

Cambridge University Press

978-0-521-62569-2 - Deinstitutionalising Women: An Ethnographic Study of Institutional Closure

Kelley Johnson

Index

[More information](#)

Index

- AAMR *see* American Association on Mental Retardation
- absconding 54
- action research 9–10
- activities *see* Unit N
- adaptive skills 71, 159–60, 176
- admission *see* reasons for
- advocates 82, 86, 87, 177
- action 100, 109, 111, 121, 122–3, 162
 - and deinstitutionalisation 160, 162
 - and the last six months 136–7
 - citizen 85, 100, 136, 162
 - in CCOR process 110–11
 - public 58, 80, 100, 109
 - researcher 121, 128–9
 - women's relationships with 41
- affection between staff and women 42
- aggressive behaviour 38, 39, 40, 42, 48, 53–4, 64, 74, 88, 118, 119
- see also specific women*
- American Association on Mental Retardation (AAMR) 70, 71
- anti-institutionalisation 151, 153
- Asch, A. and Fine, M. 64
- attention-seeking behaviour 26, 39
- Beer, Patricia (poet) 45
- behaviour *see* challenging behaviour *or specific behaviours*
- Behaviour Intervention Support Team 76, 116, 130, 139
- behaviour modification strategies 76–7, 174
- Benn, C. 176–7
- Bettina (Junisov) xi, 28, 40, 50, 53, 55, 63, 67, 175
- community placement 109, 120, 122
 - convenor's views 115
 - parents 110
- Blunden, R. and Allen, D. 73
- Bogdan, R. 8, 10, 65, 72, 171
- Booth, T., Simons, K. and Booth, W. 150, 158
- Brigid (Anderson) x, 27, 71, 115, 176
- advocate's reaction to placement decision 123, 136
 - behaviour 4, 25–6, 29, 41, 57, 121, 172
 - behaviour modification 76
 - CCOR meeting 108–9
 - departure 135
 - General Service Plan 26
 - institutional placement 121, 122
 - management support during transition 143
 - medication 26
 - researcher advocacy 128, 129
 - researcher attitude to 29
 - staff attitude to 26–7, 31
 - story 24–7
- Brown, H. 65, 73, 158, 180
- Cain, M. 165
- Carney, T. 153–4
- CCOR *see* Client Consultation on Relocation
- challenging behaviour
- and attribution of dreams or desires 173
 - and deinstitutionalisation 147, 173–4, 179
 - and discourse 72–7
 - and expression of feelings 174–5
 - and gender 77
 - and placement 120–1
 - and psychiatric illness 54–5

