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978-1-107-02991-0 - Active Citizenship and Disability: Implementing the Personalisation of Support

Andrew Power, Janet E. Lord and Allison S. DeFranco

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ACTIVE CITIZENSHIP AND DISABILITY

This book provides an international comparative study of the implementation of disability rights law and policy focussed on the emerging principles of self-determination and personalisation. It explores how these principles have been enshrined in the United Nations Convention on the Rights of Persons with Disabilities and how different jurisdictions have implemented them to enable meaningful engagement and participation by persons with disabilities in society. The philosophy of ‘active citizenship’ underpinning the Convention – that all citizens should (be able to) actively participate in the community – provides the core focal point of this book, which grounds its analysis in exploring how this goal has been imagined and implemented across a range of countries. The case studies examine how different jurisdictions have reformed disability law and policy and reconfigured how support is administered and funded to ensure maximum choice and independence are accorded to people with disabilities.

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Cambridge Disability Law and Policy Series

The Cambridge Disability Law and Policy series examines these topics in interdisciplinary and comparative terms. The books in the series reflect the diversity of definitions, causes and consequences of discrimination against persons with disabilities while illuminating fundamental themes that unite countries in their pursuit of human rights laws and policies to improve the social and economic status of persons with disabilities. The series contains historical, contemporary and comparative scholarship crucial to identifying individual, organizational, cultural, attitudinal and legal themes necessary for the advancement of disability law and policy.

The book topics covered in the series also are reflective of the new moral and political commitment by countries throughout the world towards equal opportunity for persons with disabilities in such areas as employment, housing, transportation, rehabilitation and individual human rights. The series will thus play a significant role in informing policy makers, researchers and citizens of issues central to disability rights and disability antidiscrimination policies. The series grounds the future of disability law and policy as a vehicle for ensuring that those living with disabilities participate as equal citizens of the world.

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Andrew Power, Janet E. Lord, and Allison S. deFranco, *Active Citizenship and Disability: Implementing the Personalisation of Support*, 2013

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Active Citizenship and Disability

IMPLEMENTING THE PERSONALISATION OF SUPPORT

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Abbreviations

AAH	Allocation aux Adultes Handicapés (Disabled Adult Allowance) (France)
ACCD	American Coalition of Citizens with Disabilities
ACTP	L'allocation Compensatrice de Tierce Personne (Carer's Compensation Allowance) (France)
AEEH	Allocation d'Education Enfant Handicapé (Education Allowance for Disabled Children) (France)
AES	Allocation d'Education Spéciale (Special Education Allowance) (France)
AFM	Association Française contre les Myopathies (French Muscular Dystrophy Association) (France)
AGEFIPH	L'Association de gestion du fonds pour l'insertion des personnes handicapées (Association for Managing Resources for the Inclusion of Persons with Disabilities) (France)
ANPE	Agence Nationale Pour l'Emploi (National Agency for Employment) (France)
ANPIHM	Association Nationale pour l'Intégration des Handicapés Moteurs (National Association for the Integration of People with Mobility Impairment) (France)
ANSEM	Agence National de l'évaluation et de la Qualité des Etablissements Et Services Sociaux Et Medico-Socio (National Agency for Quality Assessment of Social and Healthcare Services) (France)
AoA	Administration on Aging (United States)
APA	Allocation Personnalisée d'Autonomie (Personal Independence Allowance) (France)
APAJH	L'association pour Adultes et Jeunes Handicapés (Association for Disabled Adults and Young People) (France)

