

Design, Disability and the Planning Challenge: The Reality of Living with Severely Disabled Children

Abstract

This paper investigates the effects of the speculative and standardised house building model dominant in the UK on the residential experience of families with severely disabled children and evaluates the barriers to the provision of inclusive accommodation through the planning and development process. Unlike previous studies on the theme, this paper draws together, compares and contrasts, within one location, the experiences of families that include severely disabled members, local planners and housing developers. The results indicate that, as a result of the deficiencies of mainstream housing design and delivery, real and substantial stress can be created for families with disabled children. Moreover, it was found that institutional and attitudinal inertia restricts communication between developers and planners in responding to the needs of these families. It is argued that evidence based on experiential knowledge of the needs of disabled groups is a critical first step in meeting their requirements for appropriately designed housing.

KEYWORDS: planning; housing development and disability; physical spaces in buildings; behaviour and space.

The ability of the planning and development process in the UK to respond fully to this agenda is, however, influenced by a cocktail of circumstances. The dominant model of housing delivery and domestic house design in the UK is driven by speculative development by a small number of high volume house builders. Inevitably, developers respond primarily to the commercial imperative to produce a return of 20-30 per cent on their fixed investment, which encourages a business model underpinned by cost minimisation achieved through standardisation. The major house builders tend to adopt a portfolio of proven design and house types to achieve economies of scale in the cost of design and building materials; to establish quality assurance guarantees for those materials from a trustworthy supply chain; and to ensure reliability in terms of 'buildability', estimated costs and construction schedules (Hooper and Nicol, 1999). While these standard house-types are developed in constant iterative consultation with sales, marketing and customers (Hooper and Nicol, 1999), customisation is discouraged because of its detrimental effect on profit margins, construction schedules and ultimately the marketability of a property at resale (Barlow and Ozaki, 2003). For this reason, customisation has been limited to choices in fixtures and fittings, rather than any flexibility in design or layout (Hooper, 2002). The dominant competitive position of the house builders means that the market has little choice but to pay the prices determined by land and construction costs together with expected profits. The stimulus for product and process innovation, which is common in other consumer goods to reduce prices, is much weaker in the house building sector (Barlow and Ozaki, 2003).

The spatial organisation and architectural composition of dwelling spaces under this model has inevitably been shaped by the requirements of the dominant market,

Households (2012) suggests that the fastest growth in numbers of disabled people since 1975 has been in children. Approximately 200 babies are born with a cognitive impairment every week in the UK. There are 770,000 disabled children under the age of 16 in the UK, which equates to one child in twenty (Care Quality Commission, 2012, p.6). A range of physical and cognitive impairments affecting children were included in this research (see Table 1). These conditions had potential implications for the design and space standards of residential accommodation. The care of physical impairments requires better space standards for medical equipment, lifts, ramps and storage, while the mitigation of cognitive impairments, which might manifest itself in unusual patterns of thought and behaviour, can require attention to internal layout, safety, sound proofing and even levels of natural daylight and neutral colour schemes to control stress. The availability of segregated personal and supportive space for other family members can be equally important to ensure the well-being of the whole household. Without consideration of these conditions, mainstream housing design can create difficulties in caring for disabled children on a day-to-day basis, through inadequate and non-functional rooms to meet the carer's management of disability; a lack of space for equipment, storage and the rest of the family; poor safety features on fixtures and fittings; and an inability to move about the property because of stairs.

Families with disabled children are more likely to live in unsuitable housing than families with non-disabled children (Beresford and Rhodes, 2008). Beresford (2006) found that of those children who required specially adapted homes, 53 per cent were living in unsuitable accommodation (in comparison with only 20 per cent of people aged 65 or over). Standard domestic environments were implicated in poor physical and mental outcomes, not only for the disabled child, but also for the whole family

34 completed questionnaires were returned, representing a response rate of 33.7 per cent.

Second, as a supplement to the questionnaire survey, a focus group was undertaken with parents recruited from the survey to explore house design and experiences in greater depth. Five respondents represented a cross-section of ages, marital statuses, sexes, employment status and tenure mix. The discussion was split into two parts: the first thinking about and discussing the worst features of house design and the second focusing on the best features of house design within the context of severe disability and its management.