- challenging behaviour *cont.*
 and underlying pain and despair 173
 behaviour modification strategies 76–7,
 173–4
 CCOR committee assessment 116–17
 critique of 75
 definition 73–4
 medication use for 26, 34, 76
 staff attitudes to 31, 57–8, 74–5
 variety of 26, 38–40, 57, 132–3, 179
 women's views of 75
see also specific behaviours, e.g. aggressive behaviour
- citizen advocates *see* advocates
- Client Consultation on Relocation 82,
 98–100, 156, 164, 175
 action advocates 100
 advocate participation 110–11
 and client's rights 152
 closure project team manager's role
 116–17
 committee, assessment of challenging
 behaviours 116–17
 constraints
 availability of services in the
 community 104–5
 staff availability 103–4
 staff involved 102–3
 time 102
 consultation process 108–10
 convenors' responsibilities 99–100,
 112–15
 family participation 105–7, 110–11, 161
 Kirsten's story 105–8
 researcher's role 128
 steps 99
 unit staff involvement 111–12
 women's experience of 105–10
see also matching
- client relocation team 82, 100, 101, 138,
 139
- clients 43
 community placement of 81
see also 'ladies'; women
- closure
 institution 2–3, 5–6, 79–83, 84
 and rights 151–3
 closure project team managers'
 responses 91–2
 costs of 163–4
 families' responses 181
 Hilltop Parents and Friends
 Association responses 89, 93–4
 management responses 90–1
 physical process of 130–1
 researcher response 94, 96
 union response 92–3, 95–6
 last six months of
 closure project team managers 141–3
 convenor anxieties 138–41
 families' and advocates' roles 136–7,
 160–2
 researcher/story teller 143–5
 staff concerns and anxieties 137–8
 Una's story 131–3
 women's coping with transition 133–6
 stages of 5–6, 81–3
 Unit N
 families' responses 88–9
 researcher banned by union from
 95–6
 staff responses 87–8, 89–90, 137–8
 women's responses 84–8
- closure decision 80–1
 and staff powerlessness 7
 industrial bans 6, 88, 92–3, 103
- closure project team 6, 103
 commitment to rights 152–3
 formation 82
- closure project team managers 5, 165, 182
 and CCOR 116–17
 and matching 127–8
 and the last six months 141–3
 concerns over women's sexuality 148
 interviews with 127
 lack of concern over day programmes
 147
 managing families and advocates 160–2
 researcher role 144
 views on closure 91–2
- cluster village, campaign for 93–4
- community living
 and improved quality of life 158
 and specialist services 159
 tests for 71, 159–60, 176
- community placement 81, 88
 family anxiety about 123
 monitoring reports on 141
 outcomes 122, 136
 Parents and Friends Association
 concerns over 94
 preferences 106, 109, 110, 111, 112, 120,
 122
 union concerns over 93
- convenors 99–100
 and CCOR 112–15
 and matching process 125–6, 139, 164
 anxieties about people leaving Hilltop
 138–41, 182
 concerns over institutional day services
 141, 147
 constraints 113–14

INDEX

211

- interviews with 112–15, 125
 monitoring reports 140, 141
 perception of their role 115
 view of families as advocates 164
 work with families 113, 114, 181–2
- daily routines *see* Unit N
- Dalley, G. 160, 162
- Danziger, K. 61, 69
- Daston, L. 67
- deinstitutionalisation 1, 3, 6–7, 8, 16, 21, 148, 186
 'administering the risk' 156
 and challenging behaviour 147, 173–4, 179
 and families 160–2, 181–2
 and furthering of institutional life 185
 and gender discourse 147
 and improved quality of life 158
 and management 155–64
 and objectification of women 178–9
 and rights 149–55
 and sexuality 147–8
 and the women 146–8, 165
 and women's feelings 174–5
 as philosophy 150
 at Hilltop, goals 151–3
 definition 148
 government commitment to 80
 normalisation 156–8
 transition stage 130–1
- Despouy, L. 151
- difficult behaviour *see* challenging behaviour
- discourse 14–16
 and challenging behaviour 72–7
 and subjectivity 14, 15–16
 gender 61–8, 77, 147, 155
 intellectual disability *see* intellectual disability discourse
 power/knowledge 68–77, 164–5, 169, 183–5
- Dora (Craig) x, 23, 28, 37, 41, 43, 56, 57, 63, 68, 88, 159, 175
 aggressive behaviour 48
 convenor's concerns 125
 coping with transition 135
 family contact 47
 institutional placement 110, 115, 121, 124, 134
 medication 48
 monitoring report 140
 parents' views 46–7, 48–9, 52, 111
 staff approach to 48
 staff concerns over matching decision 138
 story 45–9
- Doris (Smith) xii, 28, 56, 110, 111, 122
 hospitalisation 134–5
- Edgerton, R. B. 8, 158, 171
- Elaine (Stone) xii, 28, 34, 40, 51, 55, 64, 71, 90, 122, 134
 friendships 86, 120
 move into open unit 135
- Emerson, E. 73, 157
- Estroff, S. 8
- ethnography 10
- Fairclough, N. 15
- families
 and deinstitutionalisation 160–2, 181–2
 and institutionalisation 19, 46–7, 52, 61–2, 63, 69, 87, 179–80, 181
 and the last six months 136–7
 attitudes towards sexuality 63, 65
 CCOR visits 105–6, 108–9
 confusion about intellectual disability 46, 61
 confusion about their daughters 61–4
 interviews with 5, 45–52, 181
 involvement in CCOR process 105–7, 110–11
 responses to unit closure 88–9
 visits 48, 50, 51, 63, 132, 181
 women's relationships with 41
- Faye (Morris) xii, 27, 49, 63, 148
 convenor's concerns 140
 departure 135
 monitoring report 141
 placement 122, 123, 124, 134, 138
- feminist
 approach to research 12–13
 theory 11, 61–8
see also specific theorists
- Fine, M.
 and Gordon, S. M. 12, 13
see also Asch, A. and Fine, M.
- Foucault, Michel 14, 79, 155–6, 165, 179, 182, 183, 184, 185
- friendships 86, 87, 120, 175, 176
- gender discourse *see* discourse; sexuality
- General Service Plans (GSPs) 5, 26, 36, 57, 71, 93, 164, 179
- genital touching 25, 66
- gentle teaching 76
- Gilman, S. L. 1
- glossary 188–9
- Goffman, E. 19
- Gordon, S. M. *see* Fine, M. and Gordon, S. M.
- Guardianship and Administration Board 58

