women, masturbation, sexual intercourse, etc., giving the opportunity for these adults practicing how to use condom, using props of penis and vagina as material was another strength of this intervention. Moreover, the parents and service workers were also the participants of this intervention as well; two adults and one married couple with ID joining with us as the instructors has earned very positive feedback for the adults, parents and service workers. By the way, from the beginning of the development, implementation and evaluation, and revision of this intervention were all working with the participants, including, adults, parents, front line service workers; and the PI and Co-PI are also from the different disciplinary background.

### **Implications**

Dealing with attitudes to sexual rights or sexual health issues in the society is not simple, it is necessary to work with social values including different persons with different social context including religion or culture taboo. For example, whether the issues of masturbation and nonproductive sexual behaviors, the pictures showing sexual intercourse, premarital or outside marriage sexual intercourse can be accepted or discussed in the society is related to the individual persons' social background. How the values of these issues among the parents, service workers including the managers of the service centers is also relevant with how these adults' sexual rights and sexual health issues are concerned and influenced. All in all, the most effective strategies of sexual health and sexual rights for adults with ID are: first, to involve parents and service workers of adults with ID in the intervention and build up

dialogues of the groups; and second, to facilitate the voices on sexual needs of adults with ID being heard and shared by the service workers and parents as well.

The focus group organized by the team members for three times after the intervention in the first year and second year respectively. According to our discussions, some primary points of our intervention have been confirmed. For example, we were very clear that our intervention would focus on rights issues instead of sexual education.

As we know sexual education has been taught to adult service users; instead, the rights for masturbation, having intimacy relationships, sexual behaviors, marriage and child-giving/parenting as mentioned as in the CRPD have not been mentioned to these adults in the society. Furthermore, we would not touch moral issues or right and wrong related to sexual behaviors, for example, no sexual behavior without marriage and whether it is acceptable to find a prostitute. Another big debate is that whether this intervention was only suitable for those adults assessed with mild ID instead of those assessed with severe. This was frequently pointed out by the service workers or parents. For example, the parents often argued that their children were too severe to have sexual needs; and some of the service workers also wondered whether those adults assessed with severe ID could follow the intervention. However, some of the service workers also replied that at least they stayed and were sitting there; and this was their rights to access such kind of intervention. In addition, we recognize that the intervention for parents and for service workers is also essential in order to claim sexual rights for the adults. Thus the parents and service workers were also the participants of the intervention at the same period time.

## **Conclusions**

Both quantitative and qualitative results show the intervention causes positive impact

on the participants' well being and aware their freedom of sexual needs. At least, this intervention results the change that sexual rights and needs among the adults with ID become the disclosed issues, even it is under debate, between the service workers and managers who are working with this group of adults in the society. We also found that the limitations of the standardized questionnaires. For example, according to the results of the quantitative data we did not find the changes of the sexual knowledge and sexual attitudes among the adults with ID. In contrast, the intervention, based on the qualitative data, received positive feedback from the adults, service workers and the managers in the experimental groups.

## References (skipped)

### 二、目前研究進度是否與預期目標一致

依據計畫書，第三年研究計畫重點工作有五：(1) post test of comparative group and follow-up test of experimental group; (2) revised the intervention program based on the findings of the evaluation in 2nd year; (3) the outcome intervention for the comparative group and 3<sup>rd</sup> year intervention for the experimental group; (4) symposium: share the evaluation outcomes with the users, parents, practitioners and researchers; (5) the handbook of the intervention.

So far one article had been published, one article has been under revision, two articles had been presented at the International conference and three articles are planning to submit to the international journals.

#### **Published:**

Chou, Y. C.\*, Lu, Z. Y., & Pu, C. Y. (2015). Attitudes toward male and female sexuality among men and women with intellectual disabilities. *Women & Health*, 55(6), 663-678. SSCI/SCI, IF=1.194, WOMEN'S STUDIES rank=Q1 (8/40) (NSC 101-2410-H-010 -003 -SS3)

#### **Under revision:**

Chou, Y. C.\*, Z, J., Lu & Lin, C. C. (2014) Comparison of attitudes to sexual health of men and women with intellectual disabilities among parents, professionals and the university students, *Journal of Intellectual and Developmental Disability* (under minor revision)

#### **Presented at the international conferences/under writing:**

Chou, Y. C.\*, Z. J. Lu, & Lin, C. C. (2014). Outcome evaluation of a sexual health program for adults with learning disability: qualitative and quantitative approaches, present at the NNDR Conference, May 6-8, 2015, Bergen, Norway. (科技部獎助) (NSC 101-2410-H-010 -003 -SS3)

**Chou, Y. C.\*** (2014). Working with adults with intellectual disabilities to promote their sexual health: Program innovation, implementation, and evaluation, present at the IASSIDD, Europe Regional Congress, 2014-07-14, Vienna. (科技部獎助) (NSC 101-2410-H-010 -003 -SS3)

Chou, Y. C.\* (2013). Attitudes to male and female sexuality among men and women with intellectual disabilities. Presented at the 12<sup>th</sup> NNDR (Nordic Network of Disability Research) conference, Turku, Finland, May 30-31, 2013. (NSC 101-2410-H-010 -003 -SS3) (國科會獎助)

目前研究進度與預期目標一致，甚或超越原來目標，敘述如下。

第一，介入及評估研究參與者涵括使用者、家長、實務工作者。在介入方案發展、執行過程也邀請前述參與者全程參與。

第二，針對實驗組部分，我們增加一個追蹤 post test，亦即在介入之後馬上進行後測，在四個月之後，又進行追蹤後測，此追蹤後測與比較組之後測同一時間進行 (August)。

第三，第一年初次測量參與者為提供日間照顧及位於南部區域者，第二年主要測量擴及到提供住宿服務單位及位於中部地區者。

第四，第一年有進行實驗組者，我們在第二年、第三年繼續進行第二次、第三次介入 (針對青年)，為期三年介入，一共九次測量。

第五，第一年兩個單位之比較組，分別於第二年、第三年邀請其成為實驗組。

第六，於第四年三月，舉辦介入研究結果分享發表會，並邀請參與使用者、家長、實務工作者及經營者分享。

第七，介入手冊的產出，依據介入研究典範：依據本土與國際發展方案、執行、修正、再次執行、再次修正、期擴大使用。

三、請依學術成就、技術創新、社會影響等方面，評估研究成果之學術或應用價值 (簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性) (以 1000 字為限)

1.學術價值:這三年的研究案是以介入研究典範強調三個部分:需求評估、方案發展及方案評估，三個步驟同時進行，可以累積國內以實務為基礎的研究、知識，對國內實務工作者、社會工作碩士及博士論文提供一個參考範本。我們也應用參與性研究、解放學(emancipatory research)研究典範，邀請智能障礙者

青年與研究者站在平等位置，一起規劃及執行，對國內發展及重視解放學研究，在學術上有創新的意涵。同時本研究評估，含量性與質性資料收集，兩者都收集智障者主觀經驗，對國內智障者相關研究提供有力參考。本研究結果也到國際會議與投相關國際期刊發表，對台灣在介入研究、解放學研究、智障研究與國際接軌的實踐及增加台灣智障研究在國際學術社群之曝光率。

2.技術創新:這是一套針對智能障礙者、家長與工作人員發展之性健康權利介入方案，方案名稱：促進智能障礙者青年性健康權利的介入方案，為期三年。第一年針對使用日間服務之青年、家長、工作人員初步試測，於 2013 年完成，以及第二年擴大測量到使用社區居住之青年、家長、工作者，於 2014 年完成，2015 年再次修正，繼續針對青年、家長、工作人員介入，同時召開成果會分享、出版介入手冊，期推廣使用。

3.社會影響:(1)呼籲相關工作者，家長、社會對智能障礙青年性健康議題的重視，爭取障礙青年性權利、社會平等位置。(2)邀請智障者參與我們的規劃及執行，與研究者站在同等位置，我們也提供同等講師薪資，提升障礙青年在台灣社會能夠平等被重視，智障青年的權能提升(empowered)。

## Appendix I: 成果發表會相關資料

### 科技部「發展與評估智障者性健康方案」三年研究 成果發表會：介入方案手冊初稿分享

時間：2015年03月27日(五)13:00~16:30

地點：台北市NGO會館(青島東路8號)

開場：陳美鈴理事長(臺灣社區居住與獨立生活聯盟)

報告者：

研究團隊：

國立陽明大學衛生福利研究所 周月清 教授

國立陽明大學臨床暨社區護理研究所 盧孳艷 教授

台北市立大學師資培育中心 林純真 助理教授

參與團隊：

心路基金會、立達啟能中心、信望愛智能發展中心、啟智技藝訓練中心、智障者家長總會、瑞復益智中心、瑪利亞基金會、德蘭啟智中心、蘆葦啟智中心

分享人：

智青-0孝、0文、0仁影片分享

家長-0倫媽媽(瑪利亞社會福利基金會)

工作人員-林心怡 督導(蘆葦啟智中心)

管理者-林網市 主任(瑪利亞社會福利基金會)

出席：青年、家長、工作人員、關心智障者性健康權者  
共34單位參加，71人出席

錄音檔：

林純真老師

盧孳艷老師

心怡

慶倫媽媽

劉于濟先生(台灣障礙者權益促進會)

王育瑜副教授(暨南大學社會政策與社會工作學系)

參與的單位

1	心路社會福利基金會
2	財團法人中華民國自閉症基金會
3	光仁社會福利基金會
4	國立陽明大學衛生學程
5	仁愛啟智中心
6	台灣省私立香園紀念教養院
7	中壢啟智技藝訓練中心
8	天使發展中心
9	財團法人苗栗縣私立幼安教養院
10	台中市愛心家園
11	瑪利亞基金會
12	財團法人天主教會台中教區附設立達啟能訓練中心
13	財團法人台中市私立信望愛智能發展中心
14	財團法人向上社會福利基金會
15	財團法人基督教瑪喜樂社會福利基金會
16	聖心教養院
17	財團法人天主教會嘉義教區附設嘉義縣私立敏道家園
18	德蘭啟智中心
19	美善社會福利基金會
20	瑞復益智中心
21	花蓮縣私立黎明教養院
22	中華民國智障者家長總會
23	中華民國殘障聯盟
24	台北市恆愛發展中心
25	財團法人桃園縣私立觀音愛心家園
26	亞洲大學社工系
27	喜憨兒基金會
28	蘆葦啟智中心
29	第一社會福利基金會
30	社團法人台東縣智障者家長協會
31	桃園市愛家發展中心
32	台灣障礙者權益促進會
33	美好社會福利基金會
34	財團法人桃園縣私立祥育啟智教養院

**Appendix II: (skipped)**

**Intervention manual**

服務使用者參與之性健康介入方案：智青、家長、工作者  
操作手冊(第三年修正版—針對第一年、第二年介入)

## 行政院國家科學委員會補助國內專家學者出席國際學術會議報告

2015 年 5 月 30 日

報告人 姓名	周月清	服務機構及職稱	陽明大學衛生福利研究所教授
時間 會議地點	2015 年 5 月 6 日 至 2015 年 5 月 8 日  挪威 Bergen	本會核定補助文號	NSC 101-2410-H-010 -003 -SS3
會議 名稱	(中文) 2013 年第十三屆北歐障礙研究網絡國際會議 (英文) NNDR 2015-13 <sup>th</sup> Research Conference-- Nordic Network of Disability Research		
發表 論文 題目	發表兩篇： I. (中文) 成年智障者性健康結果評估：質性與量性方法 (英文) <b>Outcome evaluation of a sexual health program for adults with learning disability: qualitative and quantitative approaches</b> II. (中文) ICF 在台灣的運用：醫療模式的勝利 (英文) <b>Application of the ICF in Taiwan — Victory of the medical model?</b> (論文摘要及全文詳見附件二、附件三)		

### (一) 與會經過

這是第十三屆北歐障礙研究網絡國際會議，由北歐五個國家(瑞典、挪威、丹麥、芬蘭、冰島)輪流舉辦，今年由挪威 Bergen University 主辦，共有 370 位來自 36 個國家研究者；論文發表三百多篇，共三天。

NNDR 是北歐五國針對障礙研究而成立的網絡，促成從文化、社會及環境巨視面向來從事障礙研究。NNDR 兩年召開一次，與英國的 Lancaster 大學國際研討會錯開，兩者成為 International Disability Study 社群，因此與會者蠻多來自英國。

這次會議兩整天。因為多數與會者來自北歐或鄰近的西歐、英國，會議開幕式在第一天上午，閉幕式在第一天下午，註冊費仍然十分昂貴(台幣近兩萬)。

大會討論議題包括：

- (1) body and sexuality
- (2) childhood, youth, family and parenting
- (3) everyday life and social participation
- (4) citizenship
- (5) disability and innovative technology
- (6) space, place and disability
- (7) education and liberation
- (8) labor market and employment
- (9) deaf studies

IC-008(表 B)

- (10) welfare policy and services-collaboration & funding
- (11) welfare policy and services-rights and participation
- (12) art and disability
- (13) institutions and professionals
- (14) disability research today: international perspectives
- (15) mad studies
- (16) global and transnational issues

第十三屆的北歐障礙研究網絡國際會議，這個國際會議在今年特別強調包括從社會、文化、歷史、哲學的各種面向來探討障礙的相關研究，這一次會議主要的目的是希望能夠帶來新的洞察，針對障礙研究裡提出前線的議題，包含議題及方法，所以就提出五個等待討論的問題：

1. What characterize disability studies as a field?
2. What impact does technology and innovation have on the field?
3. How has the concept of gender been dwelt open?
4. What are transnational issues in the disability field?
5. What are seen as disabling conditions or practice?

所以希望從理論的角度，經由這些主題、演講，以及相關 paper 的發表，來針對障礙研究提出重要的概念，期待障礙研究能夠有所貢獻，能夠建立一個新的研究網絡，包括研究者、實務工作者、障礙運動者，不管來自本土、國內以及國際。

## (二) 心得

北歐的障礙研究網絡，今年進入第十三屆，會發現越來越國際化，包含今年有來自 36 個國家的研究者一起來討論，今年最主要的主軸，也就是北歐障礙研究一直以來會比較有理論概念的探討，所以主題演講有時候也會非常抽象，包含第一場演講是來自法國的哲學家 (Professor Julia Kristeva)，他的主題演講 (A tragedy and a Dream: Disability Revisited) 我幾乎是聽不懂，每個單字都聽得懂，但放在一起就聽不懂，相當的抽象。

北歐的障礙研究跟英國的 Lancaster 障礙研究的研討會是一樣的，都會強調社會模式觀點，幾乎是不可能有的醫療模式觀點的相關研究報告。今年比較特別的地方是針對聯合國 CRPD，尤其是針對第 19 條，其中也有提出歐盟障礙網絡影子報告，也有相關研究探討北歐五國在針對去機構教養化現況做的調查。另外，今年最重要的議題是個人助理，相關研究報告非常多，也相當受歡迎，也看到這些個人助理的研究報告都是來自北歐國家和英國，尤其今年是挪威提出非常多個人助理的相關研究。另外一個部分，研究方法的單元非常受歡迎，尤其是針對障礙者的研究，大家也提到障礙研究應該要用一個什麼樣的觀點及什麼樣的方法論，尤其是針對智能障礙者，尤其是多重、需要高度支持障礙者的障礙研究，我們如何去了解他參與研究的自主性及其主觀看法。

這個研討會一開始在開幕式，以非常顛覆傳統的方式開始，在開幕式裡請一個樂團，這個樂團非常顛覆，講髒話、唱 rock。大會主席致辭也是，輕鬆、幽默。這個會議基本上也是在顛覆障礙的建構，顛覆傳統上國際會議一定要長什麼樣子，傳達訊息，國際會議可以是非常叛逆、自由、

自主性，這也是 NNDR 對我的吸引。

今年最特別的地方是有一場主題演講，是邀請一位患有腦性麻痺的挪威身心障礙研究者的主題演講，事實上他演講的題目是非常哲學的，因為肢體語言的關係，講得非常慢，但你也會觀察到他非常的認真、非常用力地在說話，英文很清楚，觀眾也非常用心在傾聽，當然對非英語系的人來說，同時會發現，這樣的一個「慢」對這些聽眾來說是非常好的現象，也讓我學習到障礙有時候不一定是負向的，有些時候是正向的，而且這個正向不是只有針對障礙者，也有對其他參與的人也是有正向貢獻的。

因為我自己這次有發表兩篇論文，都在第二天的下午，兩場緊扣相連，感覺有點辛苦，在這次研討會過程當中，我們也訪問挪威自立生活的相關重要人物，她 (Tove L. Brandvik) 是女性肢障者，32 歲就當了六年市長，後來又到國會當議員，她非常慷慨他自己成為妻子、母親、政治人物的生命歷程，以及分享個人助理如何協助其執行社會角色及任務。她也介紹其他人給我們訪問，包括去訪問一位唐氏症青年的家，由他的母親來接我們去訪問，我跟台北大學張恆豪老師去訪問，他的家是他購買的，在過程當中，他的個人助理也在旁邊。另外，在第二天的時候，Tove 也介紹首都的官員，請教有關障礙政策的事情。基本上這次會議雖然非常疲累，但也非常充實，除了個人自己發表兩篇論文之外，不但不能休息，還要做訪談。因為這些人從 Oslo 過來，可以同時訪問到那麼多人，也很感動的是大家都非常友善，中央單位有一個負責身心障礙的，是這次大會開幕式的致詞者，也提供很多資料給我們，包含七月時就有 CRPD 的國家報告書可以提供，你會發現非常的平民化的中央官員。

基本上參加這個北歐障礙研究的會議，我個人是覺得還蠻開心的，因為大多數是來自北歐國家，他們的障礙福利也是比較先進發展的，可以學習的地方非常多，基本上他們也是友善的。同時，你可以看到很多障礙者，包含障礙運動者、障礙研究者、各種障別(視障、聽障、肢體障礙者、坐輪椅的)，手語翻譯員、個人助理穿梭其間、手語翻譯員忙碌服務的畫面。你會發現到在手語翻譯的時候，會有一個以上的手語翻譯員站在台上，因為來自不同國家會有不同的手語翻譯員，畫面很令人感動。這些與會的身心障礙者的運動者、障礙身心障礙者的研究者，充滿自信，可以感受到障礙者是被看到的，非障礙者反而顯得渺小、顯得需要謙卑。

另外，因為這一次為推動無紙化，資料都在網站上面，所以在研討會結束的時候，由主辦單位發一個評估問卷，要大家針對這次會議無紙化的看法如何。

### (三) 建議

1. 這次學習最多的是個人助理的部分，以及針對 CRPD 的部分，也希望我們政府在 CRPD、個人助理，確實有必要多參考這些先進國家怎麼做，以及他們國家報告、影子報告怎麼寫，政策服務怎麼做。目前個人助理在台灣並不是每個縣市都有，台灣的屬性跟別人也不同，因此這方面的研究也值得去關注。
2. 這次同樣看到很多年輕 PHD 學生發表其論文，其中包括聽障、視障、肢體障礙的哦是班學生，他們也藉此機會和各國學者、或是和同是 PHD 學生建立網絡，這對未來其研究生涯其實是很有意義的；然而台灣博士班學生相對參與較少。如何鼓勵台灣更多博士班學生參與國際學術網絡，是台

灣新生代研究工作者國際連結、國際視野擴展的挑戰。

3. 鼓勵障礙者發聲，研究也當提供機會讓障礙者參與研究資料得收集；政府、專業人員、社會體制更為謙虛，退出主導性，主體是障礙者--「nothing about us without us」；而這些思維應該放入行政、服務、研究與教學工作中。

4. 無紙化的國際會議也鼓勵大家節省資源，這部分也值得我們去學習。

5. 另一個地方也值得我們學習，大會在第一天開幕式 reception party 及最後一天午餐在會議還沒開始之前就做調查誰尚未到、誰要先離開，因為不要過度準備食物及浪費，這個部分也讓我覺得印象深刻，也是很值得我們學習的地方，就是盡量站在節省資源的角度。

6. 這一次會議場所是在 Bergen City 的一個 hotel，所以整個會議場地包括溫度都非常的舒適，包含準備的咖啡、茶也都準備的非常好，讓與會者覺得開心；包含無障礙環境可以讓輪椅進出等等，這都是一個非常值得學習的地方。

#### (五) 參觀

(略，大會未安排參觀)

#### (六) 訪問 (自行安排，配合研究案，共三場訪問)：

**1. Tove L. Brandvik, ghe Norwegian Association of Disabled (NAD), Ulob Independent Living, has been MP, mayor of local authority**

**2. Torild Haland and Truls: visit Truls' apartment on Askoy. Truls with DS and living in his own flat and PA was with him when the interview conducted.**

**3. Grete Hjemtvedt and Anne Bjorshol: Norwegian directoriate for Children and Youth and Family Affairs from Oslo, State Government.**

**4. Future skype interview:**

**(1) Jamie Bolling, Sweden, European Network of IL Europe**

**(2) Hilde Hualand: Norwegian Association of Hard of hearing**

**(3) Vibeke M. Melstoom, Founder of the IL movement in Norway.**

**(4) Eli Knbsen, Equality and Antidiscrimination Ombudsman**

#### (七) 攜回資料名稱及內容

1. NNDR2015 -13<sup>th</sup> Conference: Nordic Network of Disability Research, May 6-8, 2015 in Bergen, Norway, Program Book.

