Disabled Children

Edited by Anne Borsay and Pamela Dale

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DISABLED CHILDREN: CONTESTED CARING,
1850–1979
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DISABLED CHILDREN: CONTESTED CARING, 1850–1979

EDITED BY

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INTRODUCTION: 
DISABLED CHILDREN – CONTESTED CARING

Anne Borsay and Pamela Dale

The essays in this volume span many countries and different time periods, but they are united by a common set of approaches to childhood disability. These stem from seeing experiences as the outcome of personal circumstances and social structures, and offer an experiential critique of the dominant ‘social model’ originating in disability studies and developed within materialist histories of disability. The ‘social model’ tends to emphasize ‘disabling’ factors contributing to the exclusion of disabled people from the mainstream of society and contrasts with ‘individual models of disability’ that rely on notions of personal impairment. The intention of this volume is to develop a sense of contested caring. Rather than concentrate on the role of institutional factors contributing to disability the focus is on exploring how they shaped experiences of childhood disability in a variety of complex, unpredictable and sometimes contradictory ways. The book explores the varied, but distinctive, experiences of disabled children through their interaction with a range of specialist educational (Chapters 4 and 11) and medical services (Chapters 1, 2, 5, and 7–10). Provision for disabled children initially evolved in an institutional context (see Chapters 1–5, 7 and 9) and such segregated care often involved lengthy separations from families and communities. Over time the reach of these services was extended, and care was offered in new ways. Specialist provision could still be offered in residential institutions, but day-services were also important and the home, the school and the clinic became centres for diagnosing and treating various disabling conditions (Chapters 3, 6, 8 and 10–12). The imperative to provide such care meant that countries (and regions within them) that developed children’s services could present themselves as modern and progressive (Chapter 9), while ‘slow adopters’ had to excuse and overcome their own ‘backwardness’ (Chapter 3). Most important for this volume, whether ‘modern’ or ‘backward’, these varied and changing
institutional contexts helped to shape the often complicated experiences of disabled children.

This is not the first history of disability to explore the kinship and community support networks available to groups of people with special needs in different places at various times, or to combine such analysis with an assessment of the emergence of specialist provision. Nor is it the first to highlight the shared experiences of disabled people (across time and space) or to connect historical study with the identity politics associated with the modern disability rights movement. On the contrary, a growing historiography has highlighted the role of class, gender, race, type and severity of any disability as important determinants of a disabled person’s life chances and experiences of care. What differentiates this volume is its focus on childhood. The book starts from the premise that the experiences of disabled children, now and in the past, are fundamentally different from those of disabled adults. It is further argued that the distinctive voice of the disabled child has been silenced by both the historical marginalization of disabled people and the focus of the disability rights movement on adult priorities. We argue that the social model is especially relevant to the experiences of adults of working age living with a physical or sensory disability. This helps explain why historical studies of disability issues have tended to overlook childhood experiences.

The voices and experiences of disabled children have been buried within the historical record, but they can be recovered by paying attention to what was distinctive about the services offered to disabled children and their families. This volume seeks to highlight why children were singled out by pioneering service providers, and how these organizations and facilities shaped experiences of childhood disability. It foregrounds the role of the state and a particular conceptualization of the respective roles of families and experts in raising the citizens of the future. A series of nineteenth- and twentieth-century reforms, in many western countries, tended to reconfigure the relationship between children and parents and between the family and the state. Children received additional protections, and greater investment, but this was accompanied by increasing surveillance over their development. As restrictions on child labour made children economically worthless, parents were encouraged to see their offspring as emotionally priceless in ways that complicated responses to childhood disability. There were an increasing number of experts available to encourage and even coerce families into engaging with officially approved health and education services. The very operation of such services, and their bureaucratic and professionally determined boundaries, helped forge the identities – and shaped the experiences – of disabled children.