- guardianship order 50, 53, 56
- Harding, S. 12
- Henriques, J. 14
- Hilltop see institution
- Hilltop Parents and Friends Association
106, 162
response to closure 89, 93–4
- Hoeg, P. 182
- Hollway, W. 13, 14, 170
- Ilse (Lane) xi, 27, 40, 54, 86
move into open unit 87, 90, 135
placement 120, 122
'immorality' 50
independent living skills *see* adaptive skills
- Individual Programme Plans (IPPs) 36, 71, 76, 93
- industrial bans
convenor concerns 113
over closure decision 6, 88, 92–3, 103
staff disobey over CCOR involvement 111
staff polarisation over 89, 93, 153
- Inge (Roberts) xii, 28, 49, 63, 109, 114, 122, 148, 159
father's concerns 109, 111, 112
- institution 1, 2
closure *see* closure
financial costs 163–4
geography of 20
going into 3–4
history of 19–21
management 3, 57–8, 72, 162–4
response to closure 90–1
women's paths to 45–52
- institutional day services, lack of 141
- institutional placement
convenor's concerns 138–41
outcomes 122
preferences 110, 111, 120, 121–2
staff concerns 138
- institutionalisation
and families 19, 46–7, 52, 61–2, 63, 69, 87, 179–80, 181
and nursing care 180
as family's best option 69–70
of researcher 96
reasons for 20, 45–52
allegations of abuse 50
appeals against 58
'at moral risk' 54–5
birth of another child 50
death of a parent 51
Dora's story 45–9
increasing age of parents 50–1
problems with a difficult daughter 49–50
unknown causes 51
- intellectual disabilities 1
and expression of feelings 174–5
and individual histories 177–8
and lack of voice 13, 176–7, 184
and low IQs 20
and skill levels 147, 176
as discourse (legal, medical) 149
diagnosis and assessment 61, 69–71, 146–7
family views of 46
internal worlds of people with 171–4
researcher knowledge of 7–8
rights of people with 80, 149–51
stereotyped views 72
- intellectual disability discourse 69–72, 77–8, 186
functions 179–85
- Intellectual Disability Review Panel 58
Intellectually Disabled Persons' Services Act 1986 58, 80
- intelligence measurement 69, 70, 182
- interviews
with convenors 112–15, 125
with families 5, 45–52, 181
with managers and staff 5, 31–2, 127
with women 5
- IQ tests 171, 182
basis for assessment 70
validity of 69, 70
- Iris (James) x, 27, 40
hospitalisation 134
placement 122, 124, 143
- Jane (King) xi, 28, 31, 41, 42, 63, 68, 74, 77, 88, 111, 115
advocate's reaction to placement decision 123, 136
aggressive behaviour 118, 119
at industrial workshop 64, 119
CCOR meeting 109
convenor's concerns 126, 140
departure to hostel 134
family history 118–19
guardianship order 50, 53, 56, 119
management support during transition 143
matching experience 117–20
placement preference 112, 120, 122, 133
promiscuity 55, 66, 148
researcher advocacy 128, 129
sexual relationship 66, 68, 119
staff attitude to 119
story 117–20