2. NNDR2013 -12<sup>th</sup> Conference: Nordic Network of Disability Research, May 30-31, 2013 in Turku, Finland, Abstract Book. [www.nndr2013.fi](http://www.nndr2013.fi)

3. List of participants in the NNDR2013 Conference on May 30-31, 2013 in Turku, Finland.

4. UNICEF (2013). The state of the world's children: Children with disabilities. UNICEF, May 2013. ISBN: 978-92-806-4656-6.

IC-008(表 B)

附件一：筆記

## **I. Keynote speech**

### **The possibility of other worlds. Disability studies and contingent disabling processes**

Keynote by Postdoctoral research fellow Halvor Hanisch, Oslo University Hospital

Halvor Hanisch: the possibility of other worlds

The speaker with CP

We are dissatisfaction with the world: pain,

#### **Disability Studies as agency**

What kind of agency constitutes DS?

In what context does this knowledge production takes place?

How can this production be described in terms of research design?

Where and how are researchers left by this doing?

#### **Doing something “critical”**

Facing this world's adversity towards disabled people, disability scholars often label their work as critical:

Critical DS vs “critical realism”

Critical analyses of disabling processes investigate how they depend upon social and historical conditions.

#### **Arguing contingency**

Analytical critique rests on the possibility of another world

Normative critique imagines other and better worlds

Different disability scholars imagine different possible worlds.

#### **Contingency arguments in the UK canon: Carol Thomas**

Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being

(C. Thomas, 1999, p3)

(C. Thomas, 2007)

#### **Contingency arguments in the US canon: Lennard Davis**

The social process of disability arrives with industrialization and with the set of practices and discourses that are linked to eighteenth and nineteenth century notions of nationality, race, gender, criminality, sexual orientation, and so on. (Davis, 1995, p25)

#### **The situation of Disability Studies**

A social world characterized by adversity towards people with impairments.

This adversity is seen by some as unnecessary (that is, contingent) or unacceptable (that is, wrongful)

IC-008(表 B)

It is not easy to voice the experience of wrongful contingency, not has it been easy to explore it in research.

**This idea-DS counterpart-can be found in two versions:**

Strong version: life with a disability is necessarily less good

Weak version: some aspects of life with a disability is necessarily less good

The weak version implies some degree of social contingency.

**A Disability Studies corpus (2005-2014)**

Central journals: Disability & Society, Scandinavian J. of DR,

Alter: European J of DR, Disability Studies Quarterly

Discipline-specific journals: J. of Cultural and Literary Disability Studies, Ethnographic J of Culture and Disability, Sexuality & Disability, African J of Disability, Internal J of Disability, Development and Education.

**Preliminary findings: D & S**

Disability community, culture, employment, narratives, services and policy, other social analyses, theoretical analyses

Preliminary findings: JLCDS

Early modern culture,

**Contingency and changeability**

To produce DS knowledge is to produce insights into thinkable worlds

Those insights are, most of all, insights into our world as a changeable world.

By way of this knowledge production –in itself-our world also becomes a changed world.

**The paradox as alleviation**

Contingency arguments are more than instruments

They are also responses to the trouble of disabling processes

To realize the contingency of this world is not only empowering but also alleviating

**Conclusion**

We demonstrate contingency successfully

In empirical terms, we leave some areas of contingency less explored than others

These patterns of research design may be reasonable

They nevertheless dovetail with attempts at downplaying the severity of the contingency

II. keynote speech

**Disability and gender: understanding diversity and promoting equality**

Keynote by professor Carol Thomas, Director at the Centre for Disability Research, Lancaster University

IC-008(表 B)

Main research: gender disablism; gender and disability

Social diversity within Disability studies

Critics: social model Disability, Disability gender direction: what consequences, concepts, critics within DS

Three key concepts: Disablism, impairment effect, psycho-emotional disablism

Disablism: categorized as “impaired” by those deemed “normal”.

social imposition of avoidable restrictions on the life activities,

Alongside sexism, racism, ageism, homophobia

Person to person interactions, institutionalized and other socio-structural forms

**Impairment effects:** the direct and unavoidable impacts that impairment have on individual embodied functioning in the social world. Impairment and impairment effects are always biosocial and culturally constructed in character and may occur at any stage in the life course.

**Psycho-emotional disablism:** use of words actions, images by those deemed “normal” –the impact of this on personhood is often profound: the damage psycho, emotional pathways to injure “disabled” individual self-esteem, personal confidence and ontological security

### **Disability and the global south**

New journal edited by Shaun Grech, launched 2014, online, Open Access at no cost to authors, edited by Shaun Grech and Karen Soldatic

**Social model of Disability (SMD)**-GN (global north) epistemology, academic neocolonialisation, where are GS Voices? 80% of disabled people here, ignores diversity of cultures, contexts and histories in GS (global south), against homogeneity /for heterogeneity (e.g., faiths)

**Grech:** DS remains WENA -industrial GN, obsessed with “poverty” in GS; Need “neocolonial” theory, capable of analyzing complexities & contemporary economic & discursive exploitation, ..generation of impairment (disabled women in GS)

**A political manifesto:** “for the emancipation of our bodies”

Mainstream women movement:

### **XIII EFLAC Manifesto:**

Celebrates intersectionality and diversity among all women; disabled women and their needs/demands present throughout;

themes: Critical interculturality from an intersectional perspective; the sustainability of life as priority;

body and territory: safeguarding community life

IC-008(表 B)

disablism (DM)—takes different forms, manifests itself divergently in contrasting global geographical locations –shaped by the history, culture (language, practices and beliefs) and local economies in specific places.

Impairment effects: the direct and unavoidable impacts that culturally defined “impairments” have on individual embodied functioning in their social world. Impairments and impairment effects are ...

Psycho-emotional disablism: the culturally contextual use of words, ...

III. Shadow report on the implementation of Article 19 of the UN CRPD in the European Union

Camilla Parker, Ines Bulic, Jamie Bolling

European Network on Independent Living, Ireland

**Research topic:** This report considers the action taken by the European Union (“EU”) to implement the rights of people with disabilities under Article 19 (living independently and being included in the community) of the UN Convention on the Rights of Persons with Disabilities (“CRPD”).

**Theoretical and methodology framework:** The report seeks to provide the Committee on the Rights of Persons with Disabilities (referred to as “CRPD Committee”) with information that will be of assistance when assessing the extent to which the EU has complied with its obligations under Article 19 in relation to these two areas. It does so by considering the initial EU report to the CRPD Committee, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union* (“the EU report”) and comparing it with information about the situation of people with disabilities living in the EU Member States.

**Conclusions/findings:** ENIL-ECCL are concerned that the EU report gives insufficient attention to the problems and challenges faced by people with disabilities living in the EU, in relation to the right to independent living (Article 19). It fails to provide a realistic picture of the current situation of people with disabilities, with the corresponding problem that there is little discussion on how the continuing widespread and weighty barriers to achieving the goals set out in the Disability Strategy might be addressed. In particular, while the action by the European Commission to highlight, in both policy and legislation, the need for Member States to ensure the shift from institutional care to community-based services is very welcome, more effective action is required to ensure that people with disabilities can exercise their right to independent living in accordance with Article 19.

## **Outcome evaluation of a sexual health program for adults with learning disability: qualitative and quantitative approaches**

### **Abstract**

**Key words:** intellectual disability, sexual health, intervention research, inclusive research

**Aims:** In order to promote sexual health of adults with learning disability (LD), we utilized Intervention Research and Inclusive Research paradigms to innovate, implement, evaluate, modify and re-evaluate an intervention program for adults with LD. This study aims to evaluate the outcomes of this innovative program related to sexual health knowledge/attitudes and quality of life (QoL) among the participants with ID for two years.

**Methods:** Both quantitative and qualitative methods were used in the evaluations of the two-year study between April of 2013 and January 2015. Multiple-group time series (T1 to T6) design was used for the quantitative data and 86 adults with LD from five groups participated, in different periods of time. In addition, in-depth interviews and focus groups were used to collect qualitative data, in particular on the experiences and perspectives of the included adults with LD, service workers and parents.

**Results:** Quantitative data within the groups indicated that there was a significant increase in the scores of Sexual Knowledge after the involvement in the program among the participants from two of five groups (Group 1 and Group 4); however, improvement in the scores of sexual attitudes and overall QoL was found only among the participants from one of the groups (Group 4 and Group 1 respectively). None of the groups showed significant change in all three respects (sexual knowledge, sexual attitudes and overall QoL). However, qualitative data showed that the participants liked the program and gained positive attitude to sexual needs after taking part in the program, such as “dare to show who they adore”, “discuss with each other about how to develop intimacy relationships”, “not being as shy as before”, and “enjoy masturbation”.

**Conclusions:** Based on the qualitative findings, the adults with ID were encouraged to pursue their sexual needs as the result of their involvement in the program. In this study, in terms of intervention innovation, qualitative approach seems to be more suitable for use for program evaluation than the quantitative one.

### **Introduction**

An infrastructure that promotes the well-being of persons with ID is needed especially health taking account of sexual and reproductive health (Cuskelly & Gilmore, 2007; Doyle, 2008; Edwards, 2004; Sandfort & Ehrhardt, 2004; Servais, 2006). The knowledge and attitudes of people with ID about sexuality has relevance to their well-being and quality of life (Galea et al., 2004). McCabe’s study (1999)

has presented that people with ID not only experienced lower levels of sexual knowledge and experience, but also they had more negative attitudes to sex than people without a disability. Meanwhile, the discussions related to sexuality of people with ID, the voices of individuals with ID often go unheard (Lesseliers & Van Hove, 2002).

Sexual health is not yet an issue of health policy for people with ID in Taiwan and reproduction and sexual rights of this group are not recognized by the parents, service workers including policy makers (Chou et al., 2010; Taiwan Parental Organization for people with Intellectual Disabilities, 2004). Taiwanese young people with ID rarely had opportunity to have intimate relationships due to the barriers from parents and society (Lin, 2009); additionally, the interventions and program evaluations which aim to promote sexual health and awareness of sexual rights for people with ID is lacking. In Taiwan, the users-led or users included in the research as research team members has not yet considered in the empirical studies conducted for people with disability.

The primary concern of this study is to develop the intervention program for promoting sexual knowledge and attitudes and well being among this group of people with ID and to evaluate whether the intervention program is effective. This study utilized an Intervention Research (IR) paradigm particularly suited for conducting research in a unique social context which is different from traditional research (Richman, 2010; Rothman, 1984; Thomas, 1984). As well as, in this study, the adults with ID were included in the program development, implementation and evaluation (Oliver, 1996; Walmsley, 2001, 2004; Zarb, 1992).

### **Significance of the study**

Most people with ID currently have few opportunities to develop their relationships and health sexual identity. According to WHO document (2002, 2004), the concept of sexual health is warranted to be included in the health policies and programs and applied in sexual education/intervention and health promotion in people with ID. The information and knowledge related to sexual health in people with ID including sexual rights provided to people with ID would enable this group to develop healthy sexual identity and promote their well-being. Additionally, people with ID were also given the opportunity to voice their range of desire, knowledge and experiences regarding their sexual health.

### ***Components of sexual health***

Robinson et al. (2002) indicated that sexual health reflects not only self-acceptance and respect, but also respect and appreciation for individual differences and diversity, as well as freedom from sexual dysfunction, sexually transmitted disease, and sexual assault and coercion (p. 45). Gust et al. (2003) suggested that sexual behaviour policies in residential facilities for people with ID should include sexual relations, sexually transmitted disease (STD), sexual abuse, HIV/STDs prevention programs, use of contraception, sexual behaviour and condom use. The components of **sexual knowledge** in people with ID in the scale, Assessment of Sexual Knowledge (ASK), which was developed by Galea et al. (2004) and has been identified as a reliable tool, are such as parts of body, public and private, puberty, menstruation, menopause masturbation, relationships, protective behaviors, sexuality, safer sex practices, contraception, pregnancy & birth, sexual health-screening tests, sexually transmitted infections, legal

issues regarding sexuality. Eastgate (2008) has identified a number of sexual health issues relevant to people with ID: masturbation, sexual abuse, sexual offending, consent to sexual activity, contraception, sexually transmitted infection, menstrual management and sterilization and pregnancy and child rearing. All in all, the sexual health issue in people with ID covers multi-dimensions and multi-disciplinary. Servais (2006) has urged there is a need to move beyond descriptive research and use experimental designs to ascertain the efficacy of certain sexual health interventions in people with ID. Moreover, she also pointed out that an individualized and person-centered multidisciplinary approach is warranted to provide a comprehensive sexual health care to this group. In Taiwan, sexual education programs for people with ID who are the students of the education system or services users have been established in the past decade and the contents usually focus on the knowledge about body, puberty, menstruation, menopause, relationships, protective behaviors (Ministry of Education, 1999, 2000). The term “sexual health”, the issue of sexual rights or the components such as masturbation, sexual activity/non-reproductive sexual behaviors, contraception, pregnancy, parenting or child rearing including the use of condom (Gust et al., 2003, 2004; Eastgate, 2008) have not been yet incorporated in such sexual education programs provided to people with ID, including their attitudes and voice have not been paid concern.

### **Inclusive research and emancipatory research**

Walmsley (2004) pointed out that the concept “inclusive research” and involving users with ID and their carers are vital in health improvement in the education programs and evaluations for people with ID. Inclusive research can be a kind of emancipatory research based on social model perspective which people with disability would be involved as research team members rather than the controlled or passive objects of research (Barnes, 2003; Oliver, 1996; Turner & Beresford, 2005). Through such actively participating in the research process, the participants with disability are therefore empowered and whose rights could be promoted (Walmsley, 2001). Williams and Nind (1999) indicated that disability studies means the researchers and people with disability are doing research together; Zarb (1992) suggested that the researchers should learn from people with disability; and Shakespeare (1996) suggested that research and movement could be integrated with people with disability. And all these concerns are part of research ethical issues while disability studies are conducted (Stalker, 1998). Barnes (1992, 2003) has advised that “doing emancipatory disability research” not only is a social model approach but also is associated with qualitative rather than quantitative data collection strategies. The outcome of emancipatory disability research is primarily to have a meaningful impact on people with disability as to affect their lives (Barnes, 2001; Oliver, 1997).

### **Intervention research**

As discussed as above, multi-dimensions and researchers from multi-disciplinary involved are warranted in sexual health and well-being promotion among people with ID. Intervention research (IR) has a base in social work, but is highly interdisciplinary (Thomas & Rothman, 1994) and usually requires teamwork among researchers, service providers, service users and other stakeholders (Gilgun & Sands, 2012). IR is also named as Research and Development (R & D) and it is a research-based for design and development

of interventions, and provide guidelines in practice with individuals, families and community organizations (Fraser & Galinsky, 2010; Rothman, 1984; Thomas, 1984; Thomas & Rothman, 1994). The term “developmental” also connotes the on-going revisions required to craft effective interventions (Gilgun & Sands, 2012). It also allows the conducted research not only to integrate related literature with local culture, but also to collect the clinical expertise of service providers and to interview the participants of the intervention designed for (Fraser et al., 2009; Gilgun & Sands, 2012; Thomas & Rothman, 1994) and to use multiple methods of analysis, program development and program evaluation (Fraser & Galinsky, 2010). In particular, qualitative research plays an important role in the design and development of interventions including the evaluation of the intervention (Gilgun, 2004; Gilgun & Sands, 2012).

### **The intervention for adults with ID developed and implemented**

The purpose of this study is to develop an effective intervention program for promoting sexual knowledge and sexual attitudes and well being in people with ID including awareness of sexual rights as general people in Taiwan; thus, IR is appropriate to innovate the effective intervention program for this group of people in certain society (Smith, 1989; Thomas, 1984). According to Thomas and Rothman (1994), six phases of intervention design and development: research-problem analysis and project planning; information gathering and synthesis; design; early development and pilot testing; evaluation and advanced development; and dissemination. In this study we focused on both the development and evaluation of the intervention. Mixed methods were used for program design and evaluation and interdisciplinary team members were involved in the process including the service users. The tasks are such as: integrating empirical studies, related documents; in-depth interview/focus group related to the intervention developed; practice guidelines generalization/ intervention innovation for adults with ID; pre-test before the intervention (quantitative); and intervention implemented and evaluated including pilot test and advanced development.

In terms of intervention research in promoting sexual health, Corbett (1994) has indicated that sexuality issue or sexual education program is not to tell people with disability how to behave normal or do what “other” people want you to do (Shakespeare, 1994), instead, is to be self acceptance and respected (Robinson et al. 2002). The participants’ voices can be heard and break through the traditional research which the in-balance power between researcher and the researched (Atkinson & Walmsley, 1999). First of all, sources of knowledge included related documents, international and Taiwan literature review (including the findings from the previous survey study for adults with ID and parents, 2011-2012), related international documents (UN/WHO), sexual health related education packages, and Taiwan policies and laws, local culture and practices, and inclusive/emancipatory research. The practices and specific concerns about the intervention design were collected through the interviews with eight adults with ID, four parents and three service workers; the individual interviews and focus groups were used to collect data. All these knowledge and practices were synthesized and integrated. Based on the knowledge and practice syntheses including Inclusive Research, the consistent findings, practice guidelines and intervention programs and an intervention handbook for people with ID related to sexual health and rights issues to people with ID were generalized, innovated and developed respectively.

Practice guidelines for the intervention were such as: Sexual health is a rights issue and nature,

positive, open, optional, pleasant, identity and culture related; contents include two parts, knowledge and attitudes; knowledge covers pregnancy, conception, child giving, safe sex behaviors, protective behaviors, sexual diseases, sexual assault; attitudes emphasize on masturbation, intimacy relationships, and child giving/parenting; it is an users-centered and included approach and their voices need to be heard.

In the end, eight parts (i.e., masturbation, relationships, sexual behavior, safe sex practice/ sexually transmitted infections/pregnancy, protective behaviors, legal issues—rights and illegal behavior, sexual health-screening tests and sexual health plan) and lasted for 5 hours of the intervention were designed and delivered in the morning and afternoon to the adults with ID, who were male and female separately in the different group. The intervention material has been made as the slides of the power point and we also used the pictures from the ASK Picture Booklet in which are intended for use in the accompanying documents a ASK tool for people with an ID and Administration manual. There are 18 pictures and we only used 12 pictures and skip the parts of anal and oral sexual intercourse. The props of penis and vagina were used as well; the participants had chance to practice for use of condom. The facilitators (team members of the intervention) included the PI or Co-PIs and two adults with ID. Instead of sexual education, according to the evaluation of the pilot test in the first year, the intervention in second year had been revised and in particular emphasizes on the rights issues in which have been deliberated in the article 23 of the UNCRPD such as rights for masturbation, rights for intimacy relationships, rights for non-reproductive sexual behavior, rights for marriage, rights for child giving, rights for parenthood and rights for safe sexual practice.