APF	Association des Paralysés de France (French Association for Paralyzed People) (France)
APL	Aide Personnalisée au Logement (Personal Rent Subsidy) (France)
ASPE	Assistant Secretary for Planning and Evaluation (United States)
BACI	Burnaby Association for Community Inclusion (Canada)
BC	British Columbia
BCOD	Base Mensuelle de calcul des Allocations Familiales (Basic Monthly Payment for the Calculation of Family Allowance) (France)
BCOPD	British Council of Organisations of Disabled People
CA	Carer's Allowance (Ireland)
CAF	Caisse d'Allocation Familiale (Family Allowance Fund) (France)
CAMPS	Centre d'Action Médico-Sociale Précoce (Early Years Health and Social Care Centre) (France)
C&AG	Comptroller and Auditor General (Ireland)
C&C	Cash & Counseling (United States)
CCDE	Cash & Counseling Demonstration and Evaluation (United States)
CCDSA	Commission Consultative Départementale de Sécurité et d'Accessibilité (Local Advisory Commission for Civil Protection, Safety and Accessibility) (France)
CDAPH	Commission des Droits et de l'Autonomie des Personnes Handicapées (Commission for the Independence and Rights of Persons with Disabilities) (France)
CDC	Consumer Directed Care (United States)
CDES	Commission Départementale d'Éducation Spéciale (Local Commission for Special Education) (France)
CES	Community Employment Scheme (Ireland)
CFC	Community First Choice (United States)
CHST	Canada Health and Social Transfer
CIB	Citizens Information Board (Ireland)
CIC	Citizen Information Centres (Ireland)
CID	Roman Catholic Institution for the Deaf and Dumb (renamed Catholic Institute for Deaf People in 2007)
CIL	Centre for Independent Living
CLN	Community Living Network
CLS	Community Living Services (United States)
CMP	Centre Medico Psychologique (Healthcare and Psychotherapy Centre) (France)
CMPP	Centre Medico-Psychopédagogique (Psychotherapeutic Education Centre) (France)
CMS	Centers for Medicare and Medicaid (United States)
CMU	Couverture Maladie Universelle (Universal Health Care Coverage) (France)

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CNAM	Commission Nationale d'Assurance-Maladie (National Commission of Health Insurance) (France)
CNAVTS	Caisse Nationale d'Assurance Vieillesse des Travailleurs Salariés (National Old-Age Pension Fund for Employees) (France)
CNCPH	Le Conseil National Consultatif des Personnes Handicapées (National Consultative Council for Persons with Disabilities) (France)
CNSA	Caisse National de Solidarité et d'Autonomie (National Fund for Solidarity and Independence) (France)
COTOREP	Commission Technique d'Orientation et de Reclassement Professionnel (Professional Commission for Occupational Enablement and Rehabilitation) (France)
CRC	Central Remedial Clinic (Ireland)
CRPD	The United Nations Convention on the Rights of Persons with Disabilities
CSCI	Commission for Social Care Inspection (United Kingdom)
CSG	Contribution Sociale Généralisée (The General Social Contribution) (France)
CSIL	Choices in Supports for Independent Living (Canada)
CST	Canadian Social Transfer
CTF	Child Trust Fund (United Kingdom)
CWO	Community Welfare Officer (Ireland)
DDASS	Direction Départementale des Affaires Sanitaires et Sociales (Local Directorate for Health and Social Affairs) (France)
DDTEFP	Direction Departemental du Travail Et de la Formation Professionnelle (Local Directorate for Employment and Professional Development) (France)
DFI	Disability Federation of Ireland
DHHS	Department of Health and Human Services (United States)
DLA	Disability Living Allowance (United Kingdom)
DLCG	Disability Legislation Consultation Group (Ireland)
DO	Discrimination Ombudsman (Sweden)
DPOs	Disabled Persons Organisations
DRA	Deficit Reduction Act 2005 (United States)
DWP	Department of Work and Pensions (United Kingdom)
EC	European Commission
EPSEN	Education for Persons with Special Educational Needs (Ireland)
ERHA	Eastern Regional Health Authority (Ireland)
ESA	Employment and Support Allowance (United Kingdom)
ESAT	Etablissement et Service d'Aide par le Travail (France)
ESF	European Social Fund
EU	European Union