INDEX

213

- Jodie (Ryan) xii, 27, 40, 51, 57, 68, 88
 accommodation preference 109, 110, 122
 advocate 111, 128, 136, 137
 coping with transition 133
 early departure from unit 134
 relationships 175
- Joyce (Thames) xiii, 23, 27, 38, 44, 55, 64,
 66, 68, 88, 148, 154
 departure 135
 institutional preference 110, 122
 staff concern over matching decision
 138
- June (Miles) xi–xii, 27, 38, 39, 41, 42, 48,
 51, 131
 accommodation preferences 109, 121–2
 closure project team managers'
 concerns 143
 convenor's concerns 140
- Kate (Surrey) xiii, 27, 40, 53, 57, 63, 67,
 109, 120, 122, 148, 175
 mother's concerns 111, 112, 123
- Kirsten (Jones) xi, 27, 29, 33, 38, 41, 51,
 54–5, 57, 66, 140
 CCOR meeting 105–8
 community living preferences 106, 122,
 123
 family history 107, 108
 meeting with mother 105–7
 parents' responsibility 61–2, 111
 sexually at risk 54–5, 66, 108
 staff views of 107–8
 story 105–8
- knitting 37, 39
- knowing the women
 challenging behaviour 72–7
 intellectual disability 69–72
- knowledge/power discourse *see*
 power/knowledge discourse
- 'ladies' 43
 staff attitudes to 32, 37, 68
see also clients; women
- last six months *see* closure
- Laura (Mitchell) xii, 28, 55, 64, 109, 115,
 121, 122, 128, 141
- Lena (Johnson) x–xi, 27, 35, 37, 39, 41,
 44, 64, 68, 71, 110, 175
 aggressive behaviour 54, 64
 community placement 121, 122, 123, 125
 convenor's concerns 126
 coping with placement 141
 coping with transition 136
 family appeals matching decision 136
 guardianship order 56
 researcher advocacy 129
- Levi, Primo (poet) 130
- locked unit 1, 2, 48
 legality of 58
see also Unit N
- Lonsdale Lodge 46–8, 111
- Lyth, I. Menzies 11–12, 179–80
- management
 and deinstitutionalisation 155–64
 closure team *see* closure project team
 managers
 institutional 3, 57–8, 72, 162–4
 of the women 155–6
 relocating the women 158–60
 Unit N 30, 31, 90, 111–12
- matching 82, 100–2, 156
 advocates' responses to placement
 decisions 122–3
 appeal against decisions 136, 152
 client preferences 100–1, 104, 120
 closure project team managers'
 concerns 127–8
- constraints
 availability of services in the
 community 104–5
 competition for scarce community
 places 104
 staff availability 103–4
 staff involved in 103
 time 102
- convenors' role 125–6
- decision-making panels 101–2, 103
- establishing preferences 108–10
- families' reactions to placement
 decisions 122–3, 136, 152
- Jane's story 117–20
- placement decisions 122, 134, 136
- preference criteria 101
- researcher/advocate role in 128–9
- unit staff role in 123–5
- women's experiences of 117–22
- medication
 and challenging behaviour 26, 34, 76
- Largactil 34, 54, 56, 76
- list of 189
- lithium 86
- management of 34, 35
- Melleril 26, 34, 48, 54, 76, 133
- Modecate 26, 48, 56, 133
- Neulactil 34
- side effects 76
- Stelazine 26, 48, 56
- Valium 34
- mental retardation, definition 70
- monitoring reports 140, 141
- Morris, J. 162