**Methods**

A mixed methods approach, combing quantitative and qualitative, in the evaluation was employed for this study, which was conducted between April of 2013 and January 2015.

**Research design for quantitative outcome evaluation**

In order to evaluate the effectiveness of the intervention, within two years, among adults with LD, multiple-group time series (T1 to T6) design (as shown in Figure 1) was used for the quantitative data and 87 adults with LD from five groups participated, in different periods of time for the quantitative data analyses. The independent variable was the intervention that was innovated and revised by current study; three dependent variables included the sexual knowledge and attitudes and quality of life among adults with LD. “Are adults with LD’s attitudes to sexual health, sexual knowledge and quality of life improved after receiving the intervention?” is the Research question of this outcome evaluation.

**Figure 1: Multiple-group time series design** (Shadish, Cook, & Campbell, 2002)

	Year 1/Pilot test				Year 2/Advanced develop.			
G1	T1	X1	T2	T3	T4	X2	T5	T6
G2	T1			T3	T4	X2	T5	T6
G3	T1			T3	T4			T6
G4					T4	X2	T5	T6

G5	T4	T6
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Note: G: group; X1: intervention in Pilot test; X2: intervention in advanced development; T1: pre-test of pilot test; T2 posttest of pilot test; and T3: follow up of pilot test; T4, T5 and T6: pretest, posttest and follow up of the advanced development respectively.

### *Participants and settings*

All participants in this study were adults with a primary assessment of LD<sup>1</sup> and were all voluntarily involved. As shown in Table 1, in the pilot test, the participants of the experimental and comparative group were recruited from three daycare centres and managed by a NGO in a city in Tainan area of Taiwan. There were 48 adults with LD (30 men and 16 women) in the experimental group from one daycare center; another 22 adults were invited from another two daycare centers. In the advanced development, except the participants who were involved in the pilot test, another 20 participants and 17 were recruited from three daycare combing residential care units as the experimental and comparative group respectively. In total, 70 and 108 adults participated in our pilot test and advanced development respectively.

For the quantitative data analyses, only those adults with LD who could answer the questions in the interview were analyzed in this study. The participants of the data analyses in the pilot test and advanced development were reduced to 58 and 89 respectively.

As shown in Table 2, the participants' mean ages were between 27 and 32 of five groups and we did not find the differences of the participants' age between the five groups. In stead, there were significant differences of the proportion of gender ( $p < 0.001$ ) and level of disability ( $p < 0.05$ ) of the participants from five groups. For instance, all participants were male from Group 3 and 82% of participants were female from Group 5; 90% of participants with mild/moderate disability from group 2 and 100% of participants with severe and profound disability from group 5.

Table 1: Participants and settings of the experimental and comparative groups

	Pilot test-1 <sup>st</sup> year		advanced develop.-2 <sup>nd</sup> year	
	X1(N)	Data analyses (N)	X2 (N)	Data Analyses (N)
G1	48	33 <sup>a</sup>	51	33
G2		14	14	13 <sup>b</sup>
G3		8		6
G4			20	19
G5				17
Total	48	55	85	88

<sup>1</sup>Such a diagnosis is made by a medical doctor based on the individual's IQ score and social adaptation skills. Then a certificate of disability is issued by the local authority and given to the individual. The certificate defines the person with disability according to one of four different severity levels (mild, moderate, severe and profound).

Total	73	108
Involved		

Note: X1: 1<sup>st</sup> year intervention (2 adults with LD; one mother); X2: 2<sup>nd</sup> year intervention (one couple with LD)

**Table 2:** Characteristics of the participants with LD in the groups

Characteristics		G1/LW (n=33)	G2/DL (n=11)	G3/ZF (n=7)	G4/MA (n=19)	G5/LD+ S (n=17)	Z <sup>a</sup> /X <sup>2</sup>
Mean age	Mean (SD)	27.1 (6.5)	30.73 (8.2)	30.7 (6.2)	31.7 (5.9)	28.7 (6.5)	7.4 (.12)
	Range	19-41	21-43	23-41	21-42	20-43	
Gender N(%)	Men	22 (66.7)	6 (54.5)	7 (100.0)	6 (31.6)	3 (17.6)	21.83*** (.000)
	Women	11 (33.3)	5 (45.5)	0	13 (68.4)	14 (82.4)	
Level of disability N(%)	Mild / moderate	21 (63.6)	10 (90.9)	4 (57.1)	14 (73.7)		
	Severe/ profound	12 (36.4)	1 (9.1)	3 (42.9)	5 (26.3)	17 (100.0)	11.91* (.02)

Note: The numbers of the participants analyzed were only for those who answered the questionnaires.

<sup>a</sup> Kruskal-Wallis one-way analysis of variance by ranks

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

***Procedures: pretest, post test and follow up in the pilot test and advanced development***

The process of the intervention could be categorized into two stages (pilot test and advanced development) and six steps: from T1 (pre-test) to T6 (follow up of advanced development) including two interventions (X1 in pilot test of first year and X2 in advanced development of second year).

A questionnaire package (as described as below) was conducted before and after intervention, the pre- tests, post-tests and follow-up tests in the pilot test and advanced development correspondingly.

In the first year of the pilot test, the intervention for the adults with LD was implemented in the A Daycare Center as the experimental group (Group 1) between April 25 to 26, 2013. And the participants from another two daycare centers (Group 2 and Group 3) from the same area were invited as the comparative groups. The trained interviewers (the research assistant and a student graduated from social welfare background) conducted face-to-face interview with the participants with LD before (T1, April, 2013) and after the intervention (T2 on May 2013 and T3 on August 2013) at the three service units. For the participants from comparative group only participated in the interview of T3.

In the second year of advanced development, except the participants from the experimental group in the first year, the participants from one of the daycare centers (Group 2) who were in the comparative

group became the participants of experimental group in the second year. Moreover, the new participants who were the users of the residential service from one service unit which providing residential and daycare services were invited as the experimental group (Group 4). The adults of the Group 3 continued to be the participants of comparative group in second year and the adults who were also the users of the residential service from another service unit in which provide both residential and daycare services were invited as the comparative group in second year (Group 5) (as shown in Table 1)

Each interview took 25-40 minutes depending on the adult's communication with the interviewers. All the participants involved in this study, including the interview and intervention, were invited in advance by telephone first and following a written informed consent form which was signed by both the PI and the participants with ID and their legal guardians. The current study had been approved by the Research Ethical Board of the National Taiwan University (approve number: 201207HS007).

### ***Variables and measures***

***Dependent variables.*** The intervention program innovated in the current study aims to promote sexual knowledge and positive attitudes to sexual health among adults with LD. One more dependent variable, that is adults with LD's quality of life, was evaluated as well as the outcomes of the intervention among the participants. The adults with LD's *sexual knowledge and attitudes to sexual health* were measured by the *Assessment of Sexual Knowledge Tool* (ASK Tool) (Centre for Developmental Disability Health Victoria, 2011). The *ASK Tool* is a new test that aims to assess the sexual knowledge and attitudes of people with LD. There are four components to this assessment tool: Knowledge, Attitudes, Quick Knowledge Quiz and A Problematic Socio-Sexual Behaviours Checklist. *The ASK* has been designed so that each part can be used independently or in conjunction with another. In this study the *Quick Knowledge Quiz* (25 items) and the attitudes with 40 items (Centre for Developmental Disability Health Victoria, 2011) were used. The *ASK* has been tested with test-retest and inter-rater reliability and indicated they are stable measures, consistent overtime and between examiners, by the authors (Galea et al., 2004, p.28). Cronbach's alphas

in the *Quick Knowledge Quiz* and attitudes of the *ASK* were 0.70 and 0.50 respectively for the adults with LD in this study.

*The adults with ID's quality of life* was measured by the *Personal Outcomes Scale* (POS): *A Scale to Assess an Individual's Quality of Life -Chinese version* (Chang, 2010). The *POS* was developed by van Loon et al. (2008) and made up of 48 items that represents eight domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional, physical, and material well-beings. Each domain has six indicators related to people with ID's QoL (Schalock et al., 2005; Chou et al., 2007). The *POS* is measured by the individual interviewee's own self report among people with LD (e.g., "Can you eat and get up from bed, use toilet and dress up by your own?") and also measured/observed by the persons who know the individual interviewee (e.g., "Do you think the individual can carry on his/her daily life activities, such as eat, get up from bed, use toilet, and dress up?"). A 3-point Likert Scale is used to scale the response dimensions for both sets of questions (van Loon et al., 2008). A higher score indicates a better QOL for both "self report" and "observation". The *POS* has

been used by 778 adults with LD in Taiwan and its internal consistent reliability was .87 in the “self report” and 0.85 for the “observation” (Chou et al., 2012). In this study, only those data self reported by the participants were analyzed and Cronbach’s alphas was 0.84 for the adults in this study.

***Independent variable (intervention) --The intervention program.*** The independent variable is the intervention package that was innovated in the pilot test and also revised in the advanced development by the current study, as mentioned as above.

### ***Data Analyses***

The dataset was analyzed using the Statistical Package for Social Sciences (SPSS), Version 20.0 (SPSS Inc., Chicago, IL USA). Within the group, a Friedman's Test (Non-Parametric Repeated Measures Comparisons) was used initially to test whether there were significant differences among the six time points (T1 to T6) and then the Wilcoxon Matched Pairs Signed-rank Tests were conducted as a *post hoc* test to measure if a main effect of the intervention (T1 vs. T2, T1 vs. T3, T2 vs. T3 and etc.) was found for the participants (Table 3). Due to the differences of the characteristic data and also the pretests among the participants from five groups, the Mann Whitney U-test (Non-Parametric Repeated Measures Comparisons) was used to measure if there is significant difference between the difference and difference in different groups, under the first year, second year and two years follow up. It means that, for example, the Mann Whitney U-test was used to compare the result of T3 -T1 (T3 minus T1) of Group 1 and the result of T3-T1 of Group 2 in the first year and to compare the result of T6 –T1 of Group 1 and the result of T6-T1 of Group 2 for the two years follow up.

### **Qualitative interviews after the intervention**

#### ***Participants of the qualitative study***

In order to collect data related to what the extent of the impact of the intervention that might not be measured by the standardized questionnaires, we also conduct in-depth interview and focus group after the intervention of the first and second year.

As shown in the Table 3, the participants of the in-depth interview were only recruited from the experimental groups that included the adults with LD, parents, service workers and also the research team members including four adults with LD as our research team members. After the intervention in the first year and second year, five and four focus groups were conducted and the participants included service workers of the intervention groups and research team members.

The semi-structured interviews were used and conducted by the principal investigators (PI) and the full-time research assistant between April of 2013 and December of 2014. The development of the interview guides was based on the purposes of the pilot test and advanced development (Fraser & Galinsky, 2010; Thomos & Rothman,1994) and also to collect data in relation to the effect of the intervention and strength and weakness for later revision use, as presented in the Appendix. The interviews were delivered in Mandarin or Taiwanese based on the language use of the interviewees and tape-recorded and later transcribed and translated into English and double-checked by all authors.

Table 3: Table 3: Participants of experimental groups in-depth interview and focus group in the pilot test and advanced development

IC-008(表 B)

		1 <sup>st</sup> year (04/2013)	2 <sup>nd</sup> year (March 2014-Jan 2015)
In-depth interview (n=participants)			
G1	Adults	10 <sup>a</sup>	6 <sup>c</sup>
	parents	2 <sup>b</sup>	1
	workers	8	5
G2	Adults		5
	parents		1
	workers		2
G4	Adults		2
	parents		2
	workers		4
Total	Adults	10	11
	parents	2	4
	workers	6	11
Focus group (n=times)			
workers		2	1
Team members		3	3

<sup>a</sup> Two instructors with ID; <sup>b</sup> one mother instructor; <sup>c</sup> one married couple with ID as the instructors

## Results

### Mean effect on the outcomes for the intervention within the group among adults with LD for two years

The Friedman's Repeated Measures for more than three tests and the Wilcoxon Matched Pairs Signed-rank Test as a *post hoc* test were used to compare the sexual knowledge and attitudes, and overall quality of life after the intervention within the group, as shown in Table 4. Quantitative data showed that there was a significant increase in the scores of Sexual Knowledge after the involvement in the program, in particular for the second year intervention, among the participants from two experimental groups (Group 1 and Group 4) ( $p < 0.05$ ,  $p < 0.01$ ); improvement in the scores of sexual attitudes was found only among the participants from one of the experimental groups (Group 4) ( $p < 0.05$ ). The scores for QoL in the experimental group who had been involved in the programs for two years (Group 1) ( $p < 0.001$ ,  $p < 0.01$ ) were found to be significantly improved in the second year. The participants of the comparative groups (Group 2 and Group 3) ( $p < 0.05$ ) also showed significant changes of QoL between the tests within two years. However, no experimental group showed significantly improved in all three respects (sexual knowledge, sexual attitudes and overall QoL).

The quantitative findings, based on the analyses within each group, suggested that the intervention, particularly for the revised intervention in the second year, might be more likely to be effective in sexual knowledge than sexual attitudes. Specially, the intervention caused positive impact on quality of life was

only presented in the experimental group whose participants had been involved in the intervention for two years.

Table 4: Mean effect on the outcomes for the intervention within the group among participants with LD for two years

	M(SD)						Z <sup>a</sup>	Post hoc
group	First year			Second year				
	T1 Pretest	T2 post-test	T3 Follow-up	T4 Pretest	T5 post-test	T6 Follow up		
ASK knowledge								
G1 N=33 <sup>c</sup>	26.5 (5.9)	29.5 (5.9)	28.6 (6.7)	28.1 (7.9)	28.6 (8.5)	29.8 (8.5)	13.96*	T2>T1 T6>T1 T6>T3 T6>T4
G2 N= 11	38.5 (3.6)		34.4 (8.5)	34.1 (8.2)	35.7 (8.0)	34.1 (8.8)	4.84	
G3 N= 7	22.5 (7.0)		29.3 (5.8)	23.4 (5.9)		23.7 (4.8)	4.71	
G4 N= 19				29.3 (7.2)	34.5 (5.4)	32.4 (7.3)	11.91* *	T5>T4 T6>T4
G5 N= 17				31.9 (8.0)		31.4 (7.4)	.29	
ASK attitudes								
G1 N=33	58.2 (2.7)	56.9 (3.0)	56.0 (3.9)	56.0 (3.2)	57.6 (3.5)	58.1 (3.7)	5.82	
G2 N= 11	59.6 (2.4)		54.7 (3.5)	56.0 (3.7)	57.3 (3.1)	59.5 (4.2)	8.24	
G3 N= 7	56.7 (2.3)		53.1 (3.0)	54.00 (3.5)		56.5 (2.1)	2.68	
G4 N= 19				57.3 (3.8)	59.7 (2.7)	58.6 (3.6)	9.85**	T5>T4
G5 N= 17				57.0 (4.0)		58.8 (2.4)	.40	
POS overall (self report)								
G1 N=33	106.8 (10.2)	106.8 (10.4)	104.2 (9.9)	113.9 (8.1)	114.2 (7.0)	112.9 (8.6)	30.49* **	T4>T1* T5>T1*

IC-008(表 B)

								T6>T1* T4>T2 T5>T2 T6>T2 T4>T3* T5>T3* T6>T3*
G2 N= 11	118.2 (9.0)		116.5 (8.7)	106.8 (6.1)	109.1 (7.2)	113.0 (9.8)	18.21* *	T1>T4 T1>T5 T3>T4 T3>T5 T3>T6 T6>T4
G3 N= 7	118.7 (5.6)		115.6 (8.7)	115.4 (11.7)		107.0 (6.9)	8.39*	T1>T4
G4 N= 19				117.2 (7.8)	117.8 (6.0)	115.8 (5.4)	2.51	
G5 N= 17				113.8 (8.3)		119.1 (8.8)	3.27	

<sup>a</sup>Based on Friedman's repeated measures.

<sup>b</sup>Based on Wilcoxon matched pairs signed-rank test.

<sup>c</sup> Two participants drop out (not use the service any more).

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$ .

### ***Comparison of quantitative outcomes between the experimental and comparative groups***

As shown in Table 5, we did not find the significant difference of sexual knowledge among the participants between the experimental groups and comparative groups in the first year (Group 1 vs Group 2, Group 1 vs Group 3) and second year (Group 4 vs Group 5) including the participants between two years' involvement and without involvement or only second year involvement in the intervention (Group 1 vs Group 2 and Group 1 vs Group 3).

With regard to sexual attitudes, Table 5 showed the significant difference between Group 1 and G3 for the first year and also for the two years follow up. However, first, no significant differences of pretests and follow up tests within the Group 1 and Group 3 in two years as presented in Table 4. Second, the scores of sexual attitudes among the participants of Group 1 and Group 3 all decreased in the first year; the scores of second year had been increased but they were still lower than the pretest of first year.

Comparing the participants' quality of life, we found the significant difference between Group 1 vs Group 2 and Group 1 vs Group 3 in the second year follow up (Table 5). According to the mean scores of quality of life among the participants as shown in Table 4, it suggests that the participants of Group 1 whose quality of life had been increased significantly in the second year while comparing with the participants

from Group 2 and Group 3.

Based on the analyses between five groups, difference in difference, the findings suggest that, despite of sexual knowledge and attitudes, the intervention might be effective for quality of life among the participants who had been involved in the intervention for two years while comparing with the participants from comparative groups.

Table 5: The changes of the experimental groups vs comparative groups

First year (T1 –T3) Exp. G=G1 Comp. G=G2 and G3	$Z^a$ ( <i>p</i> -Value)	Second year (T4-T6) Exp. G=G1, G2, G4 Comp. G=G3 and G5	$Z^a$ ( <i>p</i> -Value)
<b>ASK knowledge</b>			
G1(T3-T1) vs G2(T3-T1)	-.62(.53)		
G1(T3-T1)vs G3(T3-T1)	-.61(.54)		
G1(T6-T1) vs G2(T6-T1)			-.61(.54)
G1(T6-T1) vs G3(T6-T1)			-.45(.65)
		G4(T6-T4) vs G5 (T6-T4)	-1.89(.06)
<b>ASK Attitudes</b>			
G1(T3-T1) vs G2(T3-T1)	-.01(.99)		
G1(T3-T1) vs G3(T3-T1)	-2.99(.003)		
G1(T6-T1) vs G2(T6-T1)			-1.06(.29)
G1(T6-T1) vs G3(T6-T1)			-3.38(.001)
		G4(T6-T4) vs G5(T6-T4)	-.41(.68)
<b>POS overall</b>			
G1(T3-T1) vs G2(T3-T1)	-.85(.39)		
G1(T3-T1) vs G3(T3-T1)	-.26(.79)		
G1(T6-T1) vs G2(T6-T1)			-3.00(.003)
G1(T6-T1) vs G3(T6-T1)			-4.01(.000)
		G4 (T6-T4) vs G5(T6-T4)	-2.4(.02)

<sup>a</sup>Based on Mann Whitney U-test.

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$ .

## **Qualitative findings from the participants**

### ***Qualitative findings from the adults involved in the intervention***

The first and second year we interview 8 adults and 9 adults from the experimental groups respectively and almost all adults interviewed replied that they liked the intervention and they additionally suggested that such an intervention could continue.

***Shy to see the penis and vagina props and condom but most impressive.*** Majority of them shared that the most impressive part of the intervention was to see the penis and vagina props, made by plastic, and learn how to use condom and some of them also mentioned they had never seen condom and practiced. Chong (M, 30 yrs old) shared he had never seen the props and condom. Ping (F, 43 yrs old) responded she was shy when she saw those props; and Nue (F, 25yrs old) answered she felt a bit shy for using condom and felt luckily it was fake penis for the practice. Wun (F, 35) also shared she did not feel comfortable during the practice of condom use; but she liked the part related to developing intimacy relationship. Some of them responded that they hoped to develop an intimacy relationship, in particular after the intervention, but they did not think they could be able to have a marriage without their parents or siblings' agreement. They also shared that their family did not talk or mention about the issues related to their intimacy relationship or marriage. Fong (F, 31yrs old) made a boy friend in secret and it was hidden from her mother and teachers otherwise her mother would be angry with her.

