



특집

장애, 시민권, 민주주의

— 장애 연구(Disability Research)에의 참여수준 제고를 중심으로 김진우

정 은

Disability Research

김진우

덕성여자대학교

〈논문요약〉

3

■ 주요어:

1. 서론

‘ truth ’

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tion

normalization anti-discrimina-
social responsibility of disability



TV

participatory research emancipatory research
inclusive research Oliver 1992
Zarb 1992 French and Swain 1997

Chappell 2000 Gilbert 2004

2008a

Walmsley 2001

disability

gender

ethnicity

2. 시민권과 발달장애인

1) 마샬(T. H. Marshall)의 시민권

‘ civitas ’

17 18

18 19 civil rights
 19 20 political rights 20
 social rights Marshall 1963

2007

gender ethnicity minority

2013

2) 장애인과 시민권

2013

Morris 2005

Morris 2005

self-determination

Doyal and Gough 1991 53

Duffy 2003

2012

participation

contribution

Morris 2005

substituted

2012

2004

2007

3) 발달장애인과 시민권



civil rights

“ ”

2007

‘ ’

2008b

21

Redley

Maina Keeling and Pattni 2012

2

2014

1960

1970



Giddens 1998

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2008b

2014

2008a

3. 시민권과 학술연구: 실증주의의 배제 메커니즘



1970

disability studies

assumption

Oliver 1992

methodological individualism

impairments

Zarb 1997

‘ social engineering approach ’

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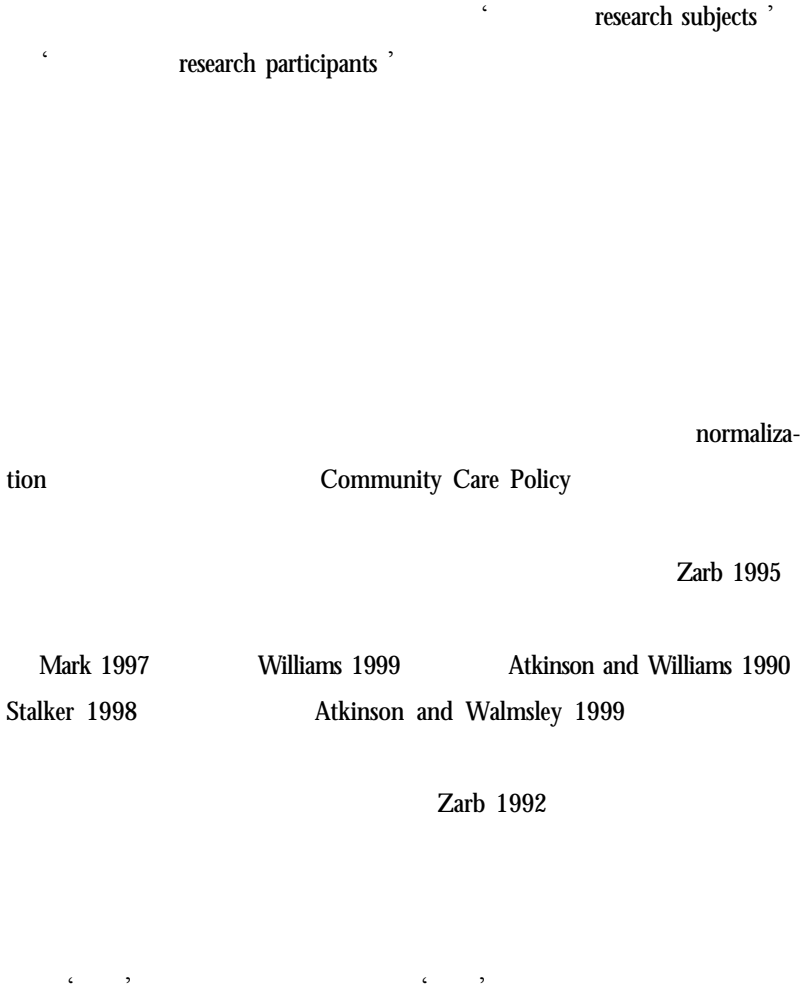
20