Scholars from many disciplines have developed important insights into the historical experiences of disabled children, aided by a growing commitment
to inclusive participant research. Yet, paradoxically, the involvement of adult activists, and the promotion of the social model, tends to divert historical attention elsewhere for two main reasons. Firstly, although concern about the health of children, and the development of specialist medical and other care for sick and disabled children, is evident over many centuries, the only really distinctive historiography concentrates on the development of special schools. It is the evaluation of this limited provision that has tended to marginalize the historical experiences of disabled children. This volume redresses this imbalance by exploring a wider range of institutional contexts for care while also building on insights from histories of the special schools where these adopt the conceptualization of sick and disabled children as children in need. This was an important spur to voluntary and statutory assistance. Yet hand-in-hand with an impulse to care often went a desire to control. Interest in the care/control paradox unites many strands of the historiography but reveals more about the intentions of service-providers than client responses. The purpose of this volume is to identify the shared experiences of disabled children, to distinguish them from those of both non-disabled children and disabled adults, and to examine the debates through which their care and control were contested.

The second reason for overlooking disabled children is a tendency, within the social model, for the promotion of independence to inadvertently foster the historical neglect of groups reliant on support services managed by third parties. Jan Walmsley has raised this concern in relation to provision for adults with learning disabilities, but disabled children are also vulnerable. The marginalization of the history of disabled children, which struggles to escape the care/control paradox, is not easily corrected with reference to the social model. Therefore, while many have found it theoretically robust, and personally and professionally empowering, the promotion of the social model, unaligned with a careful appreciation of the historical development of children’s services, may be unhelpful in shaping current and future provision.

The Social Model and Services for Disabled Children

This volume argues that one of the ways to overcome the limitations of the social model is to recognize that the delivery of children’s services, now and in the past, is complicated by factors that are perhaps less relevant to the experiences of disabled adults. Compared to the oft-mentioned neglect of the elderly and chronic sick (viewed as economically unproductive), children were historically targeted for interventions that were meant to promote their independence. Thus a child with a hearing or visual impairment unremarkable in an older person was increasingly classified as having special needs and brought within the ambit of targeted medical and educational provision. Disabled children, now and in the past, therefore
arguably had to navigate their way through a larger array of services than disabled adults. This journey was complicated by other issues. A variety of experts historically claimed jurisdiction over the disabled child. This inevitably created conflict over the best methods of care and questions about accessing and financing this. Care was contested within as well as between groups offering health and education services. There was also potential for conflict between service providers and service users, since the child’s right to either have or refuse medical treatment/specialist educational services was contingent upon a number of factors that changed over time. An important determinant of the care historically offered to disabled children was the triangular relationship between service-providers, their parents and themselves. Each was fraught with difficulties, resulting in conflicts that shaped the experiences of many disabled children.

Modern public policy documents rightly stress that service users are *The Same as You,* but historically specialist provision for disabled children was shaped by notions of difference. Research also suggests that parents tended to parent their disabled children differently. For example, parents are typically very boisterous when handling blind infants apparently with the hope of eliciting the anticipated welcoming smile spontaneously given by sighted babies. These emotionally charged experiences now, and particularly in the past, are not easily captured by the social model. There are two further departures from the social model that need to be considered when evaluating the historic experiences of disabled children. Both relate to the dependence of the child on carers (usually adults who do not define themselves as living with a disability) who may be isolated from (and even rejecting of) groups representing the rights of disabled people. Parents (and other carers) may prefer to stress the individuality of their child and/or the common humanity of all children rather than a distinct and separate identity that celebrates difference. Disabled children (or more realistically carers making decisions for them in early life) are also likely to either seek or be forced to accept a medical model of care (especially during the initial diagnosis and stabilization phase) that still focuses on individual pathology and the disabled body/mind rather than social barriers to inclusion.

While professionals can downplay the historic difficulties of inclusion, parents were and are often acutely conscious of problems with other children at home and at school. Changing expert opinion has also been problematic. Parents have been especially worried about their mid-twentieth-century designation by experts as a ‘disabled family,’ and have also explicitly rejected scientific work that had identified ‘the neurotic or rejecting mother’ behind every atypical child. These concerns, and an explicit need to protect others, introduce a certain negativity into (auto)biographical work that otherwise celebrates either the personal achievements of a person living with a disability or the dedication of their carers. In one of the first parent-authored books about raising an autistic
Introduction

child in the USA, Clara Claiborne Park mentions the interactions between E and her siblings but more attention is given to the way the other children were protected from any negative consequences stemming from either E’s behaviour or the parents’ understandable preoccupation with E’s care. A similar set of issues appear in contributions from British parents. Interestingly recent work tends to echo much earlier books, although the role/attitudes of professionals and the availability of paid domestic help does show significant periodicity.