Regarding two young adults with ID and one married couple with ID who were invited in the first year and second year respectively as the instructors; the participants gave positive feedback.

*Interviewer: Do you remember what we had learned in the class?*

*Haw (M, 21, G2): Teaching us how to use condom. ...I have never learned, but I want to experience.*

*Tin (M, 24, G2): I have never seen (condom), my face becomes red. ...First time, I saw the penis props.*

*Interviewer: Which parts that we did not cover but you hope should be included in the class ?*

*Tin: about boy friends and girl friends, ....how to make friends, boy and girl.*

*Ping (F, 43, G2): I feel a bit uncomfortable (When she saw the penis props).*

*Interviewer: Which parts of the program you like most?*

*Yu (M, 21, G4): that condom, ...those pictures help us to understand the differences between boys and girls.*

*Chun (M, 34, G4): It was not bad, use condom, ... I saw it first time.*

*Interviewer: what do you think of the program?*

*Shung (F, 32, G1): I feel good.*

*Interviewer: Why?*

IC-008(表 B)

*Shung: I want to make a (boy) friend. ...but my brother said that I cannot get married.*

*Interviewer: Which parts of the program you like most?*

*Kou (M, 38, G1): the teaching material, little bird (prop of Penis). ...sexual intercourse.*

*Interviewer: Have you thought about one day you want to make an intimacy friend or get married?*

*Kou: ...My mother says that I need to make money in order to give money to my wife.*

For the female participants who had been second time, second year, involved in this intervention did not feel shy to see those pictures or feel shy to share who she likes, Shung (F, 32) was one of the examples. Both Shung and Yi (F, 32) appreciate one married couple with ID coming as the instructor in the second year.

### ***Qualitative findings from the service workers working with the adults involved in the intervention***

First year only the adults of Group 1 was involved in the experimental group and they continued in the second year. The adults of Group 2 and Group 4 became the experimental groups who were involved in the intervention in the second year. Despite Group 2, the feedback from the service workers of Group 1 and Group 4 was quite positive.

#### ***Feedback from the service workers of Group 1 in first year***

In the first year, we interviewed 7 service workers who were with the adults with ID involved in the intervention.

***Giving a chance to the adults recognizing their sexual rights.*** The service workers interviewed all positively recognized that this intervention was valuable for the adults. First, they agreed the intervention was good for their service users to give them a chance to acknowledge their sexual rights. Sing (F, supervisor) is the supervisor for adult users in A Daycare Center for 11 years and she shared “*Involvement in this intervention is good for the service users; it is kind of challenge for them and they could advocate for their sexual rights and for their love.*”

#### ***Intervention material, the practice of condom use and two adults being the instructors appreciated.***

The service workers also replied that the most impressive parts of the intervention were the pictures, intervention material (e.g., vagina and penis props) and the practice of condom use including the content of sexual knowledge such as masturbation, sexual intercourse, and etc. They appreciated that the service users could have opportunity to practice and to speak out what they concerned and to give their feedback. As well as having two adults with ID joined to be the instructors of the research team members was good, not only these two adults were empowered through the participation but also the participants were given a positive learning sample that who could be like these two adults being an instructor one day.

*“I must say your teaching material was really good. For example the props of vagina and penis were impressive. Also giving condom to the service users to practice was really good.” (Zuei, working with the adults for 10 years)*

*“I have heard the service users talking each other; they were very impressed by the practice of using condom and the pictures. ...It is good I have to say. So the service users could recognize more. ...the part inviting the two adults with ID as the instructors was good too.” (Liang, M, working with the adults for 3 years)*

***Less shy and more openly about the sexual issues.*** After the intervention, the service workers shared that the participants were less shy and more openly talk about their needs, developing an intimacy relationship or hoping to have a marriage than earlier.

*“After the intervention, they are now not so shy to talk about intimacy relationships. ...Some of them become more active to express whom he/she adores and then he/she tries to have some actions.” (Lin, working with the adults for 4 years)*

*“One of the service users with hearing disability has shared with me that she is planning to make a boy friend and get married. ...this is a kind of empowerment because of joining the intervention” (Zuei)*

*“Before their involvement of this intervention, they were shy or they have never discussed each other about their sexual needs or how to develop intimacy relationships. Now they start to discuss about it and they are not as shy as before; they also came to ask me how to do.” (Liang)*

The interviewed service workers also gave their comments on the intervention for future revision. For example, Sing (supervisor) commented: *“Questionnaires were difficult to find out the changes after the intervention.”* And Liang (service worker) suggested: *“I think it not only gives them instructions about the sexual issues; instead, practice part could be more emphasized in order to give them strong impression.”*

### ***Feedback from the service workers of Group 1 in Second year***

Second year we interviewed the manager, supervisor and service workers including focus group with the service workers from Group 1 in which the adults with ID have been involved in the intervention for two years.

***Effect of the intervention not only on the adults but also the service workers and parents.*** The manager of A Daycare center, Group 1, was interviewed and replied that she positively supports this intervention in which causes positive changes on sexual attitudes not only among the service users but also the service workers and the parents. For example, the intervention promotes all of them to face sexual needs and rights of their service users but not to ignore. She shared this intervention emphasized on awareness and rights of sexual needs and used practical material, e.g., pictures, props of penis and

vagina, and practice how to use condom. Thus the service users learn to be brave to show who they adore; and the service workers and parents learn to be open to support these adults' sexual needs and rights.

Lee (manager, Group 1): *Sexual education is part of our programs for adult users, but your intervention did give us different perspective of it. ...our staff have been shocked by your intervention. ...see those photos, our service users were learning how to use condom that were very interesting. ...now, our staff are trying to work with the parents who can be supportive in terms of sexual rights for their adult children. Being these adults' service workers and parents, we should support them but not to avoid their needs.*

***Adults changed and become more relaxed; staff changed too, become supportive.*** Sing, the supervisor of the daycare center, also gave positive feedback to our two years intervention working with the adults with ID at their Daycare Center. She appreciated those pictures and practice for use condom and now their staff learn from us using the real pictures for their sexual education programs—"your intervention gave us enormous impact; it causes us a great change". She replied after the second-year intervention which focused on rights for intimacy relationship including having a married couple with ID coming for share and giving encouragement to the service users. Now they feel relaxed and open to share who they like each other; the staff show support and discuss with them. She summarized three positive impacts of the intervention on their staff: teaching materials, staff's own sexual attitudes, attitudes towards these adults' sexual needs and rights, and how to communicate with the parents who can accept and respect their adult children' sexual needs and rights.

One new service worker of the daycare center and first time observed the adults involved in the intervention shared that the service workers' support were meaningful for the adults to build intimacy relationships.

Sing (F, supervisor): *For these two years, our service users learn to be brave to express their needs and who they like. ...our staff learn how to support and give them opportunities to have a date and also learn how to communicate with the parents including the attitudes. For sure some staff in the beginning felt shy to see those pictures (e.g., masturbation, intercourse), but now they feel nature when they see these sorts of pictures. ...we have no idea whether some service users with ID involved in the intervention follow or not; it does not matter because they had rights to be involved too. ...after the intervention, we support our service users to go to toilet for masturbation. After that, these users' emotion becomes more stable and psychologically healthy; and they do not need to lie to us anymore.*

Some other service workers from Group 1 also shared at the focus groups. For example, Fung (F, ) described: "the intervention of first year was very important, that now the service users did not feel guilty when they do masturbation. And those pictures are good to give them correct way for doing masturbation." Zai (F, ) shared that: "this time I feel I am much better to talk about sexual issues".

***Married couple giving adults hope for pursuing intimacy relationships.*** One service worker who has

been with the service users with ID for two years shared that after the intervention in first year, the adults learn how to find a person who like and plan to build up partner friendship; continuing after the second year intervention, the adults developed more expectations having intimacy relationships. Additionally the married couple, as the instructors, gave them hope and positive idea to plan their future intimacy relationships.

Specially, the married couple with ID came to be instructors with the adults received positive feedback from the manager, supervisor and also service workers too. They all agreed that this couple gave a successful example, encouragement and hope, being married, to their service users. The service workers replied that this couple did not talk or share so much, it does not matter whether they can use languages well or not.

***Adults becoming happier, motivated for activities involved.*** Liang (service worker, Group 1) shared: “after the first year intervention, the adults start to have some good feelings and to have closer relationships each other, sending cards or gifts. It was a big shock for us working with them. Second year, they became braver to express who they like. We did not stop and we try to tell them how to plan if they are going to have a date. For example, Wun (F) and Huei (M) now express how they adore each other. ... In general, their rights in this perspective were promoted, ...sometimes they would talk one another who they like, ...now such kind of topics are getting more and more, ...they learn how to show their concern to the person they adore, e.g., writing letters. ...they become happier to come to the service center, to be more motivated for activities they involved and to have more positive interaction one another. ...Earlier we, as service workers, felt shy to talk about the sexual issues; now our attitudes have been changed, becoming open and supportive.”

### ***Feedback from the service workers of Group 2***

***The intervention might only work for adults with mild disability.*** The intervention for Group 2 in which were not involved in the first year, as the comparative group, might not be so successful according to the service workers. For example, one service worker (Female) replied that the female adults saw the pictures of nude, masturbation or sexual intercourse, they screamed. She also wondered whether our intervention was only suitable for adults with marginal disability. Continuing she also mentioned there is a gap between rural and urban areas in such sexual issues, because the parents in rural areas, like their service users' parents, are more conservative.

The manager of Group 2 replied: “*Such intervention needs to be cautious and takes time; otherwise, the service users would be misled that masturbation or marriage are important to pursue. We do not mean it cannot be mentioned, but we do not encourage; instead we encourage them involving more activities. ...as you know, our service users would get confused. ...majority our service users would not get married. One service user told me she wants to marry but her mother did not agree. So we do not pay too much attention to this issue.*”

### ***Feedback from the service workers of Group 4***

***Feel relaxed, would not be prohibited or blame any more.*** The participants of Group 4 were the users of residential services; besides, we also provided intervention for the service workers working with the residents with ID and the residents' parents at the same period of time. The service workers of Group 4 replied that the intervention gave them new idea about sexual rights and needs for adults with ID. Before the involvement in the intervention, they were used to consider what the parents' think instead of paying attention to their service users what they need in sexual issues. One of the service workers responded that it was first time for her to be involved in such a kind of intervention, watching two movies and then following small group discussion with the colleagues. She shared: "He (the residents with ID was also involved in the intervention) now feels nature and tells me he is going to toilet. ... I just tell him to keep clean and try to support. They (the residents) now feel relaxed because they know they would not be prohibited or blamed as earlier."

***My worry had not been happened; instead, adults, parents and service workers all changed.*** The front line manager of residential services of Group 4 shared: "In the beginning when you invited our service users involved as the experimental group, I had been worried that the users might learned some sexual behavior in which they did not know earlier. For example, unlike male users, female users did not show their needs for masturbation. Then the intervention might motivate them to do so; afterwards, it would give us more work. After the intervention, my worriers were not happened at all. After the involvement, the adults who need to have intensive support learn to find suitable place for doing masturbation and it was useful for them to have emotion calmed down. For those adults being more independent become more brave to express what she or he likes and say no to whom she or he does not like. ... For parents now they recognize their adult children's sexual needs and rights for having intimacy relationships. ... For workers now they use correct way to communicate with the residents including language use and support and respect the users' sexual rights."

### ***Qualitative findings from two team members with ID***

Fen and Ren were involved in this project from the beginning of the intervention developed; they had been interviewed in the focus group with other young people with ID. Ren and his mother had given their feedback to the draft version of the intervention including the content and the pictures. Not only both of them were involved in the intervention as one of the team members, but also they were involved in the team meeting after the intervention.

This was the first in Taiwan this group of people were invited as an instructor and treated equally in this kind of program provided for people with ID. First, as one of the aims of this study, both of Fen and Ren had been empowered because of the roles and positions of their involvement based on their feedback in the qualitative data. Second, Fen and Ren as the insiders and decision makers of the team made the intervention which was based on users-led perspective ( ) and therefore more persuasive and effective than those without the users' involvement according the service workers' feedback in the focus groups and interviews. Third, this project also showed a landmark to the society and people with ID themselves that they could be as good as other people to be the instructors of the programs related to themselves and

they should be also treated as equal as other people in the society.

### **The adults with ID as the instructor in the first year**

***Learned much from the issues related to sexual health.*** Both Ren and Fen were happy as one of the instructors and research team members to be involved in this three-days project at the A daycare Center (Group 1) and they all shared that they learned much from the issues related to sexual health.

First, Ren replied that he had never been taught as impressively and as practically as the contents of this intervention before, in particular the pictures showing masturbation and sexual intercourse, and the practice of using condom. He had good time with the participated adults from the service center during 5 hours of the intervention and he appreciated all the male participants who were very actively and openly involved in the program and who knew sexual knowledge a lot and bravely shared each other. Except being with the service workers during one-day intervention, he also enjoyed being with the parental group<sup>2</sup>. He shared: *“I feel a bit dull on the second day while being with the service workers. ...I listened to them, they were more reserved. ...The time with the parents were quite fine. They are parents who have been with us for long time and they know us. ...One father even says that I have good memory, ...surely I feel self achievement when he said so to me.”*

Ren did not think the payment was big to him although he said his participation was not because of the payment. If it was possible he would like to be involved again next time in order to learn more.

*Interviewer: Do you have any changes after your involved in this three-day program?*

*Ren: I feel I am more brave to speak out and getting more attentive in making girlfriend. ...After this project, I have different perspective in sexual issues.*

The most impressive part that Fen shared was the movie “The Other Sister” but she did not like another movie “The Sessions”; these two movies were shown and discussed in the intervention for the service workers and parents. She did not like “The Sessions” because she was shocked to see a woman nude while the movie was first time shown in the group with the service workers—*“When I saw the woman nude I did not feel comfortable. ...it is value issue. In the service center we are well protected and it is not appropriate to see a nude person. ...women need to be more conservative.”* However she also replied when she saw it second time with parental group she felt fine. When she went back to her residential service unit, she hardly waited to share with the service workers how much she learned from this participation. She replied the payment for being an instructor was big for her and she did not care even having no payment and she also felt very good that every person was equal and like friends in the research team. After her participation in this project, she felt she wanted to try to get married with her boyfriend who is also the service user at the same service unit. She said *“The young woman in the movie (i.e., The Other Sister) was like me who could get married. Why I cannot. The woman in the movie said that she and her boyfriend could take care of each other; they could be able to do so. ...So I want to*

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<sup>2</sup> We also delivered the interventions for the service workers (for one day, April 27,2014) and parents (half day, April 28, 2014) after the intervention working with the adults with ID and two adults also participated as the research team members.

*try. ...Earlier, my boyfriend had mentioned about marriage, I rejected. ... now I am thinking both of us can move out to have our own living; we can have a living plan.”*

*Interviewer: Do you have any changes after your involved in this three-days program?*

*Fen: Yes, I know much now. For example, I know those men and women have. I also took the photos of the props of penis and vagina and also shared with the service workers at my workplace. ... I also discussed with my boyfriend about marriage.*

*Interviewer: After you joined this project, have you and your boyfriend talked about marriage?*

*Fen: Yes. ...Before taking part in this project, I did not think I could be able to take care of myself and I have been afraid to leave the service center. Now I feel it is a challenge for me and I want to try to get married. We (with her boyfriend) can move out after we marry. We need to find a work first and then save money.*

Ren's mother assured that it was good for Ren to be involved in the project team as one of the instructors. She shared Ren was a bit frustrated that the service center, where Ren used recreation programs, did not give him to share how much he learned from this project with other members of the service unit. Mother shared that currently the service center only pays attention to these adults' employment issues instead of the issue of sexual health. Mother said that Ren changed after involvement of this project: *“Previously he did not want to talk with us about sexual issue, but now he even can talk about condom. I have asked him what he felt after participating this project. He said that he dares to talk about sexual issue, not as shy as earlier.”* Mother was also invited to take part in the parents' group and she was impressed by the second movie, *“The Other Sister”*. However she said movie was still a movie, unlike real life. In real life, having sex you need to think about responsibility, it is not simple at all. If the woman is pregnant, the man and his family need to carry on the responsibility.”

Ren had sent an email to the research assistant of this project in April of 2013, as below:

*It was a treasure for me to learn so much about sexual knowledge and needs in this three-days program. As well as, I could have opportunity to listen to the ideas and experiences about sexual issues including sexual intercourse, in love, marriage and the discussions from different views among those participants who were the adults, service workers and parents. For me, it was a very nice opportunity and experience. Many thanks go to three Teachers (i.e., PI and two co-PIs) for their assistance and guidance, and to you and CH (i.e., the part-time research assistant) for your arrangement. Many thanks again and please forward my thanks to all the Teachers.*

Yu and Ting who were Fen's service workers were interviewed and replied: *“Fen was very happy once she came back from the project and very excited to share with us how much she learned from the three-days program.”* Both of them all assured that Fen did change after her involvement in the project but they also worried that Fen would influence other service users at the service center. Yu mentioned: *“It was a big landmark for Fen, she was very excited and shared with us for almost one hour. She feels that she gained a lot and she feels very happy about it and feels self growth. ... she also mentioned about some sexual values. We have responsibility how to look at her such changes. We need to be careful; here, a residential service, is living with a group, it may cause some negative impact. ... Here, the sexual*

*behavior is only allowed after marriage. ...Users here are with different cognition levels, we need to protect them. ...Fen was growing up here and she can influence other users, if she thinks premarital sex is ok, then she will tell other users. Other users are not like her, ...We respect her choice, but we also need to take responsibility. So this is what we worry.” Ting said: “Fen has a boyfriend. Currently, she thinks they love each other and then they can have sex. Earlier she said no. ...Some of her changes are positive but in this perspective we worry.”*

Fen was interviewed by the newsletter of the Community Living Consortium in June of 2013 and she shared what she learned and experienced from her involvement in this project.

*“I have been invited to A service center to participate an activity. It was first time for me without a companion of service worker in the trip. I and Teacher C, CH, SC took high speed rail way to T City. I was a bit scared in the beginning. I have an IPAD; I’d like to play Candy Crush. When the train arrived in T City; we met Ren and her mother at the hotel. I watched the movie, “The Other Sister” and “The Sessions” which are all foreign movies. I was shocked by “The Sessions” which was the story about one disabled man asking for engagement from his care worker but he was rejected. ...After the movie, there was a discussion. I feel the women (service users) in A center were very open and some terms they talked very easily. I was like a little girl comparing with them. ...I have recommended my friends from our service center can see this movie “The Other Sister”, because “The Sessions” will be too difficult for them, particularly the leading role is a man. But Ren likes “The Sessions”, it might be he is a man so he can understand what man thinks. What he has shared was very impressive to me; he could express his own idea and speak out the meaning of the movie although he speaks slowly. I have learned very much from him. ... “The Other Sister” is a story about a woman like us. She often fought with her mother because her mother controlled her very much. One day she run back to her special school, she feels she already grew up as an adult and she could fall in love and marry with the man she loves. ...In the end her mother could accept her marriage. So I like this movie and woman like us wants to marry, this sort of story, but it does not mean to give birth to a child.”*

Conversations with two adults after the intervention at the same day:

*C (PI): Ren, you were with me at the same session in the male group. Do you have any feedback from it?*

*Ren: Today, some of them (the male participants) were very active. ...Some could not write, some could not express, but they all tried to go through the barriers. If they could not speak, they wrote or drew. ...Those pictures and teaching material were good and made them to understand about sexual knowledge. ...I am very moved I take part in this activity.*

*C : Did I get you ignored? Were you nervous being one of the instructors?*

*Ren: No, I was not ignored. ...In the beginning I was a bit nervous; gradually I was getting used to. ... Those pictures have made me a bit shy when I saw them in the first time. ... today I am fine to see it. ...talking about it also fine.*

*L (Co-PI): When we talked about boyfriend, Fen was very actively to share her experiences.*

*Fen: They (female participants) were very good and they could express their idea.*

*C: Were you nervous?*

*Fen: I was fine because they could answer themselves.*

*C: Have both of you been an instructor before? What do you feel being an instructor?*

IC-008(表 B)

*Fen: It was fun and a kind of experience. ...Next time I will be better because for me it is rarely to talk in front of many people. Today I learned a lot, very much knowledge that I did not know earlier. I will share with the service workers at my service center.*

*Ren: I feel more confident of myself. Being an instructor was different, you talk and keep talking in front of all people, and you need to concentrate and talk clearly as well, not only like a member sitting there. I'd like to try to be an instructor next time.*

*C: What do you feel about yourself after this involvement?*

*Ren: I am now more brave to speak out than before.*

*Fen: In the beginning I was not used to because I used to go out with the group and the service workers are always with us. ...I have seen the pictures (the photos of sexual intercourse) from TV. In the beginning I saw those pictures I was nervous. In the end, I do not feel scared. They (the participants) were just like us, they were normal people too; they also want to make a boyfriend or girlfriend. ...We have the same problem that was that the parents use different perspective to see us, different from normal people to have marital life.*

*C: What do you feel about the programs including the materials? Do you have any suggestions?*

*Ren: The teaching materials were very ok. ...The process was not too quick. ...But the Q and A was a bit difficult for the participants who could not answer the questions with multiple choices.*

### **The adults with ID as the instructor in the second year**

As same as first year, we invited one married couple with ID as the instructors and as the members of the research team at the A Daycare center (Group 1) for two days, working with adults with ID and parents. This couple has married for 3 years; Hong was 37 and worked at the gas station and Ling was 32 and worked at 7-11 shop when working with us. After they married, the couple lived with Hong's original family. After the intervention, we interviewed both of them including Hong's mother whom the couple living with.

