Disability on Equal Terms

Edited by John Swain and Sally French



Contents

| Acknowledgements for <i>Disability on Equal Terms</i> Introduction | | |
|--|--|----|
| Se | ction I The Tragedy View of Impairment and Disability | 5 |
| 1 | There but for Fortune Sally French and John Swain | 7 |
| 2 | Disability, Genetics and Eugenics Tom Shakespeare | 21 |
| 3 | Disabled in Images and Language Margaret Taylor | 31 |
| 4 | Institutional Abuse Colin Goble | 42 |
| 5 | The Narratives of Disabled Survivors of Childhood Sexual Abuse Martina Higgins | 52 |
| Sec | ction II From a Different Viewpoint | 63 |
| 6 | Affirming Identity John Swain and Sally French | 65 |
| 7 | Choices, Rights and Cabaret: Disability Arts and Collective Identity Allan Sutherland | 79 |

| 8 | The Art of Affirming Identity | 90 |
|------------|--|-------------|
| | Toby Brandon and Alice Elliott | |
| 9 | An Exploration of the Quality of Life of Adults with Haemophilia Karen Beeton | 104 |
| 10 | Disabled People's Testimonies Jasvinder, Arlene, Geoff and Alice | 115 |
| Sec | tion III On Equal Terms | 127 |
| 1 1 | On Equal Terms Sally French and John Swain | 129 |
| 12 | In Practice from the Viewpoint of an Occupational Therapist Elaine Ballantyne and Andrew Muir | 142 |
| 13 | In Practice from the Viewpoint of a Physiotherapist Anna-Stina with Sally French and John Swain | 150 |
| 14 | Communication Disability: Exploring New Personal and Professional Narratives Carole Pound | 156 |
| 15 | In Practice from the Viewpoint of a Disabled Nurse Rachael Spain | 164 |
| 16 | In Practice from the Viewpoint of a Social Worker Maureen Gillman | 171 |
| 17 | In Practice from the Viewpoint of Disabled People Clare Evans | 17 7 |
| | nclusion: Some Reflections on Key Questions | 184 |
| References | | 187 |
| Index | | 206 |

Index

| abortion 17, 26, 29-30, 131 | children cont. |
|--|--|
| abuse | tragedy view conveyed to 13-14, 36 |
| institutional 11–12, 42–51 | Churchill, Winston 24 |
| intra-familial 55–6 | Clare, John 96–7 |
| see also sexual abuse | 'Coming Out' 72–3 |
| | communication disability see speech |
| actors, disabled 38 | and language therapy |
| advertisements 39–40 | community care 42, 46–7, 174, 178 |
| charity 33–4, 87 | Community Care Act 132, 133-4 |
| affirmative model 65–8, 185–6 | Connect 157, 161–3 |
| and art 91–2, 98–103 | 'Creative Window Truthteller' 160 |
| critiques of 74–6 | creative writing 97–8 |
| occupational therapy 145–7 | Crescendo, Johnny 85, 86, 88 |
| self-affirmation 69-74, 91-2, 103, 110-13 | |
| see also testimonies | Crick, Francis 26 |
| speech therapy 161–3 | D : C1132 44 |
| Alison Lapper statue 40, 41 | Darwin, Charles 23, 44 |
| anaridia 121 | deafness 10, 16, 123–6 |
| antenatal testing 17, 26, 28-9 | definition of impairment 49 |
| aphasia 115–19, 157, 158–9, 161 | disability arts 79–89, 90–103 |
| art therapy 95–6 | art therapy 95-6 |
| arthropathy 105, 106, 109 | confronting tragedy model 101–2 |
| arts see disability arts | disability politics 88–9 |
| assessment, frameworks of 173 | growth of and performers 82-6, 99-100 |
| athletes 39 | historical figures/antecedents 79-82, 92-3 |
| | inspiration and dissent 92-5 |
| behavioural psychology 45 | representation of disabled 87–8 |
| Bell, Betsy 94 | Disability Discrimination Act 164, 169–70 |
| biographical disruption 107 | diversity 171 |
| blindness 9, 34, 121–3 | documentaries 36–8, 98–9 |
| Brandon, David 101–2 | Duffy, Mary 87 |
| Brisenden, Simon 82–3 | • |
| British Council of Organisations of Disabled | Eathorne, Victoria 166 |
| Doorle 23 84 | Ellis, Havelock 25 |
| People 83, 84 | empowerment 133-4, 135, 147 |
| Brockhall Hospital 94 | eugenics 21–2 |
| : - 24 88 0 | contemporary views 27-8, 29-30 |
| campaigns 34, 88–9 | defined and described 22-3 |
| celebrity 40 | history/development 23–5, 44 |
| charities 9, 10 | Nazi persecution 15–16 |
| advertising 33-4, 85-6, 87 | rise of genetics 25–7 |
| children | euthanasia 16, 17 |
| as burden 56, 57 | |
| deafness 10, 123–6 | expressivism 29–30 |
| non-acceptance by parents 8, 14 | Cashian and lifestyle 38-41 |
| and physiotherapy 151–3 | fashion and lifestyle 38–41 |
| sexual abuse 52–61 | Feeling Poorly 48 |
| | |