Each of the books written by parents tells the unique history of their family and its response to raising a disabled child but many common themes emerge. Yet, it is difficult to avoid the conclusion that it is the more affluent and articulate parents who have historically found opportunities to record their experiences. In the same way organizations seeking to elicit donations and/or state support traditionally published the life-stories of their most successful former clients with little regard to their true representativeness. A not-untypical example appears in Chapter 7 where Staffan Förhammar and Marie Nelson discuss the much-publicized case of Petter Bernhard Savela who overcame poverty, illegitimacy, abuse and ill-health with the assistance of the Apelviken institution before making his fortune in real estate. This type of selection, providing at best a snapshot of events, tends to further isolate the child receiving care from their wider family environment. Yet services designed to prevent, identify and even treat various disabling conditions in the home have been amongst the most maligned in contemporary and historical accounts. The health-visiting activities described by Pamela Dale (Chapter 8) were clearly often viewed as intrusive by families and also, significantly, failed to attract support from sections of the medical community.

The health visiting profession is often described as an uncertain one, but doubts about the care (and control) needs of disabled children infused the responses of state agencies, philanthropists, citizens and parents across the whole period covered by this volume. Indeed the proliferation of services, and fears that other countries were doing more and progressing further in developing their human resources, was as much a feature of Cold War politics as the earlier, and better known, boost twentieth-century conflicts gave to health and welfare reform. Even where the immediate physical needs of disabled children were apparently met there was increasing anxiety about their intellectual and emotional development and mental health issues (see Chapters 10–12). The gradual expansion of children’s services could provide more resources for the disabled child, but all too often the preference for specialist and targeted services only contributed to the marginalization of disabled children and adults. Paradoxically the recent policy commitment for inclusion can also work to the detriment of people with special needs as there is pressure to open up specialist resources, often acquired at great difficulty in the past through dedicated fund-raising, to general access.
These issues and debates, and different perspectives on them, help explain the 'subjectivity and contingency of historical accounts' noted by Felicity Armstrong in her survey of research and literature relating to the history of the education of disabled children. It can be argued that scholars interested in the experiences of disabled children face unique difficulties. Thus while the focus on experiences has been aided by the search for new source material (including oral histories), multiple and discordant voices have often emerged from such materials leaving partial, fragmentary and confused accounts. The history of disabled children is beset by difficulties surrounding both memory and the ownership of narratives belonging to families and communities as well as individuals. These problems, perhaps inherent in studies of all socially marginal groups, have received most discussion in relation to the history of insanity, but even in this field the historiography benefits from active participation by those who define themselves as either living with or recovering from mental health issues. By contrast, in the case of disabled children the situation is more complicated because children are unable to independently critique the historiography, determine research goals or even collaborate with investigators. Parents and parent groups may wish to speak for children, but their interest in the history of services is shaped by competition for the right to make decisions about their future configuration and individual placements within them. Implicit within these discussions is often a rejection of earlier care practices and the assumptions that underpinned them in a way that prohibits developing an understanding of either past experiences or historic opportunities for participation, negotiation and resistance.

Recovering the voices of disabled children is all the more difficult because capturing them was not the main purpose of surviving records. Indeed official documents often silenced the child by denying the legitimacy of their experiences and prioritizing the opinions of professionals, and to a lesser extent parents. This theme is explored by Lee-Ann Monk and Corinne Manning with reference to the Kew Cottages in Australia (Chapter 5), and is also documented by Amy Rebok Rosenthal in Chapter 2, dealing with an English asylum. Educationalists were perhaps keener to tell children’s stories, especially as an aid to fundraising, but also placed limits on what children could say for themselves and had predetermined ideas about the prospects of their pupils. Mike Mantin (Chapter 4) shows how desired outcomes for deaf pupils were determined by ideas about class and gender as well abilities and disabilities. The disappointments, isolation and stigma experienced by these children often have to be inferred from silences in the records. Psychological trauma arising from separation from home and parents, as well living with a serious disabling condition, also tends to be understated in documents created by residential services for physically disabled children. However, the records do at least hint at some of the physical and emotional pain experienced by child patients at the House of Charity (Chapter 1)
and Apelviken in Sweden (Chapter 9). Similar hints of the suffering of disabled children who had not gained access to specialist medical services can be found in work on the coalfield communities (Chapter 3) and health visitors (Chapter 8), although these narratives were designed to advocate for better provision not relate individual experiences.