#### ***Not bad, I like to try next time.***

*Interviewer: What do you feel when you were working with us as the instructor?*

*Hong (M, 37): I feel not bad.*

*Interviewer: Which parts did you like most?*

*Hong: All were fine.*

*Interviewer: Did you feel you learn something from this involvement?*

*Hong: Maybe talk with them (the participants with ID at the A Daycare Center).*

*Interviewer: What did you feel when you were working with the parents? ...what was the difference when working with the adults and the parents?*

*Hong: I feel not bad. Those parents understand us. ...I felt a bit nervous when working with the parents.*

*Interviewer: Have you been as an instructor? ...what do you feel?*

*Hong: no. ...not bad.*

*Interviewer: Do you feel your relationships with Ling changed after this involvement?*

*Hong: yes, ...hugging each other.*

*Interviewer: Do you think Hong has become kind to you after the involvement?*

*Ling (F, 32): Yes. ...Hugging and kissing.*

*Interviewer: Will you like to be the instructor next time?*

*Ling: I think so.*

*Interviewer: Do you feel the relationships between Hong and Ling changed after their involvement of our project?*

*Hong's mom: It was good for them to be involved. ...I have asked them about it after they came back, they told me they shared their lives with those young people. ...It is good they can learn more, ...it is good for mental health too.*

### ***Qualitative findings from research team members after the intervention***

#### **Rights issues rather than sexual education for every single adult**

The focus group organized by the team members for three times after the intervention in the first year and second year respectively. According to our discussions, some primary points of our intervention have been confirmed. For example, we were very clear that our intervention would focus on rights issues instead of sexual education. As we know sexual education has been taught to adult service users; instead, the rights for masturbation, having intimacy relationships, sexual behaviors, marriage and child-giving/parenting as mentioned as in the CRPD have not been mentioned to these adults in the society. Furthermore, we would not touch moral issues or right and wrong related to sexual behaviors, for example, no sexual behavior without marriage and whether it is acceptable to find a prostitute. Another big debate is that whether this intervention was only suitable for those adults assessed with mild ID instead of those assessed with severe. This was frequently pointed out by the service workers or parents. For example, the parents often argued that their children were too severe to have sexual needs; and some of the service workers also wondered whether those adults assessed with severe ID could follow the intervention. However, some of the service workers also replied that at least they stayed and were sitting there; and this was their rights to access such kind of intervention. In addition, we recognize that the intervention for parents and for service workers is also essential in order to claim sexual rights for the adults. Thus the parents and service workers were also the participants of the intervention at the same period time.

The focus group among the team members also invited Chen (F, a retired special education teacher and accompanied with the married couple with ID as the instructor of the 2<sup>nd</sup> year intervention at Group 1), volunteer student (Vicky) and full-time research assistant (Abby).

***Teaching material good and relaxed.*** Chen shared at the focus group that: “I like to have your teaching material that are good, giving them (the adults) basic idea of sexual issues. ...I have done this earlier, but yours look more relaxed.” However, she also shared that the barriers from parents are critical challenges—“usually mothers worry a lot. For example, the parents always think these adults having no idea for sex is better, once you teach them, troubles come. This is also the most difficult part for the front line workers how to deal with the parents. So the parents should be working with first.”

***It is good you teach these and show these props.*** Vicky (F, 18) was a volunteer student working with us at Group 1 in second year and she shared her observation: “We do not need to consider so much when we want to have intimacy relationships, but they do. We can do what we want to do and also feel it is very reasonable, but they cannot. ...I have never seen those penis and vagina props, condom and never learned how to use condom for my health education at the school. It is good you teach these and show these props. ...I was shocked they could express whom they adore. Even for me I could not do it; it is good that they are so frank one another. “

***Help them to aware their sexual rights.*** Abby (F, 30): “I have been the group (adults with ID) for several times, the intervention did help them to aware their sexual rights.”

## **Discussion**

### **The impact of the intervention**

The most important of this intervention is to initiate the talks about sexual rights issues for adults with ID even it is a debate; in particular this issue had not been discussed in the society.

First, in terms of our innovative intervention, not only the service users but also the service workers and two team research members with ID and one married couple with ID appreciated and were impressive by our current intervention based on the qualitative data in this study. We did not use the term “sexual education” to name the intervention that we had developed and implemented among the adults with ID. Instead, promoting positive attitudes toward sexual health issues and awareness of sexual rights among this group of people was the main concern of this intervention. As mentioned as previous, the terms “sexual health” and “sexual rights” had never been used or discussed among people with ID in Taiwan except our current intervention. Instead, sexual education is almost included and provided for the adult users with ID in the education and welfare service units in Taiwan. However, the issues such as masturbation, sexual intercourse, rights of gay and lesbian relations including use of condom were not included in such kind of sexual education programs. Moreover, the service workers might worry that the knowledge related to masturbation, sexual intercourse or gay and lesbian relations might motivate these individuals therefore having such desire in particular for those people with higher level of care needs. For example, before our intervention, we had discussed with one supervisor working with residential care service for adults with ID and she did not agree such issues (i.e., masturbation, sexual intercourse and gay/lesbian relations) could be included in the intervention for the participants with ID. She said “...if he has no idea about masturbation or no such sexual needs, or has no idea about gay or lesbian, and then you let them know about it and he might go to do it. Actually they are just friends, after you teach them and then they may go to try. So for those young people with higher care needs, this kind of intervention might cause troubles. ...For us when we provide the services or we have group activities, we need to consider many conditions that might be happened to any individual member of the group. So I will suggest this kind of intervention needs to be more careful and meet the need of every individual case’s special condition.” Another service worker working at an institution for service users with ID and interviewed and replied

“When we know any service user is doing masturbation, we try to keep his attention away, in stead we encourage him to do more exercise.”

### **The changes among female adults**

In the second year, female participants with ID from Group 1 showed nature instead of shocked or uncomfortable when seeing the props or practicing condom in the first year intervention. Even couple of them could share how their experiences when doing masturbation.

### **Quantitative vs qualitative method in terms of intervention evaluation**

Second, according to the quantitative data within the two experimental groups (Group 1, Group 4), we found that the positive changes on sexual knowledge, sexual attitudes and quality of life were more likely to show intermediate changes than to present long-term effectiveness with regard to the outcome of the intervention among the participants with ID. Based on the two years' quantitative data, including the comparisons within and between the groups, related to changes of sexual knowledge, sexual attitudes and quality of life among the adults with ID who had been involved in the intervention from experimental groups (Group 1, 2 and 4), the results did not show clear effects of the intervention. However, the level of quality of life among the participants with ID from Group 1, who had been involved in the intervention for two years, had been increased in the second year according the comparisons within the group 1 and the comparison with group 2 and 3.

It is necessary to point out, in contrast, that the qualitative data collected from both participants with ID and service workers revealed that the intervention did cause the participants' positive changes of their sexual knowledge and attitudes to their sexual needs. First, it suggests that the mixed methods used for the outcome evaluation in such intervention research and conducted for this group of people is warranted. Furthermore, it also implies that using qualitative approach is rather than the standardized questionnaires for collecting data related to the impact of the intervention. Third, the standardized questionnaires might not be suitable to collect data from the participants with ID, although the ASK Tool which was designed for this group of people. Gilgun (2004) and her colleagues (Gilgun and Sands, 2012) have argued that qualitative approach is more suitable for program evaluation as our study showed that qualitative study might be more suitable than the quantitative one for collection data among this group of people in particular.

A Daycare Center (Group 1) is organized by a NGO which is organized by Catholic church and the manager had been worried whether the intervention would cause some impacts which was against the Catholic rituals, such as sexual intercourse without marriage. However, after the two years intervention, the feedback from the service users with ID, the service workers, the supervisor and the manager all appreciated this intervention and now they were even expecting to be involved for the third year intervention. To sum up, from the service users' perspective, their life coming to the service center had been changed to be livelier than before. For example, masturbation would not be prohibited but supported and viewed as nature but not as deviant behavior. They became brave to express whom they adore and to

learn how to show their concerns to whom they like. They are more motivated to join the activities and try to be the same group with whom they like. The topics between the service users are increasing and their emotions become more stable than earlier. The married couple with ID came to share in the second year had given an encouraging example for the service users who now have an expectation that they could be possible to have a family of their own in future. “They are happier when they come to service center” as shared by the supervisor. The changes among the service workers and the center, sexual issues could be discussed openly and the sexual needs among the service users are not ignored as early as told by parents; instead, the service workers now have been trying to communicate with the parents actively.

According to the qualitative data and comparison between three experimental groups (Group 1, 2 and 4) for two years, we found consistent findings that the participants with ID who were involved in first year showed most impressive for the penis and vagina props and also the condom practice. Instead, for the participants who had been involved for two years felt more impressive to the married couple with ID who came to share with them during the intervention. It worth to point out that inviting the adults with ID as instructors of the intervention was not only to empower these instructors but also to empower the participants.

Majority of the adults’ family never had discussed sexual issues with them. Even the adults hoped to have intimacy relationships or to have marriage, they need to have the agreement from their parents/family first. Before we worked with A Daycare center (Group 1) whose service users were involved in our intervention, we had been rejected by couple of service centers where we invited their service users taking part in this project. The reason they rejected is that the pictures and themes related to masturbation and sexual intercourse could not accepted by the parents of the adults with ID. However, the manager and service workers of A Daycare Center accepted our invitation and helped to have the service users’ parents/families informed consent to be able to take part in this project and therefore the service users of A Daycare Center became the participants of the intervention since the first year. Based on the findings of this study and as discussed as above, the service users gained opportunity to be aware of sexual health issues including sexual rights because of their participation in the intervention. On the contrary, for those service users whose managers or providers rejected our invitation lose such an opportunity. Doubtlessly it suggested that rights of parenting and non-productive sexual behaviors among these adults with ID is still under controlled by the service workers in particular their parents. Furthermore, it implies that who are the managers and providers is related to the service users whose well being would be like, as discussed as above, sexual health is an issue of well being ( ), this has been approved by both quantitative and qualitative findings of this study, e.g., the findings from participants of Group 1. Additionally, it means that the intervention promoting sexual rights and sexual health in this group of people cannot only focuses on these adults but also their service workers and parents.

### ***The strengths of this intervention***

In general our first strength is that this intervention was the first and innovative one to advocate the rights of masturbation and intimacy relationships for this group of adults in the society. Second, in terms of

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the intervention, the use of the pictures printed in the manual of ASK tool that we purchased from the Centre for Developmental Disability Health Victoria (2011) in which showing the nude bodies of men and women, masturbation, sexual intercourse, etc., giving the opportunity for these adults practicing how to use condom, using props of penis and vagina as material was another strength of this intervention.

Moreover,

the parents and service workers were also the participants of this intervention as well; two adults and one married couple with ID joining with us as the instructors has earned very positive feedback from the adults, parents and service workers. By the way, from the beginning of the development, implementation and evaluation, and revision of this intervention were all working with the participants, including, adults, parents, front line service workers; and the PI and Co-PI are also from the different disciplinary background.

### **Implications**

Dealing with attitudes to sexual rights or sexual health issues in the society is not simple, it is necessary to work with social values including different persons with different social context including religion or culture taboo. For example, whether the issues of masturbation and nonproductive sexual behaviors, the pictures showing sexual intercourse, premarital or outside marriage sexual intercourse can be accepted or discussed in the society is related to the individual persons' social background. How the values of these issues among the parents, service workers including the managers of the service centers is also relevant with how these adults' sexual rights and sexual health issues are concerned and influenced.

All in all, the most effective strategies of sexual health and sexual rights for adults with ID are: first, to involve parents and service workers of adults with ID in the intervention and build up dialogues of the groups; and second, to facilitate the voices on sexual needs of adults with ID being heard and shared by the service workers and parents as well.

### **Conclusions**

Both quantitative and qualitative results show the intervention causes positive impact on the participants' well being and aware their freedom of sexual needs. At least, this intervention results the change that sexual rights and needs among the adults with ID become the disclosed issues, even it is under debate, between the service workers and managers who are working with this group of adults in the society. We also found that the limitations of the standardized questionnaires. For example, according to the results of the quantitative data we did not find the changes of the sexual knowledge and sexual attitudes among the adults with ID. In contrast, the intervention, based on the qualitative data, received positive feedback from the adults, service workers and the managers in the experimental groups.

### **References**

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附件三：發表論文摘要及全文-第二篇

## **Application of the ICF in Taiwan — Victory of the medical model?**

## Abstract

**Key words:** ICF, medical model, social model, participation, disability, service user with disability, Taiwan

**Aims:** Before 2012, disability was in Taiwan diagnosed by physicians based on the level of bodily impairment. The International Classification of Functioning, Disability and Health (ICF) was embraced in the 2007 Taiwan Disability Act as the definition of the disability and since July 2012 a person's eligibility for disability benefits has been assessed based on the ICF. This study interviewed disabled people who were assessed according to this new assessment system in order to explore their experiences and to understand whether the new assessment based on ICF incorporates the concepts of social model and participation.

**Methods:** An in-depth, semi-structured interview was employed and 24 persons with disabilities had completed our interviews between December of 2013 and January of 2015. The participants includes 20 received the new assessment and four assessed only by old system and as well as waiting for the new assessment.

**Findings:** From the participants' view, the new assessment is like old wine in a new bottle and the victory of medical model because it is: hospital-based assessment, rather professional dominating, only body impairment and functioning concerned, users controlled rather empowered and eligibility screening rather than life support. The findings suggest that, like in the old system, the application of the ICF in Taiwan is as a tool of eligibility assessment for social benefit rather to meet the needs of the service users.

**Conclusion:** The concepts of social model and participation are actually not practiced in the new assessment system based on the ICF in Taiwan; instead, medical model still determines the outcomes of the assessment.

## Introduction

Since 2001, the International Classification of Functioning, Disability and Health (ICF) was endorsed by the World Health Organization (WHO) member states as the global model of disability definition and assessment. Dismissing the negative terms used in the "International Classification of Impairment, Disability and Handicap" (ICIDH) in the 1980s, the ICF undertakes on the assumptions of biopsychosocial (BPS) which both medical and social models are integrated, and individual's activity and participation, in particular the factor of the environment or social context become the core concerns (see Press Releases WHO/48, 15 November 2001; WHO, 1999, 2002). In general, comparing with the former classification, the ICF has been considered more acceptable to the international disability rights movement (**Hurst, 2003**; McIntyre & Tempest, 2007); it has been widely used for variety of purposes (Mitra, 2014).

Although Taiwan is not a state of the WHO members, the ICF has been viewed as a change in defining disability and therefore it is now incorporated in the 2007 Disability Act. Based on this amended act, the ICF becomes the new assessment framework for resources allocation, named “New Assessment System”, for the new applicants of social benefit from the public sectors since July of 2012. Until 2014, like the case in Taiwan, ..countries have developed the ICF system and used as the tool for resources allocation for disabled people ( ). Nevertheless, the arguments or limits of the application of the ICF have been discussed by several western researchers (Anner et al., 2012; de Camargo, 2011; Conti-Becker, 2009; Hammell et al., 2004; Imrie, 2004; Lutz & Bowers, 2003; McDougall et al., 2010; Nordenfelt, 2006; Ueda & Okawa, 2003; Wade & Halligan, 2003; Hammell, 2004 ; Imrie, 2004 ; Lutz & Bowers, 2003 ; Barile, 2001 ; Pfeiffer, 2000 ; Whalley, 2004; Bickenbach, 2014; Trani et al., 2011; Dubois & Trani, 2009; Taylor & Geyh, 2012). Since the ICF adopted in Taiwan as the new tool for resource allocation for people with disabilities, Taiwanese researchers (Chang, 2013; Chiue, 2011) have argued that the ICF as the new system in Taiwan is a tool only for qualification screening rather a framework for meeting the individuals’ needs. However, to what extent of the perceptions among the individuals who have been assessed by this new system based on ICF have never been explored in the society.

The recipients of welfare disability benefits in Taiwan must go through official registration based on the eligibility assessment. Before 2012, the assessment was based on medical diagnosis which was conducted only by physicians according to the individual’s physical or mental “impairment” and ICD codes were used; and about 111,000 of Taiwanese population of 23 million (48.3 per thousand) has been diagnosed with disabilities in 2011 (Department of Social Affairs, Ministry of Interior, Taiwan, 2011). According to the 2007 Disability Act, the critical differences from the old assessment system ( Lin et al., 2009; Chiu et al., 2013; Teng et al., 2013), **the individual’s activities, participation and social life including the needs of her/his care services, family life and social life should be included in this new assessment system (Article 7)** and the implementation of the assessment should be carried out by an interdisciplinary team including physicians and other professionals such as social workers, occupational therapists, nurses or psychologists (Article 5). Since July of 2012, the ICF was adopted as the new assessment tool, the former assessment system named as the old one, the disability categories had been changed from 16 to eight in the new system but the levels of disability remains the same, four levels (mild, moderate, severe and profound) as the indicator for resources allocation. Regardless of the old or new system, the individuals would be given a certificate, like an ID card, if she or he were assessed with disability in order to be eligible recipient of social benefit from the public sectors. According to Chiu, and his colleagues (Chiu et al., 2013; Teng et al., 2013) as the primary team members designing the new assessment system in Taiwan, the steps of the assessment are conducted in two places, one is in the hospital for the eligibility assessment and another one is final identified by the local authority based on the assessment from the hospital. In the hospital, first, one physician (i.e., first assessor) gives the ICD-9-CM diagnosis codes and performs the b/s assessments (body functions and structure ); continuing another hospital professional (i.e., second assessor) assesses the d/e components (activities/participation and environmental factors). The medical information of disability determination, such as type of disability and level of disability, are

sent to the local authority; accordingly the eligibility for disability benefits is determined and the disability identification, a certificate card, is issued to the applicant by the local authority.

A Taiwanese taskforce, named as “Taiwan ICF Team”, mostly organized by health researchers and professionals, in charge of the development of the new assessment tool, pointed out that this new assessment system integrates the medical model with a biopsychosocial model based on the ICF to link disability evaluations and needs assessments and to “provide more resources to people in need” or to “arrange appropriate welfare support” (see detail from Chiu et al., 2013; Teng et al., 2013); such needs met would therefore enhance people’s social participation (Chiu et al., 2013).