Third, a short questionnaire survey was undertaken of the views of some of the major house builders in Torbay regarding the barriers preventing inclusive home construction. A questionnaire survey was favoured over interviews because of the likelihood of a higher response rate as potential respondents could complete the survey within their busy working schedule. Using Torbay Council's Planning website to establish contact details, developers who had commenced planning permissions for one hundred residential units or more in Torbay over the last ten years were targeted. The sample included nine companies, who had built 2,476 units of accommodation in Torbay over the last ten years (2003-2012) (see Table 2). Enquiries were made with each company to establish the most appropriate member of their staff to complete the questionnaire, which in most cases was the person with responsibility within their organisation for completing Government and National House Builders surveys. The questionnaire asked about the perceived barriers to housing delivery, internal design, and awareness of disability and design. Two reminder telephone calls were made

over half renting from the private sector or as social tenants. About three-quarters of households contained four persons (husband, wife and two children), with the remaining one-quarter of households containing between five and eight persons. In most cases, households comprised both parents living together, although three respondents were single-parent households.

Nearly three-fifths of the sample had a child with one disability, with a further two-fifths having a child with two or more diagnoses. By far the most common disability experienced was autism (11), followed by cerebral palsy (8), global developmental delay (7), Down's syndrome (6) and epilepsy (6). There were five other conditions affecting a smaller number of families (see Figure 1). Not surprisingly, the respondents' experience and satisfaction with their residential environment, together with their identification of the features of an 'ideal' home, were highly inter-related.

Experience of current accommodation: The most common negative responses about current accommodation was that it was too small for the needs of a family with a disabled child or children (14), needed adaptation (10), had poor access (9), lacked adequate storage space particularly for the additional paraphernalia required for the care of disabled children (9), possessed insufficient sound insulation (7) and inappropriate flooring (6). The most common positive responses concerned level access (14), a separate bathroom for the disabled child (13), the possession of an enclosed safe garden (11), comfortable accommodation (10), and security (9) (see Table 3). The appearance of some features in both lists, such as level access, sufficient living and storage space, and security indicates the importance of these design features for families with severely disabled children. Although it is

sensory neuropathy, epilepsy, global developmental delay, cerebral palsy and ADHD. The proportion of non-structural adaptations were at a lower magnitude across all diagnoses, except for Williams syndrome, motor sensory neuropathy and ADHD (see Table 5). Only just over one-quarter were aware of the local Torbay Council's adaptation service, which provides support and advice about structural and non-structural modifications to properties for these groups. Many families had therefore undertaken property adaptations without awareness or the support of this service (two-fifths of those undertaking structural and nearly three-quarters of those undertaking non-structural changes). One respondent in the focus group indicated that, because of the struggle in obtaining an adaptation, they felt tied to their current dwelling which acted indirectly as a constraint on their residential mobility:

'It took a long time for us to get an adaptation and so if we moved we would probably have to start all over again: better the devil you know'.

Features of an 'ideal' home for a disabled child: Although the small sample size precluded the development of a completely comprehensive model of the housing design requirements for different diagnoses, a number of general features of an 'ideal' home for families with a severely disabled child were observed (see Table 6). First, above all other features, the importance of an enclosed garden space to allow meaningful interaction with other members of the family and to contribute to the child's quality of life was mentioned by nearly half of the families across the different diagnoses. One respondent noted: 'It's very confined where I am so a garden to play sensory games would be lovely for X'. Second, all conditions (with more than three responses) emphasised the value of level access across the layout of the house to ease for movement of the disabled child and any associated equipment. Third, high

importance was attached to the demands for more space, which covered an array of requirements from larger room sizes with open-plan layouts to wet rooms; drying rooms; spare rooms for sensory, physiotherapy, soft play or time-outs; storage areas and lockable cupboards; and independent living spaces for the rest of the family.