FAM	Foyers d’Accueil Médicalisés (Residential Medical Unit) (France)
FÁS	Foras Aiseanna Saothair (Training and Employment Authority) (Ireland)
FDC	Fond Départementaux de Compensation (Local Compensation Fund) (France)
FEDESAP	Federation National des Services à la Personne et de Proximité (National Federation of Local Individualized Services) (France)
FI	Fiscal Intermediary
FIPHP	Fonds pour l’Insertion des Personnes Handicapées dans la Fonction Publique (Fund to Support Persons with Disabilities into Public Roles) (France)
FMAD	Fonds de Modernisation de l’Aide à Domicile (Fund for the Modernisation of Homecare Services) (France)
FMR	Fair Market Rent
FNATH	Fédération Nationale des Accidentés du Travail et des Handicapés (National Federation of Injured and Disabled Workers) (France)
GDP	Gross Domestic Product
GEM	Groupe d’Entraide Mutuelle (Peer Support Group) (France)
GIP	Groupement d’Intérêt Public (Public Interest Group) (France)
GNP	Gross National Income (expressed in purchasing power parity)
GPEC	Gestion Prévisionnelle des Emplois et des Compétences (Forward Management for Workforce and Skills) (France)
HALDE	Haute autorité de lutte contre les discriminations et pour l’égalité (High Authority Against Discrimination and in Favour of Equality) (France)
HCA	Homes and Communities Agency (United Kingdom)
HCBS	Home- and Community-Based Care
HeBE	Health Board Executive (Ireland)
HO	Disability Ombudsman (Sweden)
HSE	Health Service Executive (Ireland)
HUD	Department of Housing and Urban Development (United States)
IAN	Irish Advocacy Network (Ireland)
IASE	Irish Association of Supported Employment (Ireland)
IBA	Individual Budget Allocation
IBSEN	Individual Budgets Evaluation Network
IC	Independent Consultant
ICA	Irish Countrywomen’s Association (Ireland)
ICF	International Classification of Functioning, Disability and Health
ICFs/MR	Intermediate Care Facilities for Persons with Mental Retardation
ICTU	Irish Congress of Trade Unions (Ireland)
IDS	Irish Deaf Society (Ireland)

IEM	Institut d'Education Motrice (Mobility Rehabilitation Service) (France)
IES	Institut d'Education Sensorielle (Sensory Rehabilitation Service) (France)
IHSS	In-Home Supportive Services (California)
IME	Institut Médico-Educatif (Health and Education Service) (France)
IMPRO	Institut Medico-Professionnel (Health and Vocational Service) (France)
INMO	Irish Nurses and Midwives Organisation
INO	Irish Nurses Organisation
INSEE	Institut National de la Statistique et des Études Économiques (French National Institute for Statistics and Economic Studies) (France)
IRIS	Include, Respect, I Self-Direct (United States)
ISL	Irish Sign Language (Ireland)
IWA	Irish Wheelchair Association (Ireland)
LOV	Choice Act (Sweden)
LPPR	Liste des Produits et Prestations Remboursables (List of Refundable Products and Services) (France)
MAJ	Meusure d'Accompagnement Judiciaire (Judicial Assistance Measure) (France)
MAPA	Maison d'Accueil pour Personne Agées (Residential Unit for Older People) (France)
MARPA	Maison d'Accueil Rurale pour Personne Agées (Rural Residential Unit for Older People) (France)
MAS	Maison d'Accueil Spécialisée (Specialist Residential Unit) (France)
MCCI	Modelling Community Change and Innovation (Canada)
MCFD	Minister of Child and Family Development (Canada)
MCO	Managed Care Organization (United States)
MDPH	Maison Départemental des Personnes Handicapée (Local Agency for Persons with Disabilities) (France)
MFP	Money Follows the Person Grant (United States)
MHC	Mental Health Commission (Ireland)
MSRB	Medico Social Research Board (Ireland)
MSWFP	Making Services Work for People (Canada)
MTP	Majoration pour Tierce Personne (Carer's Allowance) (France)
MVPA	Majoration Pour la Vie Autonome (Additional Allowance for an Independent Life) (France)
NAD	National Association for the Deaf (renamed DeafHear) (Ireland)
NAMHI	National Association for the Mentally Handicapped of Ireland (renamed Inclusion Ireland in 2007)
NCI	National Core Indicators (United States)