Between July 2012 and end of 2014, more than 330,000 people completed the assessment by the New System and obtained a new copy of the disability certificate, with pink color (the old one with green color) (Ministry of Health and Welfare, Taiwan, 2015). This study aims to explore whether the contextual factors and the consideration of participation issues within the ICF in which the emphasis has changed from a medical to a bio-psycho-social focus while the application of the ICF in Taiwan, from the users’ point of view. Additionally, based on the users’ perceptions, whether the results of the new assessment provide more resources to meet the needs of the applicants who have been assessed with a disability.

### **New definition of disability within the ICF**

The ICF is expected to change people’s thinking to disability (Dahl, 2002; Anner et al., 2012); disability is therefore viewed as the rights issue (Hurst, 2003). Disability hence is not only the consequence of a health condition (Dahl, 2002), it is rather the outcome of an interaction of the person with a health condition and the environmental factors (Schneidert et al., 2003). Environment factors include physical environment, the services available, attitudes and legislations (Dahl, 2002). Conti-Becker (2009) optimistically and positively supported that the ICF could be a potential powerful tool to improve the lives and experiences of individuals while the ICF could be applied with BPS theory into practice.

Many researchers (Imrie, 2004; Oliver, 1990; Dahl, 2002) have pointed out that within ICF functioning and health need to be understood as comprising with how the body are socially constructed in the society. de Camargo (2011) urges that within the ICF the users included in the process is critical and he also remind that the process should integrate between systems, professionals and service users. The interventions and supports are not based on the health and functioning assessment alone, but take into account the context and participation goals of the users and link with personal’s every day life situation to support person with disability in describing what the matters most to them in the intervention planning (Adolfsson, 2013).

**Universalism** is another concern of the ICF (Imrie, 2004; WHO, 2001; Imrie, 2004; McDougall et al., 2010; Conti-Becker, 2009; Koutsogeorgou et al., 2014). For example, the WHO (2001) has commented that the ICF is not only about people with disabilities, instead, it is about all people and it has universal application. Bickenbach (2012) has suggested that the ethical and human rights applications of the ICF

have to be paid concern in order to reflect the notion of the UNCRPD; as well as, the data and information within the assessment system should be collected appropriately and used in a manner based on the positive effect of people's life.

McDougall et al. (2010) and Schneidert et al. (2003) explained that the interactional approaches linking the biological and psychosocial systems, it is a "dynamic interaction", need to be within a holistic context; accordingly all these systems cannot be analyzed separately because the whole is greater than the sum of its parts (McDougall et al., 2010, p. 207). She suggested that the person's quality of life and development across time should be incorporated in the modified version of the ICF model (see McDougall et al., 2010, p. 208). For example, between the health condition and context factors in which interact with individual factors and environment what extent to be in a constant state of interplay and a persons' education, religion, spirituality, dignity and social roles linking with activities and participation should be considered and promoted (McDougall et al., 2010; Scherer & Glueejanf, 2005; Hurst, 2003).

To sum up, the new definitions of disability within the ICF and its systems are based on following gears: (1) interactivitism, multidimensionism, universalism, and holism perspective between bio-psycho-social factors, (Anner et al., 2012; Dahl, 2002; de Camargo, 2011; Imrie, 2004; de Camargo, 2011; McDougal et al., 2010; Nordenfelt, 2003; Scheidert et al., 2003; Schneidert et al., 2003; ); and (2) its ultimate goals are for improving the quality of services (Dahl, 2002) and promoting person's wellbeing, included in the community, independent living and positive growth (Hurst, 2003; Conti-Becker, 2009; McDougall et al., 2010; Hurst, 2003; Bickenbach, 2012).

### **Limitation of the ICF**

Several studies have criticized that ICF is still based on medical view (Trani et al., 2011; de Camargo, 2011; McIntyre & Tempest, 2007); disability is still seen as a consequence of disease (or impairment) rather than the bio-psycho-social impact on the individuals. Pfeiffer (2000) has even debated that disability issues are even getting medicalised under the conceptual basis of ICF. Accordingly, comparing with Capability Approach, the challenges of the ICF applications have been discussed by the researchers recently (Bickenbach, 2014; Mitra, 2014; Trani et al., 2011; Dubois & Trani, 2009).

Dubois and Trani (2009) and Taylor and Geyh (2012) argued that the ICF primary purpose is for classification in which might be comprehensive for measuring prevalence of disability, a guide for practitioners, a framework for research; however the limitations of the ICF cannot be ignored. For example, lack of user involvement and opportunity to have their personal belief, values and preferences/choices/will involved in the process have been questioned by many researchers (McIntyre & Tempest, 2007; Nordenfelt (2006; Trani et al., 2011; Bickenbach, 2014; Mitra, 2014; ). The ICF definition cannot describe causal relation, the dynamism of development of disability, identification of barriers to inclusion, in particular the individual's feelings of functioning and disability are not concerned and personal factors are not included (Anner et al., 2012; Dubois & Trani, 2009; Taylor & Geyh, 2012; Ueda & Okawa, 2003). McDougall et al. (2010) stated that the viewpoint of the individual with respect to

their own health and wellbeing is important to be understood with the ICF conceptual framework. It is also echoes that the disability right movement (e.g., the DPI) who advocates “nothing about us without us” (Harpur, 2012). Solli and Silva (2012) have debated that the ICF model focuses on holistic point but it is still lack of pluralistic and multidimensional view of human being as the acting person whose will and goal should be included as the fundamental factors. To what extent are the views of users when the ICF as a tool used for determining the resources allocated remain uncertain.

What is wrong with the ICF? Wade and Halligan (2003) recognize that the WHO ICF is a good but incomplete framework for a person with long-term ill health. Mitra (2014) pointed out the ICF cannot be expected to provide the person’s experiences; Bickenbach (2014) recommended that the convergence of Capability Approach and ICF can be a way to reconcile the limitations of the ICF: not embody a theory of justice, does not incorporate choice and personal goals and not distinguish resources and environment (Bickenbach, 2014; Mitra, 2014). Up to now, the limitations of current ICF model include: (1) the impairment and medical model is still the major concern (Egilson & Traustadottir, 2009; Trani et al., 2011; de Camargo, 2011; McIntyre & Tempest, 2007); (2) the objective observations on capacity and performance are too much focused rather than the individual’s subjective experiences including the person’s will and choice (Hemmingsson & Jonsson, 2005; Wade & Halligan, 2003; UEDA & Okawa, 2003; Nordenfelt, 2003; McIntyre & Tempest, 2007; Nordenfelt, 2003; Wade & Halligan, 2003; Ueda & Okawa, 2003) (Perenbrom & Chorus, 2003), (3) opportunity (Nordenfelt, 2003) and dynamic between all components (Anner et al., 2012 ) have not been incorporated in the framework; and (4) it does not consider personal values and quality of life (McDougall et al., 2010).

### **Research framework and questions**

This study aims to explore the experiences among those individuals who have been assessed by the new system based on the ICF framework and to probe whether the new system was based on the new definitions of disability in which the ICF was established by the WHO as well as stated in the amended disability act of 2007, as discussed as above. Additionally, this study also studies how the ICF framework is applied in Taiwan and what the differences of the new system are from the old system from the users’ perspective.

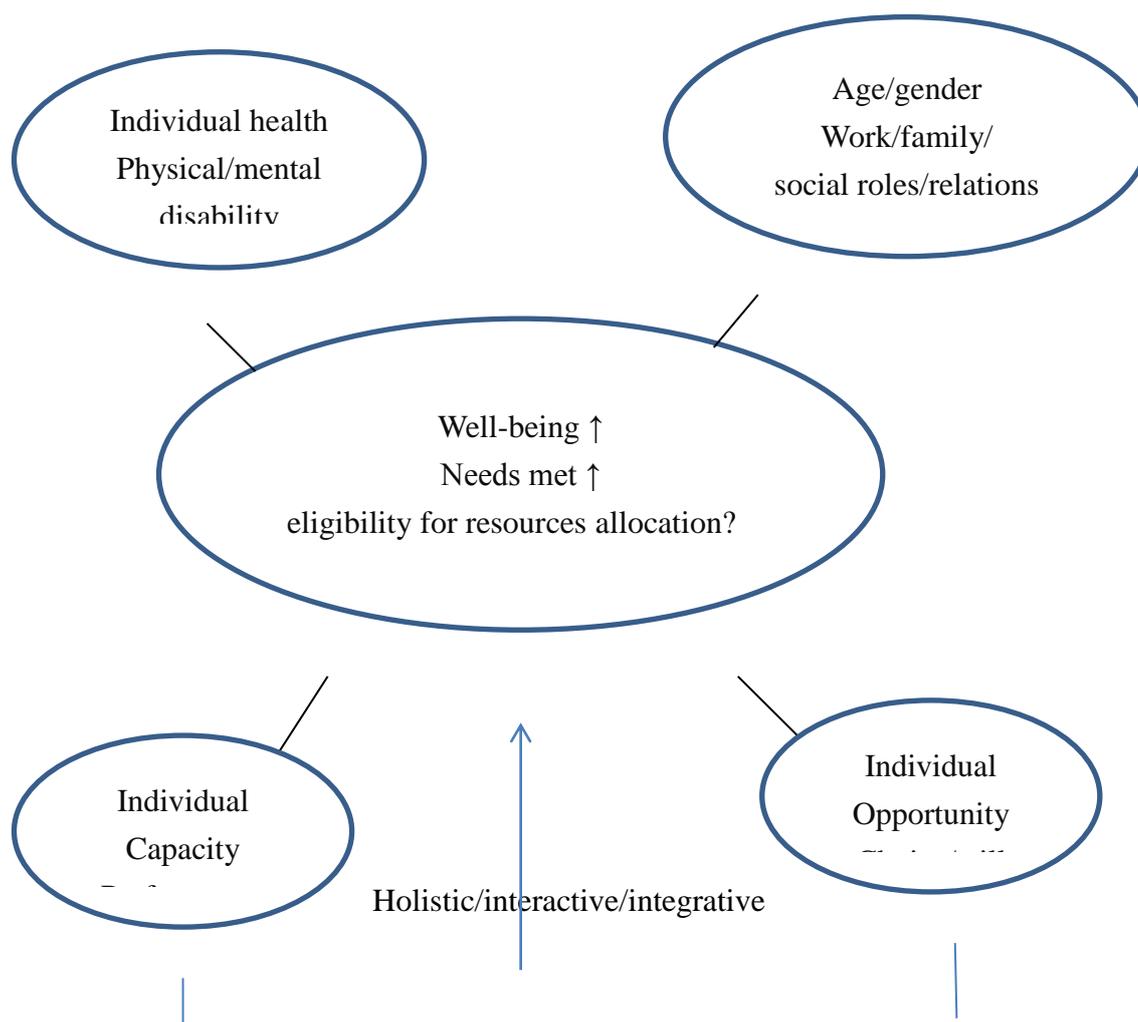
Based on the literature review as discussed as above, the research framework of this study is shown in Figure 1.

The research questions of this study are: (1) to what extent do the individuals experience the assessment including the application, process and the outcomes of the assessment? (2) Do the individuals experience their individual and environmental factors in which have been paid concerned and incorporated in the assessment process? (3) Do the individuals’ personal views have been incorporated in the assessment? (4) Do the individual’s needs and well-being have been taken account in the assessment?

Figure 1: Research Framework

Body factors/ medical perspective

Environmental factors/social perspective



## Methods

### Participants

Based on the regulations, between July 2012 and June 2015 the new system is only available for those persons who are new applicants for the assessment in order to have disability benefit or only for those who had been required to have reassessment to continue for having the benefits. The new assessment system for those had been assessed with disability by the old system and recipients of disability benefits would only be available between July 2015 and July 2019 and all of these persons need to go through the new assessment otherwise they would lose the eligibility for welfare benefits.

This article focuses on the users' experiences of the new assessment system which is used for welfare benefit allocation in Taiwan. Initially the baseline criterion for inclusion in the study was who had been assessed by the new system and indentified with disability, in particular those who had been assessed and indentified by both old and new systems. Lately this study also invited those people who were with old certificate and were waiting for the new assessment to participate in our interview.

In the end, three groups of participants were involved in this study: 9 persons who were only assessed by the new system, 4 persons with disability certificate had only been assessed by the old system, and the remaining 11 persons had been assessed by both old and new systems and who had obtained the old certificate and currently obtained a new disability certificate. The data analyses of this study involved these 24 persons indentified with disabiliy. Three of them were with intellecual disability and one was aged in 5 whose service workers or mothers were interviewed; the remainder were adults and interviewed themselves. One of these 24 participants was with physical disability, rare disease and using wheelchair and working at the independent living association was interviewed not only representative herself but also the disabled members of the association. The participants were involved in a variety of disability, which are listed in Appendix A. Their age range was 5 to 66 years; 5 of them were women and 19 were men. Among the participants, 7 were employed or self-employed, 3 were doing casual work, 9 could not be employed because of disability, 4 were the users of daycare center or institutional care and 1 was a preschool child.

### **Data collection**

Some participants were recruited via an Independent Living Center where the organizers and majority members are disabled people with mobile dificulties; some were invited through day care, residential service centers for disabled people, or NGOs working with disabled people.

In-depth semi-structured interviews, including face-to –face interview and telephone interview, which were audiotaped and later transcribed verbatim, lasted between 50 and 90 minutes. All the interviews took place in private such as in the participant’s home, at the service centers where the disabled people as the users or the care worker’s place of work between December of 2013 and January of 2015. Interviews were guided by a schedule constructed from the research team’s pilot work and existing literature on the ICF, especially focusing on activities participation, environment and social model perspective (as shown in the Appendix). Participants’ brief characteristic data (e.g., age, sex, occupation, marital status, family members, residential city, hospital and clinical centers of the assessment implementation, and type/level of disability assessed by both old and new system) were also collected. All the interviews were conducted by the first author of this study. Before each interview began, participants were told that confidentiality would be respected and that identities would not be revealed; an informed consent form and all the conversations audiotaped were agreed to sign via post and to be carried on by the participants. The participants were also told that the interviews would be audiotaped and transcribed and the transcripts of hers/his would be mailed to her/him for checking whether all the transcripts were as what she/he replied during the interview. The current study had been approved by the Research Ethical Board of the Sunshine Social Welfare Foundation (approve number: SU103003).

### **Analysis**

The analytic strategy began by examining each transcript in terms of (a) how the participants experience the process of assesement including the professional’ attitudes and the length of assessment, the content

IC-008(表 B)

of the assessment; (b) how the participants feel that she/he is respected as the centered of the assessment; (c) whether the participants think the assessment is link with their activities participation and life environment.

The analysis for this study was conducted as follows. First, the first author of the study read the transcript three times and made the original transcript become second and third version of transcript after cutting out those conversations or words not related to the study. Second, the researchers reviewed the transcripts at length to identify an initial set of themes. As themes emerged, the researchers re-evaluated the theme as they considered the transcribed data. Themes that continued to be supported in successive readings of the transcripts were retained. Themes that did not have broad support in successive readings of the transcripts were removed. Once the researchers had concluded this initial independent analysis, they brought their findings together for comparison and additional analysis. The remaining suggested themes were evaluated by all researchers to determine whether or not there was sufficient evidence to warrant inclusion of the theme. Themes were retained only if the research team was able to commit consensus to their validity.

## **Findings**

Based on our findings, the new assessment system has been implemented in the hospital; there was no difference while comparing the old system; and the social model and participation had not been considered while the services provided. The ICF application has been medicalised and the users were controlled.

### **Hospital –based assessment**

As mentioned as above, the types and level of disability were determined right away only by the physicians in the old assessment based on the conditions of impairment in the hospital and the benefits provided according to the level of disability, from mild to profound. The current new system uses the questionnaires in which was developed and revised based on the WHOICF and the health and social care professionals and sectors are required to be involved based on the amended Disability Act of 2007. An individual applicant for the disability benefit, she or he first goes to the social welfare sector in her/his local district authority for registration and having the assessment questionnaires and then the applicant brings the questionnaires to the hospital where she/he has applied for intake in advance based on her/his disabled and health conditions. Three parts are included in the assessments based on the new system, two parts are implemented in the hospital and the physician is charged with first part for evaluating b/s codes (body functioning and body structure), and the second part, in charge of d/e codes (activity/participation and environment), might be assessed by social workers, occupational therapists or nurses in according with the different hospital.

Based on the ICD codes and the first part assessment, similar to the old system, the type and level of disability (i.e., from mild to profound) shown in the certificate card are also determined by the physician at the outpatient service unit in the hospital; and it may only take 5 to 10 minutes. Following activities are as performance asked by 6 dimensions (cognition, 12 items; mobility, 10 items; self care, 8 items;

IC-008(表 B)

social relations, 10 items, home activity and work/learning activities, 18 items; action, 14 items) with difficulty level. Social participation are asked by 16 items by difficulty level; and the questions related to environmental factors are reduced to 8 items and asked as with or without barriers. All these items are implemented by the second assessor in the hospital; it may take around 20 to 30 minutes.

Social services provided by the local authority such as residential care (institutional care, community living--i.e., group home) home care, personal assistant, car parking permission and free charge, recreation facility use (e.g., museum visit, recreation center), occupational rehabilitation services, psychological rehabilitation, are assessed by the third assessor from social care sectors from the local authority, named as the third part of the new assessment. Based on the assessments completed by the hospital, the final result of the assessment is issued by the same social care sector of local county/city government in order to give the final decision for the resources allocation. Cynically, the new system, like the old system, the eligibility and amount of welfare benefit, such as cash subsidy for buying assistive equipment or using residential and daycare services, disability allowance, health insurance premium, are all based on the level of disability in which are categorized into four levels of severity, from mild to profound. The level of disability is only based on the sum of the b/s codes that are done by the physicians, calculated by the computer that is and operated by the social workers from local authority.

For example, the subsidy for buying an electric wheelchair is only available for those who is assessed with severe or profound level of disability regardless this individual's activity or social participation because of her/his age, gender, family roles (e.g., mother, family carer, breadwinner of the family) or social roles (e.g., student or worker).

### **Old wine in a new bottle**

In this study three groups of participants participated in our interview and their primary reactions to the new system could be categorized into three types according to which group they were.

#### ***No idea about the new system***

In this study, 9 persons who were only assessed by the new system and generally these participants had no idea about that the assessment had been categorized into old and new until they were invited to be involve in our study. Majority of these participants applying for new assessment were referred by the physicians who were in charge of their care in order to receive the disability welfare benefits. Eight of them did not attend the forums in which the new system had been explained. Some of the participants had forgotten who were the assessors, in particular, majority had no idea who were the second assessor; or even they did not know about the assessment process. Most of them did not remember any social worker contacting them after the assessment in the hospital.

“My sister-in-law helped me to apply for the assessment. She is with polio; so she knows that a person who wants to have disability benefit needs to apply for the disability assessment. ...I do not think any social worker had contacted me. They just called me to get the certificate card. ...the benefits are such

IC-008(表 B)

as receiving discount when I go to see the medical doctor and also the health insurance premium” (Chen, Male. 51-year-old, Facial and language disability)

“I was a bit late to apply for the assessment, because the physician in charge of my care did not tell me. Instead I was told by other patient. I do not remember who were the assessors. ...I do not know the difference of old and new assessment system. ...no any social worker had contacted me, not even telephone.” (Kou, M. 63, facial and language disability)

### **Satisfaction determined by the level of disability assessed**

The reasons that 11 participants with disabilities who had received the old assessment system applied for the new one before the appointed date, starting from July 2015 included: to apply for higher level of welfare benefit because of the disabled condition becoming severe, to apply for new service (e.g., personal assistant) or electric wheelchair, or to continue to use residential services. For example, Chou (male, 39-year-old, physical and language disability) had assessed with cerebral palsy (CP) and had institutionalized until one year ago he left the institution and moved to Taipei and now he joins in the Independent Living Association. He applied for the new assessment in order to apply for personal assistant (PA) service. If he was assessed with severe or profound level of disability and then he would have 48 hours or 60 for PA service in which was subsidized by local authority.