The chapters of this book are organized chronologically. As we move towards the present day it might be assumed that parents and professionals, responding to the evolving disability rights movement, offered disabled children more opportunities to speak for themselves and determine their own care. Where documentary and other sources become more child-centric over time it is certainly easier for scholars to recover both the voice and experiences of the child but this process was neither automatic nor straightforward. Although it is erroneous to assume that children in the distant past were totally silenced it is also inaccurate to suggest that later generations of professionals (and parents) consistently sought to empower children. Attention to the rights of children and parents involved recognition of tension between the two and also risked conflicting with professional interests. Arguably children were only empowered when and where professionals committed to this agenda. This orientation also served to encourage the collection of oral testimony and retrospective accounts from service-users. The rich potential of these initiatives is shown by Angela Turner’s evaluation of special education in Glasgow (Chapter 11). Yet, this chapter demonstrates it is often painful and difficult to tell these personal stories; when they challenge powerful state bureaucracies it may even be dangerous. This theme is developed further in relation to the Spanish polio survivors (Chapter 9), whose experiences have only come to light as a result of political change in that country. Here recent activism associated with maintaining and improving services for survivors in the present day has facilitated efforts to understand the past through discussions that highlight personal, family and community experiences of disability.

The importance of these factors is highlighted by Chapter 10 where Sue Wheatcroft explores child guidance services for ‘hard to place’ evacuees. While there is a growing historiography (drawing on oral testimony and written records) about child evacuees this group is conspicuous by its absence. We argue that this is because there is no survivor network in place to help this group identify itself and no independent way of tracing its former members, many of whom had only a brief encounter with facilities that quickly disappeared. Vulnerable people need help to tell their stories from contemporary actors as well as current scholars and activists. Here the attitude of professionals appears to have been unhelpful. In its pioneer days the child guidance movement was inward looking and expert-led so the voice of the child is often absent. Similar problems of relating expert debates to actual experiences apply to the chapters looking at advice literature and hyperactivity (Chapters 6 and 12). In both cases professional
concerns were heavily mediated by the way parents responded to the advice and modified their own practices. Very young children typically retain limited personal memories of this period of their lives. Although some parents do recount their experiences it is not entirely clear how their parenting styles were influenced by either the child’s disability or their own or other people’s response to it. In the case of hyperactivity, the willingness of parents to talk about their child’s problems and their efforts to overcome them have dominated the debates. Work by Matthew Smith and others is only just starting to probe their children’s responses. In these accounts, it is noticeable that some of these now adult children are supportive of their parent’s faith in various experts, but others reject not just the recommended treatments but the idea that they had a disability. It is difficult to assess how influential the advice literature was without a defined set of service users, for example patients admitted to a specific institution. However, it is probable that people who were unusually accepting or rejecting of the advice offered are prominent amongst those coming forward to share their experiences. And, these are likely to be presented as personal biographies and family sagas that will tend to downplay wider social, economic and political issues. The family is obviously central to the experience of growing up, but for the disabled child the role of the state (and/or wider community support networks) also needs to be kept in focus.

The State and the Disabled Child

This volume explores the experiences of disabled children with particular emphasis on the contested nature of their care. Discussions about the contested delivery of publicly-funded care and the development of state services, usually under expert direction, foreground these issues. While individuals may or may not have viewed themselves as a disabled child, expert opinion in our study period offered strict, though changing, definitions of childhood and disability and allocated people to services deemed appropriate for them. The very existence of such provision did much to define what disability was (as definitions expanded from conditions easily recognized by lay people to those requiring expert diagnosis) and how different conditions should be managed. Growing interest in both children and disability issues was an international phenomenon that dated from the mid-nineteenth century. In this volume, Pat Starkey (Chapter 1) locates pioneering initiatives to support disabled children within a network of charitable activities and highlights the importance of religious beliefs and royal patronage in creating and sustaining services. In the United Kingdom, and elsewhere, medical innovators and/or educationalists combined with philanthropists to develop new provision for various groups of disabled children. At other times these pioneering projects developed under the aegis of the local and national
state, sometimes as part of national projects that celebrated and furthered the role of the state (Chapters 7 and 9 dealing with tuberculosis care in Sweden and polio services in Spain). Conflict within and between states also provided an important impetus for service-development, although a focus on children as the future of the nation encouraged a certain ambiguity towards disabled children. Such children were simultaneously viewed as potential future citizens and also a likely source of deviance and dependency. These issues are explored in an important collection of essays edited by Roger Cooter, but his focus on childhood tends to neglect the experiences of different groups of disabled children. By the mid-twentieth century, Matthew Smith (Chapter 12) argues that ‘disabilities’ were not conceived in terms of recognizing an individual’s special needs but were instead defined by an inability to contribute to the goals of the state.