institutional abuse cont. films 34-6 Finkelstein, Vic 84, 89 song of protest 94 women 131 freak shows 32, 37 Fry, Stephen 99 funding 132, 136, 173-4, 180 Kahlo, Frida 82, 89 Laing, R.D. 99 Galton, Francis 23, 24, 44 Laughlin, Harry 23-4 genetics and genetic screening 2, 17 Lawnmowers, The 99-101 development of 25-6 Lear, Edward 81 eugenic overtones 27-8 and termination 29-30 learning difficulties Getting Better 48 community care 46-7 health inequalities 47-51 Goffman, Erving 46 impairment and eugenics 24 institutional care 43-6 haemophilia 104-6, 113-14 normalizing philosophy 45-6 factor replacement 108-9 performing arts 99-100 impact of diagnosis 107 joint-care/coping strategies 109-10 Leonard Cheshire organisations 177-8, 179, 180, 181-2, 183 self-affirmation 110-13 lifestyle and fashion 38-41 health inequalities 47-51, 131-2 London Disability Arts Forum 84 health professionals/service providers client relationships see power McQueen, Alexander 38 control and dehumanisation manic depression 99 49-50, 51, 120-1 media 9-11, 15, 31-3, 87 gatekeeping and resources 132 independent living 136-7, 177-83 charity advertising 33-4, 85-6, 87 policy/practice reform 133-6 fashion and lifestyle 38-41 surveying users' views 182-3 film and TV 34-8, 98-9 see also occupational therapy; physiotherapy; social work; speech photography 32-3, 87 and language therapy medical model 30 described 1, 130-1, 147, 164 hearing impairment 10, 16, 123-6 Heaton, Tony 87-8 and institutional care 48-50, 68 Heazell, Nikki 166-7, 168 in social work 171-2 Hevey, David 87, 89 mental impairment and eugenics 24, 44 HIV 105, 108, 111, 113 normalizing philosophy 45-6 see also learning difficulties 'I Am' 97 Mental Patients' Union 98 identity 18, 115 Milton, John 79, 80 cultural 67-8, 100-1, 103 Mobility Centre 153-4 Deaf identity 123, 124, 125 models of disability 1, 2, 130 disruption by abuse 52, 54, 57-9, 60 see also affirmative model; medical model; haemophilia as part of 110-13 Jasvinder's struggle with 117-18 social model; tragedy model Muller, H.J. 25 key ideas about 67 murder 12, 15 narrative identity 76 through arts 84, 98-101, 103 narrative accounts and tragedy model 8 creative writing 97-8 images of disability see media Independent Living 136-7, 177-83 narrative identity 76 changes and influence in provision 179-82 researching sexual collective and self-organisation 178-9 abuse 52-61 see also testimonies Service Users Networks/Support Teams Nazi persecution 15-16, 17, 24, 25 177-8, 182, 183 surveys and evaluation 182-3 NHS Direct 169 infanticide 12, 15 normalizing philosophy 10-11, 45-6, 91 nurses, disabled 164-5 institutional abuse 11-12, 42-7 barriers and training 165-7 dehumanization 54 health inequalities 47-51 becoming disabled 167-8 physical/sexual abuse 54-5 value of 168-70