“I apply for the new assessment because I want to apply for the PI service and I was told by the IL association.” (Huei, F., 35, physical dis, use wheelchair)

Some participants shared that they had been very nervous when they were waiting for the results of the new assessment in which the level of disability would be reduced and then the level of welfare benefit reduced as well. However four of them after the new assessment, the level of disability was reduced, two from severe became moderate, two from moderate to mild. Two of them lost the eligibility for cash subsidy for buying electric wheelchair; and both of them felt unhappy for the assessment process and unsatisfied with results while they were interviewed. One of them had applied and completed the re-assessment and another one was under the application for re-assessment while they were interviewed.

One mother of adult child with ID shared “He was assessed with moderate level of disability by the old system, now it becomes mild level after the new assessment. The cash subsidy was less than earlier for NT\$1,000,... now we use money attentively. ...how can I do, my kid has become like this (disabled)...” Another one was a young child aged 5 and mother was interviewed and she felt the benefit was the same even the level of disability reduced by the new system. It suggests that in fact the users or family are concerned about the level of benefit instead of level of disability.

One social worker on behalf of her two service users with ID in the institution responded to our interview: “the staff working at the district told us to reuse the result of the old system instead of applying

IC-008(表 B)

for new assessment system, because the new one might make the level of disability lower than old one. ...it will decrease the subsidy for residential service use for the users. For example, if the user is assessed from with moderate level of disability to with mild level by the new system, the user would not be subsidized to use institutional care services.” It implies that the result of the new system only means the level of disability in which the eligibility of welfare benefit determined.

One of the participants replied that the differences between old and new was that there was a social worker from the local authority would give a contact after the assessment for the new system but not for the old one. However, after receiving the new assessment, some of the participants of this study had never been contacted by any social workers from local authority.

For example, the social services provided counts on the applicants to tick themselves in the cover sheet of the questionnaires; if the individual did not tick from it, no social worker would contact the person and would not have any services provided. It intends to reserve the resources.

Like the old system, the attention of the new system is only for the eligibility evaluation rather the individual needs. As well as, like the old system, the system was ruled by the central government and the benefits are provided by local authority. It could be happened that for those the participants resided in the county located in eastern side of Taiwan would not subsidized by cash or personal assistant provided while comparing with the participants from other local authorities. One participant (male, with facial and language disability) recommended that such kinds of benefits should be allocated by the central government under national consistence, otherwise, for those disabled people living in rural counties, he is the case, would be double deprived.

One social worker from the residential service interviewed for her service user with intellectual disability and responded that it was good there was a big sister (the second assessor) chatting with the service user. However, she also answered that the outcome was similar between two systems.

One participant (male, 29, physical disability) had been assessed by the old system with mild level of disability and now he was assessed by the new system with moderate. Thus the cash allowance from the local authority was increased because of the level of disability increased; he replied that the new system had considered his economic condition, so he supported that the new system had the environment factor involved. However, this participant did not know if he were assessed by the old system, the cash benefit would be promoted as well because of the disability level issue. He also shared: “...I prefer the new one; it goes through three parts. It can save the resources for the person who really need. Unlike the old one in which was depending on the relations between you and the physician.” (Chi, male, 29-year-old, physical disability). It implies that the new system is for cutting resource for those who are not severe enough; however, like the old system, the benefit is still only based on the level of disability. The users assessed may have no idea.

IC-008(表 B)

One participant (male, 46-year-old, facial disability) has assessed by both old and new system within three months, before and after his throat operation, he replied that the only difference was the level of disability changed, from mild assessed by old and then moderate by the new. However, he did not receive any cash subsidy from local authority (unlike other local authorities), no any social worker contacting him from the local government either.

### **Waiting until the last moment for the new system**

Four participants who had only received the old assessment system interviewed and shared that they had heard that the new one was stricter than the old one. For example, the person assessed with moderate level of disability by the old system might be assessed and become with mild and the severe level might become with moderate under the new assessment. This would influence the level of benefit in which the person receives. These three participants also answered if they could chose they would chose the old system.

Three participants were also involved in the disabled group and both of them had participated in the forums that was for explaining for the new system. One of them had even been involved in the pilot project of the new system. Two of them had been told while joining in the disabled group their disabled condition could be assessed from severe to profound by the old system; thus before the new system started in July 2012, they applied for the re-assessment of the old one and then they were reassessed with profound level of disability.

*“I do not have confidence for the new system, I do not want to take such a risk. That is the reason I applied for the re-assessment before the new system coming. ... For the new one, I will wait until the last moment of the deadline” (Lieu, male, 30-year-old, physical disability and rare disease, using wheelchair).”*

*“I am nervous for the results of the new assessment system; the results might be very surprised. ...I am not ready for it.” (Chuen, female, 35-year-old, physical disability, using wheelchair).*

The participant who had been involved in the pilot project of the new system shared that he had decided not to take the risk, going for the new assessment until the last required moment. He shared as below.

*“The new assessment system seems to be very professional, but the person assessed feels bullied by the professionals. Many codes are in the questionnaires, I do not think there is any relevance with my needs. ...They (i.e., the assessors) seemed to chat with you, but you might be trapped from it. The outcomes are determined by them and I could not understand the process. ...A person is put into so many parts and the belongingness is excluded. ...The things you trust are getting less. ...The strength of the ICF has not been existed. I do not think the environmental factors are considered in the new one. ...If you want to have assisted equipment, you need to go for another assessment. The wholeness is not happened. ...It is just like operating a tool for nothing. ...For the old system, you only go for once*

IC-008(表 B)

*to the hospital; instead, the new one, you might go for three times. Moreover, the level of disability might be assessed lower than the old one. ...The new system is the government's excuse to cut the resources. Resources cut can be done by several ways, why does the government operate the new system in which makes the process so complicated, ...it does not really consider to meet the needs of the disabled people (Ye, male, 33-year-old, physical disability, using wheelchair).*

Another participant was not involved in the related group but heard about the news of the new system from his friend who was also with disability. He had had very negative experiences when he applied for the disability benefit some years ago. He felt he was insulted and treated unfairly during the assessment application process. And now for the new assessment, he worried that he might be assessed with the disability level from moderate to mild and it would influence his welfare benefit. He replied:

*"My friend told me the new system is stricter than the old one. ...Waiting for the new assessment makes me feel nervous; my friend is nervous too for waiting. ...I feel scared to be hurt. ... It is not fair. ...I do not feel secure. ...It seems to me that I am harmed by the big stone. ...I wish it (i.e., the new assessment system) could be stopped (Lin, male, 40-year-old, facial and vision disabilities)*

### **Victory of medical model**

#### ***Whether the third assessor existed?***

Almost for those participants who only experienced the new system replied that they did not remember that any social worker from the local authority had contacted them, except one certificate card mailed to them.

For those social services listed in the questionnaires provided by the local authority, the users need to tick first, otherwise the third assessor, social workers, would not give any contact.

*".....Nobody has contacted me after the assessment. ...you are not informed to know about any welfare services or resources; instead I was told by people around; it counted on nobody but yourselves ...the assisted equipment needs to reapply, ...I did not receive cash subsidy" (Lan, F, 35, vision)*

"People are used to have no assistance from the government. People have learned to count on own selves." (Yang, Female, 37, vision disability).

"Last time, I did not know to tick the PI service, but this time for re-assessment I did. Different from last time the social worker from local authority come to visit me to see whether I do need the PI service. (Huei, F., 35, physical dis, use wheelchair)

#### **Social roles and social participation not be concerned**

According the amended Disability Act of 2007 in Taiwan, the new assessment, Unlike the ICIDH, emphasizes individual needs not only based on individual health/functioning factors but also the

individual's activities/participation in particular the environmental factors. However, in this study, none of the participants who had received the new assessment system replied that the assessment had not paid attention to the activities in which she/he participated.

The mother of a disabled child in age of five participated in our interview and responded that she frequently drove her disabled child for doing rehabilitation but the parking benefit had been taken away after the new assessment.

One participant (male), in the age of 20s and with physical disability, enjoyed travelling around the island and he used a walker instead of electric wheelchair because he was assessed with moderate physical disability. The subsidy for buying an electric wheelchair was only eligible for persons assessed with severe or profound level of disability. It means that the new assessment system as like as the old one, did not involve the individual's needs for activity and social participation.

Codes related to activities, performance, environment –doing for doing; not related to the resources allocation—as less the resource as allocated

Two participants who were only assessed by the new system shared that they lost their original work because of becoming disabled; unfortunately after the assessment, they did not receive any occupational services in which assisted them back to workplace.

“I am a primary school teacher and I had been the responsible teacher of the students, ...now I am disabled thus I could not be the responsible teacher as earlier. ...salary is higher for being the responsible teacher, ...and now I cannot be the responsible teacher; I do not feel I am equal with my colleagues as well. ...surely work is related to dignity. ...I do not think I will be helped to have my work condition changed. ...Before I became disabled, I went to community college to take course. Now I quit because I do not have transportation to go. ...I do not feel the new system has any special” (Lan, female, vision impairment).

“The assessment is based on the standardized questions instead of coming to know my life, my work and activities, and life environment. I am likely wonder to what extent they evaluate only within half an hour. They asked very briefly, every person is very individualized. ...They did not give me any opportunity to ask them questions. ...We became disabled, during the process our family has been suffered too. But zero service has been provided to my family. ...Individual needs or differences are not considered. ...” (Yang, Female, 37, vision disability).

Ironically, family support and family counseling services are included in the Amended Disability Act and also in the questionnaires of the new assessment, the applicants for the assessment had no idea how to access such social services that are provided by the local authority. The needs of social services are assessed by the third assessor from the local government. Thus, first, our findings imply that the third

part of assessment did not work out to meet the individual needs; second, like the old system, the individual's social roles and social environment are ignored by the new assessment. After becoming disabled, some participants lost their work after becoming disabled; some participated shared that their social roles and social participations were influenced, even changed or stopped. However, the new system did not take these perspectives into consideration and did not give any support either.

One participant (female, using wheelchair) was not satisfied with the result of the new system because the level of disability was assessed from severe level to moderate in which she would lose the eligibility for subsidy for buying electric wheelchair. So she therefore had applied re-assessment and then gained back severe level of disability after the reassessment when she was interviewed. She also shared that she had been locked at home for over thirty years, and now she could use electric wheelchair for going out and participating social activities, e.g., attending the new year concert that was held by the City Government and being involvement in the independent living organization which was organized by disabled people in Taipei City. It is pity she said that "the new system does not consider what an electric wheelchair is important for me to be involved in social activities. ...Going out once a week is very important for me, because I feel happy. ...I had been locked at home over 20 years (Huei, F., 35, physical dis, use wheelchair)

### **Eligibility concern rather than needs met**

Chou (male 39) and Fan (male 50) had been assessed with "forever disabled" and applied for the new assessment before the appointed date, July 2015, both of them had unhappy experiences. For example, they needed to have the diagnoses from the physician before they went for registration at the local district authority but they were not informed in advance and they went for nothing for their first time of registration. For them, using wheelchair, transportation was a big issue. In particular, Chou uses body language and only the peer members of the IL association could follow his body language. So the first and second assessors could not communicate with him; all those questions in general made no sense to him. Chuen was working at the IL association and herself with rare disease and she helped Chou to reply: "the medical doctor could not communicate with the persons with body language. ...you already use the wheelchair, why need to be asked so many questions. ..If you are not experienced to respond to the answer, the level of disability of yours will be assessed lower. ....you want to have a wheelchair, why it is related to the level of disability in which was assessed?"

Chuen continued saying: "The assessment related to activities performance has asked whether you can bring up a ball pen or get the button up. For sure we can take bath ourselves, but it may take three hours without assistance. For some disabled people, such a kind of question does get them hurt. Does the ICF aim to respect the person's differences? We care about whether we can receive services for our independent living. Why do we need to care about whether the ball pen could be hold or fallen down? ...ICF has been told to emphasize on environmental factors, but the current system is not like that, it has no differences from the old one." (Chuen, female, 35, physical disability and rare disease)

IC-008(表 B)

One participant (Lee, male, 40, kidney disease) complained that “I need to have financial support for my daily life, but the social worker told me I am only eligible to have financial support for medical care use. ...It means that I just stay in the hospital forever.”

**Professionals dominating rather than users included**

The first assessor is the physician and the applicant needs to make an appointment with the physician by her/his own at outpatient unit. Usually the physician working at the qualified hospital for disability assessment have many patients on the queue; the applicant as the general patients is required and queue for their turn. Because of time pressure, the medical doctor might just spend 5 to 10 minutes for the first part assessment (b/s codes). The second part assessment has been usually set on another day based on the different hospital; normally the applicants have no idea who was her/his second assessor, social worker, nurse or occupational therapist.

“I do not know who were the second assessor? ...all those questions were standardized, ...I do not think they asked me whether I have any suggestions or questions to ask.” (Lan F, 35, Vision)

Fan (Male, 50, physical and vision, using wheelchair) shared his experiences with both first and second assessors in the hospital: “He (physician) did not tick in the questionnaires until I was not with him. ...it just around 5-6 minutes, he asked me to leave. ... I feel the physician is very arrogant. ...The second assessor was on second day. My wife went with me. Some questions he asked my wife, not me. ...I have told them I want to have PA service, but they said I need to be disabled severely enough. ...the forum said that the medical doctor’s assessment is not important, the purpose of the new system is the needs assessment, but it is not true, ...the new system is just like a liar

One participant with mental difficulty shared that the second assessor requested her to present whether she could open the button or not. She felt the request made her feel insulted. Another participant with physical disability and needs to have assistance for using his hand and he shared that he also felt insulted when he was required to show how to open the button.

“The physician did not talk with me, he just checked my tongue. ...he knows me and he has empathy, unlike the former one for the first assessment. ..., no he did not give me chance to ask questions. ...it spent around 10 minutes for the physician. They just ticked in the questionnaires themselves “...(Huei, F., 35, physical dis, use wheelchair)

“...from the plan, implementation, the whole process of the new system, there are no disabled people involved. Do those decision makers know us? Is it medical or social model? Does it say that the ICF is necessary to have disabled people involved? Does it say that the disabled people have rights to access the information? ...when the physician or social workers as the assessors ticked the answers of the questionnaires, they hide them. Do the answers should be done by both sides and agreement? Otherwise

IC-008(表 B)

why we should take it. ... the whole process is doing without the users' involvement. ...” (Chuen, female, 35, physical disability and rare disease)

If the assessor had been the applicant's doctor in charge of her/his care, it would make the applicant different feedback from the assessment process. Some participants applied for disability assessment when they were hospitalized, the first assessors were the physician in charge of their care who had known their health conditions, these doctors just answered the questionnaires without asking the applicants.

The findings suggest that if the applicants are not so familiar with the hospital and the assessors where and who are new for them, they do not feel comfortable or respected but feel controlled including the assessment space, atmosphere and the assessors' attitudes.

Some participants had recommended that the staff working at the district bureaus and the medical professionals could be more competent and friendly and the individual and unique needs could be recognized.

### **Users controlled rather than empowered**

According to the process of the new system as mentioned as above, the first and second parts are implemented in the hospital and the third one means the final decision for the benefit allocated in which was completed by the local authority. However, the applicants had no idea about the process even who were the assessors or how many assessors who had met.

Majority participants who had received the new assessment replied that they were informed by the physicians otherwise they had no idea about the new assessment, the process of the assessment, and who were the assessor of the second part and even some of them never contacted by the assessor by post from local authority. Most of them after the assessment in the hospital, they just received the disability certificate from the local authority, no any home visit or phone call, around one month after.

If the applicant was not satisfied with the assessment results, level of disability, she/he can apply for reassessment, but they need to pay for the assessment fee if the result would be the same. One participant of our study was not satisfied with the result, because he then lose the eligibility to have subsidy for buying electric wheelchair, he replied that he had no idea he could apply for reassessment until he was told by the disability group where he had visited.

The services provided by the local authority are printed in the questionnaires and the applicants need to tick that she/he is going to apply for use. However, if the applicant has no idea what those services, she/he would have no idea to tick that service for future use. For example, personal assistant and community living are still unknown by majority people in the society, the applicant would be unlikely to tick the service for use.

IC-008(表 B)

For example, one participant (Female, mental difficulty) replied that she wants to use psychological rehabilitation service, but she did not know she needs to tick in the questionnaires once she registered from the local district.

Chuen, the member of the Independent Living Association was upset and angry with the new assessment system. She shared:

“...in the beginning when we heard about the new tool for needs assessment, we were excited; because it was said that, instead of the old one that only focused on the impairment, the new one would emphasize the disabled people’s citizenship rights, to respect how different we are and to meet our needs. But we have been disappointed, it feels like you were cheated by the commercial advisement. ...we wonder if the disability benefits are our rights to have, why we need to go through so complicated assessment and see so many assessors. ...the new system is only for the state to save resources, ...Does it assess our performance or needs?” She continued: “Does this say that the ICF is a human rights issue? ...So many problems are coming; the state spent so much money and time for the assessment, we do not understand to what extent they are doing. ...Where are the services for living? ... We are in such uncertain condition.” (Chuen, female, 35, physical disability and rare disease)

### **Unfriendly and inaccessible information**

Before the new assessment implemented in July 2012, the central government had hold forums for having related people informed what the new assessment system would be. Some of the participants who were involved in the related disability groups had participated in the forum and replied that they could not follow what they said.

“...I have attended the forum explaining the ICF, the IL association invited me to go. ...I do not understand well, it was very complicated, something like activity, participation,” (Huei, F., 35, physical dis, use wheelchair)

“I have attended the forum but it was not so clear. ...I do not know what the special of the new system.”  
*(Lan, F, 35, vision)*

“I participated the forum related to the new assessment system; but I could not follow even I am from special education training background. ...who were the assessor? Who were the medical social workers and who were the social workers from local authority? It was not clear. ...” (Yang, Female, 37, vision disability).

During the assessment, the participants answered they did not know what the assessors were writings or giving the code numbers in the questionnaires. Even in the end, the participants had no idea what the code symbols of the final assessment written in the disability certificate means.

The applicants have no idea about the process and those code numbers. For example, The mother of the

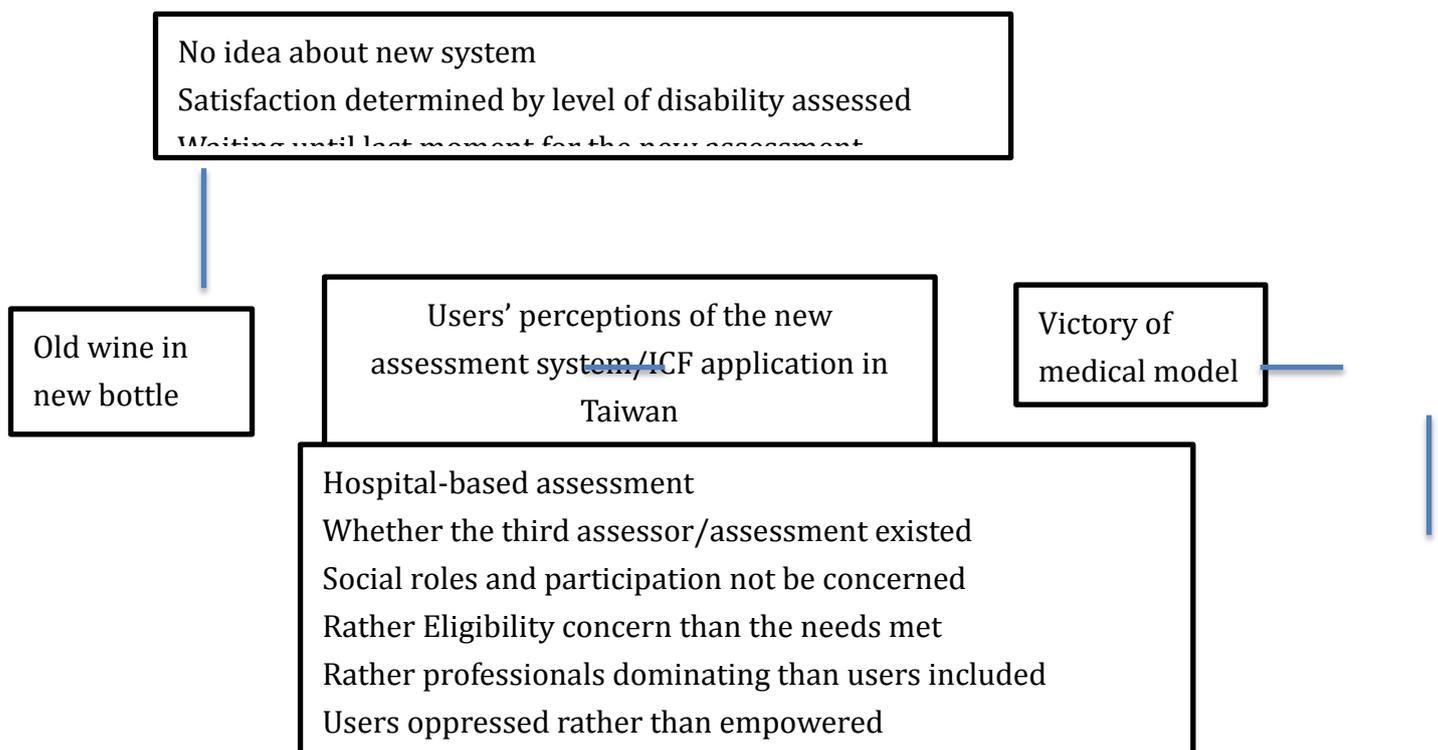
IC-008(表 B)

adult child with ID shared: "...No, I do not know the new system. ...I do not know who were the assessors or how many assessors. They just asked me to wait and the took Ming going with them. ...No, I do know any thing written in the certificate card."