Throughout this volume the case studies reveal that the expansion of state services for disabled children was a contested process. Here it is essential to recognize that the much-discussed maternalist policies adopted by many nation states in the first decades of the twentieth-century did not start from the position of a blank canvas. Parents, and others, had an established concern with child health although changing expert opinion increasingly politicized debates about child rearing. Increased state support for and surveillance over families went hand in hand with anxieties about the financial commitment involved. This encouraged discussion about the most appropriate balance of providers in a mixed economy of care. There was also a concern to enforce rather than undermine family responsibilities while promoting the future economic independence of the disabled child by providing specialist training that the family might well not be able to afford. All these themes are discussed by Steven Thompson (Chapter 3), who draws attention to the often neglected point that provision, both in terms of the scope of services and their underlying ideologies, varied as much within as between different countries.

Childhood disability was an issue for all social groups. Yet the organization of state services meant that the poorest were singled out for official intervention. In the past it was too readily assumed that socially marginal groups had a disproportionate number of inherent defects. Anxiety about the implications of this for the future of national economies, social and political institutions, and gene pools fed unattractive eugenic arguments while also providing a spur to service development. Nowadays there is greater recognition that disabling conditions are both the cause (through loss of family income and additional expenses incurred to meet special needs) and consequence (as people in poor districts are exposed to worse environmental conditions, have greater vulnerability to life-changing accidents, are more likely to suffer nutritional deprivation, and have less access to preventative healthcare and treatment services) of poverty,
this can still lead to suspicion of clients of health and welfare services (whose case records and the negative comments therein are accessible to researchers).  

This source-base paradoxically may lead historians to neglect the experiences of other disabled children whose parents made private arrangements for their care. Since the role of experts has been identified as a problem in the care of all disabled children it seems possible that wealthier children suffered disproportionately from more frequent contacts with a wider range of professionals. This might encourage parents to either pursue overly aggressive treatment options and the often vain search for a cure, or send the child away to a private institution. Health surveillance and the identification/treatment of conditions that the child might not experience as disabling but surrounding adults had a problem with were also likely to be earlier (and more intense) experiences for the more affluent family. The quest for the perfect child in the twentieth century increasingly required interventions by medical experts (including the recent involvement of geneticists), often with mixed results for the child. Wealthier children were not necessarily healthier children, or less prone to congenital or acquired disabilities. An important collection of essays edited by Mark Jackson makes it clear that although there was persistent concern on both sides of the Atlantic about the threats to health posed by the material (and moral) environment of slum dwellings there were periods in the twentieth century when the hazards of the middle-class home received even greater scrutiny.  

It remains true, however, that the majority of children living with disabling conditions fell into the ambit of state-supported services and were assessed as being dependent as well as disabled in some way. The problematic association of dependence with deviancy cannot be overlooked when evaluating services and children’s involvement with them but it is important not to forget the difference small services could make to deprived children's lives. In the United Kingdom, the Edwardian School Medical Service first noticed that many needy children were unable to read because of poor eyesight. The provision of spectacles helped, although there were many obstacles to developing other schemes to address more complex problems. Since poorer people were more reliant on state aid their experiences were determined by the way this was delivered. In England the workhouse was reviled by many working-class communities but historians continue to emphasize its importance as an embryonic social service, especially for the elderly and infirm. Children were also an important client group for the Poor Law authorities but by the late nineteenth century statutory and voluntary effort encouraged their redirection towards specialist services which emphasized education and training. These concerns embraced children with special needs, and residential schools emerged from the end of the eighteenth century to cater for blind and deaf pupils. Over time, other groups were identified and offered distinctive provision. Assessment of the aims, methods and achievements of this
special schooling shows much continuity over time and commonality between countries although many published histories celebrate particular institutions and pay only limited attention to wider developments in health and welfare policies. A more thoughtful account, that notes the contested nature of many developments in the fields of deaf education, can be found in Mike Mantin’s work on the oralism debate (Chapter 4). He reveals conflict between the key actors and the continuing importance such educational policies have for understanding Deaf/deaf culture.