| | . 1 11 |
|--|---|
| occupational therapy 142–3 | social model |
| affirmative model 145–7 | criticised 66 |
| policy reform 143–5 | described 1, 2, 75, 77 |
| practice 147–9 | in social work 171–3 |
| • | in speech therapy 158, 159 |
| paedophiles 55 | social work |
| parents 153 | medical/social model tensions 171-3 |
| child as burden 56, 57 | policy and budget control 173-5 |
| | " |
| disabled parents 14–15 | risk management and assessment 174–5 |
| intra-familial abuse 55–6 | suggested reforms/changes 175-6 |
| media view as saintly 9 | 'Social Workers' 101–2 |
| non-acceptance by 8, 14 | songs 93–4, 103 |
| partnership 134–5, 147 | Spastics Society 33 |
| paternalism 135 | Special Educational Need and Disability Act 167 |
| pathologization of disability 42, | speech and language therapy 116, 156–63 |
| 48–50, 51 | affirmative model 160-3 |
| Patients Charter and You 48 | interactions/report writing 159-60 |
| Pauling, Linus 26 | reform and barriers to change 157-8 |
| performing arts 85–6, 99–100 | therapists' roles 158-9 |
| photographic images 32–3, 87 | training 158 |
| | stereotypes 9, 34–5, 68, 87–8 |
| physiotherapy 150–5 | |
| politics, disability 34, 88–9 | sterilization 16, 24 |
| Pope, Alexander 80 | stigmatization 18 |
| power relationships 131, 132, | storytelling 59–60, 76, 97–8 |
| 135–9, 148 | stroke 116 |
| sexual/physical abuse 54–7 | 'Sub Rosa' 70–1 |
| social care 179–80 | super crip 36, 74 |
| therapy sessions 159–60 | |
| professionals see health professionals | Telethon 34, 88 |
| punishment, disability as 8, 115 | television 36–8, 98–9 |
| , , | termination see abortion |
| quality of life study see haemophilia | testimonies |
| Quinn, Marc 40 | aphasia (Jasvinder) 115-19 |
| Quilli, Maic 40 | blindness (Geoff) 121–3 |
| - : 11: 22 24 25 44 | (14) \ 15- (|
| racial hygiene 22, 24, 25, 44 | deafness (Alice) 123–6 |
| reproductive rights 26, 27–8 | wheelchair user (Arlene) 119–21 |
| research | thalidomide 26, 36, 72, 81 |
| genetic 25–6, 28–9 | The Barrier' 95 |
| narrative methodology 53–4 | The Healthy Way 48 |
| supporting tragedy view 15 | tragedy model 7–20, 57, 184–5 |
| resources 132, 136, 173-4, 180 | confronting 70, 100–2 |
| risk and risk management 174–5 | defined and described 7-9 |
| Rosenhan, D.L. 96 | explanations for 17-19 |
| • | media portrayals 9–11, 15, 31–41 |
| 'Scars' 82–3 | negative consequences 11-17 |
| schools and colleges 123, 153, 154-5 | Tragic but Brave' 73-4 |
| sculpture 87–8 | 111810 040 21110 70 |
| | UPIAS 49, 66, 83, 84 |
| service providers see health professionals | 01 110 47, 00, 03, 04 |
| Service Users Network/Support see under | Walning Dankle 10 |
| Independent Living | Valuing People 48 |
| sexual abuse 52–4 | Van Goth, Vincent 79, 81–2, 92 |
| identity disruption 52, 54, 57–9 | visual impairment 9, 34, 121–3 |
| power abuse/oppression 54–7 | |
| storytelling/emotional | 'Watershed' 12–13 |
| re-engagement 59–61 | Watson, James 26, 30 |
| sexuality 27, 58, 59 | Wiltshire and Swindon Users Network |
| in TV/film 35 | 177-8, 179, 180, 181, 182-3 |
| shamans 93 | WING 169 |
| sickle cell anaemia 26 | Woolf, Virginia 24 |
| Slattery, Tony 99 | Workhouse, The 84–5 |
| Gracioty, 10tty // | |