- normalisation 156–8, 178
 and rights 158, 185
 definition 157
 nursing care 180
- Oakley, A. 11
 observation, participant 4, 10, 69
 occupational therapy 34, 47
 Office of the Public Advocate 58, 80, 100, 109, 115
- parents *see* families
 Parents and Friends Association *see* Hilltop
 Parents and Friends Association
- placement *see* community placement;
 institutional placement
- possessive individualism 160
- power/knowledge discourse 68–77, 169, 183–5
 and Hilltop closure 164–5, 184
- powerlessness *see* women
- preferences *see* matching
- professional regard, legitimisation of 182–5
- psychiatric illness 54–5
 psychoanalysis 11–12
 psychotherapeutic methods 76
- qualitative research 8–9
 quality of life 21, 153, 154, 158
- Ramazanoglu, C. 14, 15, 184
 Rapoport, R. N. 9
- reasons for admission
 to Hilltop 45–52
 to Unit N 53–8
 researcher investigation of 58–9
- reflexivity, rationale for 10–11
- regional liaison team 130, 138, 139
- relationships 175–6
 between women living in the unit 40–1, 175
 of women with people outside the institution 41
 of women with staff 42–3, 176, 180–1
- relocating the women
 and rights 158–60
 appeals concerning 136, 152
- research
 feminist approach 12–13
 methodology 3–7
- researcher
 advocacy 121
 as author 16–17
 as participant 43–4
 in management process 144
- attitude to women 68
 banned by union from unit 95–6
 contact with women after closure 143–4
 conversations with the women 43, 44
 feelings about closure 145
 investigates women's admission 58–9
 last six months 143–5
 observation 4, 10, 69
 positions of 7–16
 reaction to closure 94, 96
 reinstatement after unit staff lobbying 96
 relationship with staff and managers 42–3, 97, 144
 relationship with women 143
 staff attitudes to 2, 3
 Unit N activities 4–5
see also interviews
- Rhonda (Lee) xi, 27, 43, 50, 65
 family secures her release 58
 move into community 88, 90
- Rich, Adrienne 22, 169
- rights 80
 and closure of Hilltop 151–3
 and deinstitutionalisation 149–51, 154
 and gender issues 155
 and normalisation 158, 185
 and relocating the women 158–60
 competition across groups 154
 critique of 153–5
 relationships and quality of life 153, 154
- Rilke, Rainer Maria (poet) 19, 98
- Rosalind (Maitland) xi, 27–8, 40, 50, 56, 122
- Rose, N. 9, 10, 15, 20, 61, 65, 69, 149, 156
- Said, Edward 167
- screaming 23, 38, 55, 57, 107, 108, 121, 133
- self-injury 56–7
- sexual abuse 30, 39, 41, 50, 55, 65, 66, 77, 148
- sexual counselling 66
- sexual expression 66
- sexual preference 184
- sexual relationships 66–7
- sexual vulnerability 55, 67, 108, 111, 148
- sexuality
 and subjectivity 64–7, 147–8
 and women 30, 54–5, 57
 families' attitudes towards 63, 65
 management 65–6
 staff attitudes towards 65, 66, 67
- Sinason, V. 8, 11, 63–4, 76, 171, 172, 173
- smashing windows/furniture 48, 55, 57
- Soderquist, T. 183
- Spelman, E. V. 61