Reflecting the experiences of caring for a disabled child discussed earlier in the paper, a number of the design features reflected concern for safety. Non-structural adaptations to reduce the risk of harm to the child, such as higher electric points and switches, non-tamper light switches, automatic water taps and padded walls for the child's bedroom, were also highlighted. Under-floor heating in all rooms was mentioned by a number of respondents to reduce the risk of burning and scalding from standard wall-mounted radiators. Other suggestions were designed to improve the convenience of running the property, such as soft-tiled floors for easy cleaning, especially in dining areas, and closed-circuit television monitoring in all rooms with hand-held monitors to provide surveillance of the disabled child at all times. Another involved the location of bedrooms on the north-facing side of a house to prevent children from waking up early in the summer months and so allowing the rest of the family more time to sleep.

While such adaptations would benefit most diagnoses, each condition has slightly different requirements (see Table 6). Children diagnosed with autism and cerebral palsy, as two of the better represented categories in the survey for example, would benefit from different types of adaptations in house design. While the care for autism might be better accommodated in houses with enclosed gardens, level access (bungalows) and soundproof rooms, the care of cerebral palsy, while also needing

level access, required extra space for care rooms and wet rooms as well as flexibility in room layout. The care of children with GDD required sound proof rooms, flexibility in room layout and extra care rooms, while the care of children with Down's syndrome required more storage space.

Perhaps unsurprisingly, over three-quarters of families with a disabled child were in agreement regarding provision for their needs being stipulated in planning policy, although five did not know and three disagreed. Over two-thirds felt that such a policy should not concentrate housing for the disabled in single-site clusters, which might offer benefits for the provision of support services and mutual self-help. There was instead a preference to be integrated as part of the community, because of a fear that stigma and prejudices might emerge through the potential 'ghettoisation' of this group. The results of both the survey and focus group demonstrated that there is a clear demand for more inclusive residential accommodation for families with disabled children.

Survey of developers and planners

All five developers and seven of eight planners interviewed confirmed emphatically that there is an awareness of the problems caused by mainstream housing design to disabled groups, especially families with disabled children. A developer admitted that 'we know that standardised housing designs do cause problems for people with disabilities', while a planner noted that 'it has been known for years that there is a need and a market [for inclusive homes]'. However, there appear to be institutional processes or attitudes preventing these inclusive needs from being met. Several

possible explanations were revealed from the responses of both developers and planners in the survey.

First, the issue of inclusive housing for disabled groups did not appear to be a priority for either developers or planners. The main concern for developers was managing the risk of their financial investment in new housing developments before returns were secured. Developers worked towards the local authority's minimum room sizes in order to maximise density and thus generate a gross profit from housing development sites. Gross profits of between 20 and 30 per cent were required by developers over the predicted sales period. A developer stated that: 'Our company likes the current plan-led system and the National Planning Policy Framework because it does not increase the availability of land for new development or increase plot and room sizes, making development a viable proposition'.

Only two of the five developers included in the survey had been consulted about the design requirements of the disabled by any public authority (in this case, a social housing company and a local authority affordable housing manager). Amongst some of the planners, there was an assumption that if a family-sized home was not adequate, then the family would adapt it accordingly and pay for the work with a Disabilities Funding Grant (a means-tested grant for adaptation work to property) or their own resources (DCLG, 2009). All planning professionals felt that the 'Homes for Life' sustainable standard, by making properties capable of adaptation and extension as needs arose, appeared to dampen recognition that other interventions should be made, such as planning conditions or new tenure types. The system in the UK is thus

geared to adaptation at the post-build stage and this feature redistributes responsibility onto already stretched families.

Second, perhaps as a consequence of the first point, there had been far too little progress towards establishing an evidence base for disabled housing needs in the area. As one planner stated: 'We have carried out some work around the needs of the elderly and mobility, but none on specific housing supply and design for the severely disabled... we have no evidence base in this area'. Planners in Torbay had tended to give more attention to the housing needs of the elderly (sheltered accommodation and care homes) rather than undertake more systematic research into the specific housing supply and design issues for families with severely disabled children. Another planner highlighted the problem of not having clear guidance from central government over housing needs assessments in that: '...every other authority in the region is using a number of different methodologies to assess the need... so there is little by way of a joined-up approach or evidence base'. As a consequence, the planners lacked an evidence base, and so did not possess the confidence to impose planning conditions or refuse planning applications on the basis of provision for disabled groups. There was a fear that refusals without evidence-based policy would result in appeals and, in all probability, the award of costs against the Council. One of the developers noted: 'Provisions of all types of housing is slow and a protracted process. Greater reliance upon the evidence base of need and demand is required'.