Disability Alliance 1989 Oliver 1992

4. 장애연구에서의 참여적 연구와 해방적 연구

1) 참여적 연구 패러다임

participatory research



2) 참여적 연구 패러다임에 대한 비판적 입장

(1) 연구생산에의 사회적 관계(Social Relation of Research Production) 변혁 실패

of research ’ the rape model

1993 Thomas and Parry 1996 French

research products social relation of

(2) 정책적 대안마련에의 한계

2012

white papers

Department of Health 2001

Walmsley 2004

Miles and Huberman 1994

3) 해방적 연구 패러다임

Oliver 1992

French and Swain

1997 27



social reality

institutional disablism

disablism

Oliver 1992 112

Oliver 1992

Zarb 1992

commissioner

Stone and Priestley 1996

objectivity

Barnes 1992

〈표 1〉 장애연구에 있어서 양 접근의 비교

	참여적 접근방법	해방적 접근방법
연구방법론	현상학적(연구주체의 경험 내부로 들어가기)	정치적 행동으로서의 연구 질적, 양적연구 포괄
이데올로기	특정한 것은 없으나 정상화(normalization) 또는 장애에 대한 사회적 모델	장애에 대한 사회적 모델 채택 장애인에게 실질적인 혜택을 줄 수 있는 연구 수행
누가 통제권을 갖나?	자료수집과정에 있어서의 장애인과 협력관계에 있는 연구자	연구질문 형성과정에서부터 연구결과 배포까지 모든 국면에서의 장애인
연구자의 역할	연구주체와 관련하여 전문성을 함께 공유할 수 있는 전문가. 때로는 조연가/지원자	장애인에 대한 책임을 지는 전문가
연구주제	장애인의 삶과 관련된 이슈	변화를 추진할 수 있는 적절한 경로를 탐색하고 명확하게 하는 주제
책임성	연구자금 제공자에 대한 책임성	장애인과 그들의 단체(기관)에 대한 책임성

자료: 월슬리(Walmsley 2001), 김진우(2008a)

impairments

Barton 2005 321

Walmsley 2001 196 1.

4) 해방적 연구 패러다임에 대한 비판적 입장

Stone and Priestley 1996

personal and academic integrity

assumption

social reality

“ ”

differences



commonalities

Oliver 1996

sociological interpretation of impairments

differences

2007 2010

French and Swain 1997 29 30

OPCS Office of Population Censuses and Surveys

approach limitations individual

NHS National Health Service Department
of Social Service

French and Swain 1997



5. 발달장애인에 대한 참여적 연구와 포섭적 연구의 의미

1) 참여적 연구의 의미

Walmsley 2001

1960

1970

1970

Walmsley 2001

190

Chappell

2000

Goodley 1997



Atkinson 1997

Atkinson 1997

involvement

Chappell 2000 Walmsley 2001

2) 양 연구 패러다임의 적절성 논의: 포섭적 연구의 등장

Stalker 1998

3

involvement



complementary

inclusive research

Walmsley 2001 187 188

Barton 2005

Johnson 2003

Walmsley and

Walmsley 2004 56

.

concept

term

6. 장애연구에의 발달장애인 참여과정

Gilbert 2004

Gilbert 2004

1) 시작 단계

Stalker 1998

3

Burke Burke

McMillan and Cummins et al 2003

2) 참여과정 발전 단계

Stalker 1998 Williams 1999 Booth and

Booth 2003

Stalker 1998

Burke et al 2003

3) 자료 수집 및 분석

‘Yes’ Stalker 1998

2013

Booth and Booth

2003

Booth and

Booth 1996

Goodley 1996

4) 자료 배포

7. 결론

inclusion



_____ 2010 “ ” 『 』 41 1 39 63

_____ 2012 “ ” 『 』 6 2 103 128

_____ 2014 『 』

_____ 2004 “ ” 『 』

8 2 1 20

2013 “ ” 『 』

_____ 2007 『 』

2012 “ ” 『 』

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Civil Rights and Exclusion · Participation of People with Developmental Disabilities

Focused on Enhancement of Participation Level in the Disability Research

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The purpose of this research is to search paradigm and methods which allow people with developmental disabilities to be involved more than as research participants. To do this there needs to reveal the true life image of people with developmental disabilities suffering from developmental disabilities on the basis of three dimension: self-determination, participation and contribution. It is very important for people with developmental disabilities and non-disabled researcher to cooperate and co-work with partnership. The relation should be focused on the enhancement of the level of involvement and control of people with developmental durabilities. Finally, at the last part this research suggests the significance of communication support and reciprocity at the stage of data collection and analysis for further involvement of people with developmental disabilities.

Key Words: People with Developmental Disabilities, Participatory Approach, Emancipatory Approach, Inclusive Approach, Research Process

투고: 2014.4.3 심사: 2014.4.18 확정: 2014.5.19