- staff
- and group programme 35–6, 71–2
 - and the last six months 137–8
 - assessment of women 71
 - caring behaviours 68
 - concerns over placement decisions 124–5, 138
 - control over women 43
 - duties 32–3
 - frustration with women's behaviour 31
 - in Unit N 2, 4, 30–3, 74, 137
 - interviews with 5, 31–2
 - lack of knowledge about women's history 63
 - lobby for researcher's reinstatement 96
 - polarisation over industrial action 89, 93, 153
 - qualifications 32
 - redundancy packages/redeployment opportunities 81, 82
 - relationships with women 42–3, 176, 180–1
 - response to unit closure 87–8, 89–90
 - role in CCOR process 111–12, 176
 - role in matching process 123–5
 - shocked at ban on researcher 95
- staff attitudes
- and matching 121
 - to challenging behaviour 31, 57–8, 74–5
 - to researcher 2, 3, 96
 - to sexuality 65, 66
 - to women 4, 26–7, 31, 32, 42, 67–8
- Steier, F. 11
- study, the
- assumptions 9
 - ethnography 10
 - goal 8
 - rationale for 1–3
- subjectivity 13, 14
- and discourse 14, 15–16
 - and sexuality 64–7, 147–8
 - and the women 13–14, 64–7, 146–8, 169, 170
 - definition 14
 - loss of 170
 - management 146–65
 - problematic nature of 14
- Taylor, S. J. 8, 9, 72, 158, 171
- theory development from research experience 10
- Thomas, R. S. 146, 187
- 'time out' 76
- transinstitutionalisation 93, 94, 153
- transition, coping with 131, 133–6, 145
- Traustadottir, R. 52, 159
- Una (Harris) x, 27, 32, 57
- challenging behaviour 40, 57, 132–3
 - community placement 115, 122, 123, 131, 133
 - family advocacy 131
 - family assistance in settling in 137
 - family history 50–1, 131–2
 - family visits 132
 - medication 133
 - staff responses to 133
 - story 131–3
- union
- bans researcher from unit 95–6
 - concern over staff job losses 92
 - reaction to closure 88, 89, 90, 92–3
 - staff disobey bans in CCOR process 111
 - see also* industrial bans
- Unit N
- activities 37–40, 44
 - as punishment 58
 - bath times 34
 - bed time 35
 - closure
 - families' responses 88–9
 - staff responses 89–90, 137, 138
 - women's responses 84–8
 - daily routines 33–5
 - families' views of 48–9, 53
 - formal life of 4–5, 33–7
 - geography 22–3
 - group programme 35–6, 71–2
 - informal life in 37–43
 - meal times 33–4, 35
 - music in 37
 - noise in 23–4
 - physical closure 134, 145
 - reasons for admission 45–59
 - absconding 54
 - administrative 56
 - aggressive behaviour 53–4
 - 'at moral risk' 54–5
 - diagnosed psychiatric illness 55–6
 - guardianship order 56
 - screaming or making noise 55
 - self-injury 56–7
 - smashing windows/furniture 55
 - recording life in 37
 - relationships
 - between women living in 40–1, 175
 - with family or advocates 41
 - with staff 42–3
 - researcher activities in 4–5, 58–9
 - smell in 24
 - snapshot 27–30
 - staff in 2, 4, 30–2, 74, 111–12, 123–5
 - teeth cleaning in 34, 35

- Unit N *cont.*
 television 28, 37, 47
 toileting in 34, 35
 women living in 2, 24–30
 women's path to 53–8
see also specific women
- United Nations
 Declarations on the Rights of Disabled Persons 150
 Declaration on the Rights of Mentally Retarded Persons 151
- Vera (Waters) xiii, 27, 40, 64, 71
 aggressive behaviour 87
 family history 85–6
 friendships 86, 87, 120, 175
 'going home' 85, 86–7, 88
 move into open unit 87, 90, 135
 placement 120, 122
 psychiatric diagnosis 55–6, 85–6
 researcher advocacy 129
 story 85–7
 violence 4, 25, 35, 39, 40, 41, 42, 74
- walks 35, 47
 Weedon, C. 13, 15, 170
 Willer, B. and Intagliata, J. 80, 148, 150
 Wolfensberger, W. 19, 21, 70, 72, 149, 150, 157
- women, the 16–17
 activities 37–40
 and deinstitutionalisation 146–8, 165, 172–3
 as 'failed' daughters and sisters 61–4
 as 'failed women' 61–8
 behaviouristic view 172–3
 caring behaviours 68
 communication problems 28–9, 44
 contact with/feelings towards men 66, 68
 employment 64
 establishing preferences 108–10
 experiences of CCOR 105–10
 experiences of matching 117–22
 expression of feelings 174–5
 family ambivalence towards 173
 fantasies, dreams and desires 171–4
 home visits 64
 independence 34
 interviews with 5
 lack of voice 13, 176–7, 184
 last six months 131–6
 living environment 178–9
 objectification of 165, 170–9
 placement outcomes 122, 134
 powerlessness 176–7
 relationships 175–6
 between women living in the unit 40–1, 175
 with people outside the institution 41
 with staff 42–3, 176, 180–1
 reluctance to leave Unit N 134
 responses to unit closure 84–8
 skills 71, 87, 176–7
 views on challenging behaviour 75
see also specific women
- Woolf, Virginia 60