"...I do not know those codes written in the certificate card until I checked from the computer." (Huei, F., 35, physical dis, use wheelchair)

"so many the forums related to the new system had been held, after the decision had been made. The information uploaded in the website, all those languages use are difficult to follow. We do not know what are those codes numbers in the certificate card, Even now some of our members say the ICF to IFC. Even for me I could not know so long words. It seems that you need to be very knowledgeable to follow. (Chuen, female, 35, physical disability and rare disease)

**Figure 2: Key themes from interviews**



## Discussion

Our study found that the application results of the ICF in Taiwan would make Hurst, an disability activist, disappointed that she has hoped that the ICF would change people's thinking to disability as a rights issue and policy makers would use the environmental factors as a basis for assessing appropriate services (Hurst, 2003).

First, similar to the old system, like the old wine in a new bottle, the disability benefits or services provided are still based on the level of disability in which is according to the body function and body

structure and assessed by the physician. Second, the environmental factors combining with the activities and performance items are involved in the new assessment and are assessed by another professionals, such as social workers, occupational therapist or nurses; however these assessments are done for nothing, different from the commitment of the ICF application in Taiwan in which was said that the use of ICF was for providing appropriate services to meet the needs of the individuals assessed (Chen et al., 2013; Teng et al., 2013). The services provided are general, similar to the services provided by the old system, such as transportation cost discount, free charge of using public recreation facilities, subsidy for health insurance premium and cash allowance. The individual person's social roles and social participation are not taken account for the services provided. Third, the ICF applications did not change the thinking of the disability as a rights issue in the society including the professionals, administrators and the policy makers based on the findings of the current study. Further, it even makes the disabled people who had experienced the new system feel devalued and excluded. For the applicants, the process of the new system has been more complicated and felt controlled by the administration process and the professionals. In particular, those questions related to contextual factors just make the individuals feel hurt.

All in all, the application of the ICF in Taiwan, like the ICIDH in which fails to acknowledge the presence of social barriers (Bickenbach et al., 1999) and the individual and social elements are not both integrated (Imrie, 2004; Schneidert et al., 2003). The assessment has divided into three parts and three assessors have been involved but not worked together as a team. Instead, the individuals are requested to go through three windows, local district for registration and hospital for first and second assessments. The process of the new assessment/ICF system has been even more complicated for the individuals than the old one. Instead of the integration of the person's bio-psycho-social perspectives, interaction of the person and their environment (Anner et al., 2012) or the whole of the person ( ), disability has only defined by the sum of ICD codes, that is the biomedical part/body functioning and body structure in which is assessed by the physicians. As long as, like the old system and echoed to Pfeiffer (2000), the ICF application is a medical model, disability issues is still medicalized.

To have disability benefit the participants who were the first time applying for the assessment did not know about the assessment in which had been categorized into old and the new. Our findings also showed that majority participants did not have idea about the assessment process including who were the assessors and how many assessors and even they did not know how their disability level and types were determined. Generally the users were not involved and not informed in the new system. Nordenfelt (2003) pointed out that the individual's choice or should be concerned in the process of ICF. Unfortunately, in Taiwan, during the assessment process, the individuals are not even given any opportunity to ask questions, instead, the individuals are just be asked to perform certain activities as the items in the questionnaires. Obviously, the ICF is not the approach to meet the needs of the individuals; as well as it is not the way to change the thinking of disability. Instead, it is medicalized and it is a tool to assess eligibility for disability welfare benefit as indicated by Teng et al. (2013, p. 692).

Rather the needs for daily life and independent living to be met, general benefits given more widely are

such as transportation cost discounted, free charge while using public recreation units in which had been available before the new system applied. In contrast, the electric wheelchair is very important for the individuals to have an independent living; but it is only based on the level of biomedical factors and the person's social participation and social roles are not encountered by the current assessment system. McIntyre & Tempest (2007) indicated that the ICF is more "user friendly" and the ICF needs to refer to the Convention on the Rights of Persons with Disabilities (CRPD) such as data collection appropriately (Bickenbach, 2012). Instead, the findings of this study found that the application of the ICF in Taiwan is not friendly for the individuals, in contrast the users felt it is a tool in which is used to cut resources. The limitations of the ICF have been stated by several Western researchers (Conti-Becker, 2009; Anner et al., 2012; Nordenfelt, 2006; Wade & Halligan, 2003), however, the application of the ICF in Taiwan is rather a political issue. Additionally, as long as, the disabled people have not been involved in the development process of the new system.

Care service users in Taiwan are used to be controlled by the social institutions and professionals in particular the physicians (Chang, ...Liang, ); and the standardized indicators are widely used for the determination of the intervention from social systems. It is not surprised that social model perspective, including universal application to all people, has not been recognized by the ICF working group in which is organized by professionals who are mostly from health training background (Chang, ...). Under these circumstances, the ICF applied in Taiwan, as the same as the old system, the new thinking of disability or the impact of culture and social factors has not been acknowledged. Like in the old system, based on the sum of the ICD codes (i.e., the b/s codes), the results of the new assessment are still categorized into four levels for resources controlled not for the needs of the individuals. It can be said that for the old system the level of disability and level of resources allocated were controlled only by a single physician with pen; now for the new system such four levels of disability and resources allocation are also controlled by the physician through computer. For the former one the result determining the level of benefit could be known right away; and the later one would be informed one month after; and both are all based on the sum of the personal bio-medical conditions (b/s codes). All in all, the application of ICF in Taiwan is against the disability movement, against the value of the UNCRPD, against the new thinking of disability; certainly it is old wine in a new bottle only.

## **Implications**

Based on the findings of this study, the implications are summarized as follows. First, the service users, e.g., disabled people, should be included in the ICF task force to work with the professionals and administrators and to be involved in the decision making process related to the ICF application in Taiwan. Second, except the service users involved, this work team should be organized as an interdisciplinary learning group in which aims to integrate health, culture and social perspectives. It means that the current questionnaires developed based on the ICF should be revised and undergone by an integration of a team in which is organized by the users/disabled persons, the practitioners, the researchers and administrators from both health and social science and care systems. Third, the introduction of social model and integrative/interactive/universal approach as the principles of the ICF is warranted to be included in the

pre-/in-service training in which is proved for front line assessors and administrators. Fourth, the orientation is essential when the applicant registers for the assessment at her/his local district authority including the assessment process and who would be the assessors in charge of the part of the assessment and how long the assessment would go. Fifth, the first part of assessment can be conducted in special outpatient service unit instead of the ordinary one. Seventh, unlike the current condition, the second part of assessment as the contextual factors, such as activities, social participation and environmental factors, should be encountered into the needs assessment as the critical references for services provided. Moreover, the questions related to the individual's social roles and social participation including the open-ended questions should be included in the second part and third part of the assessment. If it is possible and necessary to meet the individual's needs, such parts of assessment could be conducted in the applicant's real life, e.g., her/his work, family and social life. Additionally, in order to meet the individual's needs, all three parts of assessment could be completed together by the interdisciplinary team as stated in the Disability Act. Therefore, the resources allocation would not be only based on the individual's health and functioning conditions; instead the services and benefits provided to the individual are based on the integration of her/his bio-psycho-social factors including her/his social roles and social participation.

### Conclusion

The application of ICF, named as the new assessment system, is implemented with a package of standardized questionnaires and is viewed as the eligibility screen tool for welfare benefit; and except the bio-medical questions, the items related to activity, participation and environment are included in the package too. Not only the physicians but also other professionals (social worker, occupational therapist or nurse) are involved as the assessors in this new system. However, like in the old system, the person's eligibility of welfare benefit is only based on her/his bio-medical functioning in which was summed up by the ICD codes (i.e., b/s codes) and then categorized into four levels of severity, from mild to profound. In contrast, the person's social roles and social participation are not considered while the resources allocated from public sectors. To conclude, the new thinking of disability and the principles of the ICF in which focused on combination of medical and social model remains undoing; instead, the application of ICF in Taiwan is victory of medical model.

### References (Skip)

Table 1

Participants' simple demographic description (N=24)

	N (%)
<b>assessment system</b>	
Both new and old	11
only new	9
Only old	4
Sex	

IC-008(表 B)

Male	19(79.2)	
Female	5(20.8)	
<b>Age (years old)</b>		
<6	1(4.2)	
20-30	3(12.5)	
31-40	8(33.3)	
41-50	7(29.2)	
51-60	3(12.5)	
>60	2(8.3)	
<b>Type of disability</b>		
Type 1	4	
Type 2	2	
Type 3	6	
Type 4	1	
Type 5	1	
Type 6	0	
Type 7	7	
Type 8	7	
More than one Type	11	
<b>Level of disability among the participants assessed by both old and new (n=11)</b>	Old	New
Mild	2	2
Moderate	4	4
Severe	3	4
Profound	2	1
<b>Level of disability among the participants assessed by only new (n=9)</b>		
Mild		1
Moderate		6
Severe		1
Profound		1
<b>Level of disability among the participants assessed by only old (n=4)</b>		
Mild	0	
Moderate	1	
Severe	0	
Profound	3	

you intake? How was it going when the medical doctor carried on the assessment? How long did it take? How did you communicate each other? How did you feel about the assessment from the

### Appendix: Interview guide

1. Was this assessment for you first time or not? If it was not first time for you, why did you go to do it before the required date, July 2015?

2. Now we'd like to invite you sharing with us about your experiences of the new assessment system:

(1) How did you go through the registration for the new assessment system? Where did you go and what did you feel about the registration process? Was it convenient for you? How about the staff was working with you there?

(2) For the new assessment, which hospital did you go and why? How was the intake going through in the hospital? Did you receive any assistance for the intake and the assessment process? For the first part of assessment, which medical doctor did

- medical doctor? How did you feel about the interaction between you and the medical doctor?
- (3) How long did you wait for the second part of assessment? Who was the second assessor? Was she/he a social worker, occupational therapist, or other professional? How was it going when she/he carried on the assessment? How long did it take? How did you communicate each other? Did she/he give you any chance to ask him/her questions or to share your idea? How did you feel about the assessment from the second assessor? how did you feel about the interaction between you and the second assessor?
  - (4) How was happened after the assessment in the hospital? Was there any social worker from local authority contacting you, by visiting or by phone call?
  - (5) How long did you receive the disability certificate card?
  - (6) What kinds of social benefits or services do you receive after the assessment?
3. Now we'd like to know about your feedback to the new assessment system?
- (1) Do you know about the new and old assessment system? If you know, how did you know about it? Do you know any differences of the new system from the old one?
  - (2) Have you attended the forum related to the new system and organized by the government? What do you feel about the forum?
  - (3) How did you feel about the results of the assessment? Did you feel the results of the new assessment meet your needs?
  - (4) According to the Article 5 of the disability act, the new system aims to promote your quality of life and also, not only health and functioning issues, focuses on activities, participation, environmental factors related to your social roles and relations. How did you feel all these factors had been included in the assessment and the goal of the new system had been approved?
  - (5) From the users' perspective, what do you think the strength and weakness of the new assessment system?
  - (6) If you can chose the old and new assessment system, which one you prefer?
4. From your point of view, as a service user receiving the new assessment, do you have any suggestions given to the government, the administrator, the hospital and the assessors in charge of this new system?

101年度專題研究計畫研究成果彙整表

計畫主持人：周月清		計畫編號：101-2410-H-010-003-SS3					
計畫名稱：發展與評估智障者性健康方案							
成果項目		量化			單位	備註（質化說明： 如數個計畫共同成果、成果列為該期刊之封面故事...等）	
		實際已達成數（被接受或已發表）	預期總達成數（含實際已達成數）	本計畫實際貢獻百分比			
國內	論文著作	期刊論文	0	0	100%	篇	兩份期中報告、一份期末報告、一份操作手冊
		研究報告/技術報告	4	0	100%		
		研討會論文	0	0	100%		
		專書	0	0	100%		
	專利	申請中件數	1	0	100%	件	「促進服務使用者性健康與生活品質介入方案」操作手冊：智青、家長、工作者
		已獲得件數	0	0	100%		
	技術移轉	件數	1	0	100%	件	「促進服務使用者性健康與生活品質介入方案」操作手冊：智青、家長、工作者
		權利金	0	0	100%	千元	
	參與計畫人力（本國籍）	碩士生	0	0	100%	人次	
		博士生	0	0	100%		
博士後研究員		0	0	100%			
專任助理		0	0	100%			
國外	論文著作	期刊論文	2	0	100%	篇	Published: Chou, Y. C.*, Lu, Z. Y., & Pu, C. Y. (2015). Attitudes toward male and female sexuality among men and women with intellectual disabilities. Women & Health, 55(6), 663-678.

						SSCI/SCI, IF=1.194, WOMEN'S STUDIES rank=Q1 (8/40) (NSC 101-2410- H-010 -003 - SS3)
						Under revision: Chou, Y. C.*, Z, J., Lu & Lin, C. C. (2014) Comparison of attitudes to sexual health of men and women with intellectual disabilities among parents, professionals and the university students, Journal of Intellectual and Developmental Disability (under minor revision)
		研究報告/技術報告	0	0	100%	
		研討會論文	2	0	100%	Chou, Y. C.*, Z. J. Lu, & Lin, C. C. (2014). Outcome evaluation of a sexual health program for adults with learning disability: qualitative and quantitative approaches, present at the NNDR

							Conference, May 6-8, 2015, Bergen, Norway. (科技部獎助) (NSC 101-2410-H-010-003 -SS3)  Chou, Y. C.* (2014). Working with adults with intellectual disabilities to promote their sexual health: Program innovation, implementation, and evaluation, present at the IASSIDD, Europe Regional Congress, 2014-07-14, Vienna. (科技部獎助) (NSC 101-2410-H-010-003 -SS3)
		專書	0	0	100%	章/本	
專利		申請中件數	0	0	100%	件	
		已獲得件數	0	0	100%		
技術移轉		件數	0	0	100%	件	
		權利金	0	0	100%	千元	
參與計畫人力 (外國籍)		碩士生	0	0	100%	人次	
		博士生	0	0	100%		
		博士後研究員	0	0	100%		
		專任助理	0	0	100%		
其他成果 (無法以量化表達之 成果如辦理學術活動 、獲得獎項、重要國 際合作、研究成果國 際影響力及其他協助 產業技術發展之具體 效益事項等，請以文	I. 三年研究過程簡介： 一、方案發展、執行、評估邀請使用者、家長、實務工作者全程參與。 二、實驗組，增加追蹤post-test，即介入後之後測，四個月後進行追蹤。 三、第一年初測參與者為日間照顧/南部區域者，第二年主要測量擴及住宿服務單位/中部地區者。 四、第一年實驗組者青年與家長，共三年介入/九次測量。 五、比較組後續邀請成為實驗組。 六、舉辦研究結果分享發表會，邀使用者/家長/實務工作者/經營者分享。						

字敘述填列。)

七、介入手冊產出：依介入研究典範/本土國際發展方案/執行/修正/再執行/再修正/擴大使用。

II. 學術價值與創新與社會影響

一、學術價值：這三年的研究案是以介入研究典範強調三個部分：需求評估、方案發展及方案評估，三個步驟同時進行，可以累積國內以實務為基礎的研究、知識，對國內實務工作者、社會工作碩士及博士論文提供一個參考範本。我們也應用參與性研究、解放學(emancipatory research)研究典範，邀請智能障礙者青年與研究者站在平等位置，一起規劃及執行，對國內發展及重視解放學研究，在學術上有創新的意涵。同時本研究評估，含量性與質性資料收集，兩者都收集智障者主觀經驗，對國內智障者相關研究提供有力參考。本研究結果也到國際會議與投相關國際期刊發表，對台灣在介入研究、解放學研究、智障研究與國際接軌的實踐及增加台灣智障研究在國際學術社群之曝光率。

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三、社會影響：(1)呼籲相關工作者，家長、社會對智能障礙青年性健康議題的重視，爭取障礙青年性權利、社會平等位置。(2)邀請智障者參與我們的規劃及執行，與研究者站在同等位置，我們也提供同等講師薪資，提升障礙青年在台灣社會能夠平等被重視，智障青年的權能提升(empowered)。

	成果項目	量化	名稱或內容性質簡述
科 教 處 計 畫 加 填 項 目	測驗工具(含質性與量性)	0	
	課程/模組	0	
	電腦及網路系統或工具	0	
	教材	0	
	舉辦之活動/競賽	0	
	研討會/工作坊	0	
	電子報、網站	0	
	計畫成果推廣之參與(閱聽)人數	0	

# 科技部補助專題研究計畫成果報告自評表

請就研究內容與原計畫相符程度、達成預期目標情況、研究成果之學術或應用價值（簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性）、是否適合在學術期刊發表或申請專利、主要發現或其他有關價值等，作一綜合評估。

1. 請就研究內容與原計畫相符程度、達成預期目標情況作一綜合評估

達成目標

未達成目標（請說明，以100字為限）

實驗失敗

因故實驗中斷

其他原因

說明：

2. 研究成果在學術期刊發表或申請專利等情形：

論文： 已發表  未發表之文稿  撰寫中  無

專利： 已獲得  申請中  無

技轉： 已技轉  洽談中  無

其他：（以100字為限）

So far one article had been published, one article has been under revision, two articles had been presented at the International conference and thee articles are planning to submit to the international journals.

3. 請依學術成就、技術創新、社會影響等方面，評估研究成果之學術或應用價值（簡要敘述成果所代表之意義、價值、影響或進一步發展之可能性）（以500字為限）

I. 三年研究過程簡介：

一、方案發展、執行、評估邀請使用者、家長、實務工作者全程參與。

二、實驗組，增加追蹤post-test，即介入後之後測，四個月後進行追蹤。

三、第一年初測參與者為日間照顧/南部區域者，第二年主要測量擴及住宿服務單位/中部地區者。

四、第一年實驗組者青年與家長，共 三年介入/九次測量。

五、比較組後續邀請成為實驗組。

六、舉辦研究結果分享發表會，邀使用者/家長/實務工作者/經營者分享。

七、介入手冊產出：依介入研究典範/本土國際發展方案/執行/修正/再執行/再修正/擴大使用。

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障礙者青年與研究者站在平等位置，一起規劃及執行，對國內發展及重視解放學研究，在學術上有創新的意涵。同時本研究評估，含量性與質性資料收集，兩者都收集智障者主觀經驗，對國內智障者相關研究提供有力參考。本研究結果也到國際會議與投相關國際期刊發表，對台灣在介入研究、解放學研究、智障研究與國際接軌的實踐及增加台灣智障研究在國際學術社群之曝光率。

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