While the appropriateness of special education can be debated, it was for many years quite a marginal but somewhat exclusive activity underpinned by strict entry criteria for pupils and the social status of patrons, board members and donors. Although some services were configured to meet regional as well as local need there was no sense of coordination, and such provision as there was must have been easy to avoid if unacceptable to parents until the last decades of the nineteenth century. It was the introduction of compulsory schooling, itself part of a reassessment of the state’s duties to and rights over its future citizens, which did more than anything else to reveal the number of children with special needs. Subsequent legislation encouraged recourse to existing and new facilities but the principles of voluntarism were increasingly replaced by official medical assessments and bureaucratic arrangements for the correct disposal of cases. Here it is hard to escape the dualisms identified by Harry Hendrick at the heart of increasing concern about child welfare from the 1870s. These included children as victims and threats, children’s bodies and minds and the management of the normal and abnormal.

Understanding the Past, Looking to the Future

Tension between the rights of adults and the needs of children has become an important theme in recent work exploring changing meanings of welfare. Harry Hendrick attributes many modern anxieties about the nature of childhood and the status of children in western societies to cultures of adult individualism and economic uncertainties that took root in the 1970s. He views feminism as a particularly insidious influence on policies and practices that affected children without necessarily being child-friendly. This analysis however has little to say about children with special needs, although journalists have recently used the abusive care of disabled children as the ultimate examples of selfish parenting. Likewise, disability research has embraced many feminist perspectives, but its focus on adult experiences and opportunities for self-expression and self-determination says little about children living with a disability or the special needs of the children, disabled or not, growing up in a household where one or more of the other children or adults has a disabbling condition. There is also concern that
there may be discrimination even within the disability movement, with people living with learning difficulties (traditionally viewed as child-like regardless of age) apparently the main victims of this.40

The rhetoric of independence and social inclusion, derived from the social model, is strong, but the way this might apply to children living with disabling conditions in the past, present or future is still underexplored and it seems possible that specialist services (even additional support provided to facilitate access to mainstream provision) designed to promote such goals may unintentionally frustrate them, especially in medical and educational settings.41 The legacy of past services, together with assessment of their ideological roots and institutional cultures, is also clearly important here. However, with the explicit scholarly rejection of any whiggish notion of linear progress in the provision of disability services any sense of change and continuity over time may be lost in analysis of power-relations embodied in professional practices and/or particular institutional settings. Children’s historic experiences of coping with ill-health and disability in a variety of settings and contexts thereby risk being lost,42 even as more attention is given to oral history projects and life-story work.43 The special needs of disabled children can too easily become marginalized within wider debates about both children and disability.44

This was a historical problem but is particularly acute today given present anxieties about children in the social investment state (where scarce public resources are targeted to address future labour-force requirements) and concern about the financial burden of caring for an ageing population.45 The global economic downturn following the banking crisis in 2008 has also raised significant questions about the ability of either the statutory or voluntary sector to sustain let alone develop the existing level of services in many countries. The full impact of these events is as yet unknown but it is not unrealistic to suggest a similar loss of confidence to that seen at the end of the long boom in the western economies in the early 1970s. This was associated with a decline of support for collectivist principles, reduced funding growth, restricted entitlements for service-users, and significant new pressures on staff that fed into a developing literature on stress and burnout.46 It is no coincidence that the 1970s and 1980s saw the promotion of ‘inclusivity’ alongside the closure of large-scale, long-stay institutions.47 This positively asserted the normalization agenda and brought many benefits but it was also associated with the withdrawal of specialist support, the inappropriate use of facilities poorly adapted for those with special needs and a heavy reliance on family carers.48

It seems unlikely that families will be able to do more indefinitely.49 Indeed recent developments have tended to encourage expectations that disabled young adults will leave home at the same time as their peers to access opportunities for education, work, independent living and new relationships.50 New barriers to