NCSE	National Council for Special Education (Ireland)
NDA	National Disability Authority (Ireland)
NDP	National Development Plan (Ireland)
NESC	National Economic and Social Council (Ireland)
NESF	National Economic and Social Forum (Ireland)
NGO	Non-governmental organisation
NHIS	National Health Insurance Society (Ireland)
NHS	National Health Service (United Kingdom)
NI	Northern Ireland
NPIRS	National Psychiatric In-Patient Reporting System (Ireland)
NPM	New Public Management
NRB	National Rehabilitation Board (Ireland)
ODI	Office for Disability Issues (United Kingdom)
ODSP	Ontario Disability Support Program (Canada)
OECD	Organisation for Economic Co-operation and Development (Ireland)
OHM	Office for Health Management (Ireland)
OIC	Order-In-Council
OIG	Office of Inspector General (United States)
PA	Personal Assistant (Ireland)
PAA	Projet d’Accueil et d’Accompagnement (Care and Support Project) (France)
PAS	Personal Advocacy Service (Ireland)
PCH	Prestation de Compensation du Handicap (Disability Compensation Allowance) (France)
PDs	Progressive Democrats (Ireland)
PNA	Psychiatric Nurses Association (Ireland)
POA	Power of Attorney
PPC	Plan Personnalisé de Compensation (Personal Compensation Plan) (France)
PPS	Plan Personnalisé de Scolarisation (Personal Education Plan) (France)
PRSI	Pay-Related Social Insurance (Ireland)
PTC	Provincial/Territorial Council (Canada)
PwDI	People with Disabilities Ireland
RA	Representation Agreement (Canada)
RAF	Royal Air Force (United Kingdom)
RFP	Request for Proposals
RNID	Royal National Institute for Deaf People (United Kingdom)
RQIA	Regulation and Quality Improvement Authority (United Kingdom)
RRF	Retirement Research Foundation (United States)
RSMH	Swedish National Association for Social and Mental Health

RWJF	Robert Wood Johnson Foundation (United States)
SAAD	Service D'aide et d'Accompagnement a Domicile (Home Assistance and Support Service) (France)
SALAR	Swedish Association of Local Authorities and Regions
SAMSAH	Service d'Accompagnement Medico-Social pour Adulte Handicapé (Health and Social Care Support Service for Disabled Adults) (France)
SAVS	Service d'Accompagnement à la Vie Sociale (Social Life Support Service) (France)
SESSAD	Service d'Éducation Spéciale et de Soins A Domicile (Education and Health Care Services at Home) (France)
SGA	Substantial Gainful Activity (United States)
SMA	State Medicaid Agency (United States)
SPASAD	Service Polyvalant d'Aide et de Soins à Domicile (Multipurpose Assistance and Care Home Service) (France)
SSA	Social Security Administration (United States)
SSAH	Special Services at Home (Canada)
SSDI	Social Security Disability Insurance (United States)
SSI	Supplemental Security Income (United States)
SSIAD	Services de Soins Infirmier a Domicile (Home Nursing Care Service) (France)
SSLU	Support Service Living Unit (Canada)
TB	Tuberculosis
TD	Teachta Daila (member of Dail Eireann, the lower house of the Oireachtas (Irish Parliament))
UCD	University College Dublin (Ireland)
UEROS	d'Evaluation de Réentraînement et d'Orientation Sociale et Professionnelle (Unit for Assessment and Social and Professional Rehabilitation) (France)
UK	United Kingdom
UN	United Nations
UNA	Union Nationale de l'Aide, des soins et des services aux domiciles (National Union of Assistance, Nursing Care and Homecare Services) (France)
UNAPEI	Union nationale des associations de parents, de personnes handicapées mentales et de leurs amis (National Union of Parents, People with Learning Disabilities and Their Friends) (France)
UPIAS	Union of the Physically Impaired Against Segregation (United Kingdom)
US	United States (of America)
VA	Department of Veterans Affairs (United States)
VAT	Value Added Tax

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VFM	Value for Money Review (Ireland)
VMRG	Value for Money Review Group
VPN	Valuing People Now
VR	Vocational Rehabilitation
VTs	Visiting Teacher Service
WHO	World Health Organisation
WPG	Woodlands Parents Group (Canada)