Third, despite the potential for disagreement between the planners and developers about how to deliver inclusive housing accommodation for families with severely disabled children, there was a surprising degree of consensus. Yet there appeared to

be little communication and collaboration between the professional groups responsible for the planning and development of housing for disabled groups to facilitate real change in housing delivery. A planner stated: 'We agree that if an evidence-based need had been identified for a particular form of housing, then we (the local planning authority) should be able to prescribe provisions to meet that need'. Planners felt that new planning regulations would be required, because 'developers would be less happy to provide inclusive homes without imposing new planning regulations'. These regulations would have to be very prescriptive by requiring, for example, '...a two per cent bespoke home provision in every fifty new homes' (ie. one in 50). Such mechanisms might prove to be rather too crude to obtain a housing stock comprising sufficient numbers and in the right locations, irrespective of whether the restrictions offered a commercial proposition for the developers. It had been the experience of half of the local authority officers questioned that some resistance to existing housing policy, mainly based on the cost implications/profit reduction of improved space standards, had been made by developers in the past. Indeed, one developer commented: 'We have incurred extra cost and had to delay completion of projects because of new changes to Part M Building Control regulations'.

Nevertheless, all but one of the developers felt that local authorities should impose a policy to provide a minimum percentage of inclusive accommodation as long as there was a proven need and viable market. One developer stated that '...they thought it would be the right thing to do'. Half of the developers thought that the minimum figure should be between 5-10 per cent, with the other half placing the figure at 10-20 per cent. Developers were not necessarily averse to responding to the needs of disabled people and to supply accommodation with a higher space standards. One

developer suggested that 'any extra cost might not necessarily be passed onto the market... sale prices of bespoke homes would be reduced because land values for such properties would be lower than that for the general residential market'. This finding points to the importance of improved communication to resolve any misunderstandings and misconceptions between the key stakeholders. The implications for developer costs and profit margins might be minimal because, in most cases, disabled groups required different rather than additional features in their housing specifications, such as heating, flooring and socket heights. These specifications did not necessarily impose additional costs, so long as these features could be incorporated at the construction stage (Imrie and Hall, 2001). Extra expenditure might be absorbed through a reduced profit margin. These issues require further investigation in future research.

Discussion and Conclusion

The original contribution of this paper has been to investigate the issues of housing design and delivery for families with disabled children from the perspectives of three different stakeholders within the same geographical region. While there is recognition of a 'problem', structural constraints imposed by the economic model of housing construction, the uncertainties within the development and planning process, and the lack of communication between stakeholders create very real barriers to the satisfactory resolution of housing design for families experiencing difficulties. In many respects, the development and planning process situates the provision of housing suitable for disabled groups within the 'medical' model of disability, whereby standard designs can be adapted to ameliorate physical and cognitive impediments. A shift to a 'social' model, where disabilities can be ameliorated through more inclusive

design incorporated at the construction stage, requires a substantial transformation of the business model, regulation and stakeholder communication/collaboration within the planning and development process.

The speculative model of housing development in the UK, driven by the need for developers to deliver profitable schemes through volume construction, maximised densities and standardised design, can be argued to discriminate against disabled groups, such as families with severely disabled children. Building controls for disabled needs are not necessarily a complete solution as they can establish a 'least acceptable solution' through minimum compliance, define disability in narrow terms of 'visitability' and wheelchair users rather than a broader range of objectives, and focus on disability in adults rather than children.

The results of this study in Torbay have illustrated the experiential reality of families with a disabled child living in a mainstream designed property. Issues related to the importance of level access, sufficient living and storage space, and adequate sound proofing indicated the deficiencies of standard housing design for this group. As a result, the effect on all members of the family was evident in the level of stress experienced in the home environment through having to contend with the need for constant vigilance and monitoring, disturbed sleep, a lack of personal space, and high utility bills. In some cases, the stress caused ill-health in the other members of the family, especially parents, and so arguably rendered the properties as 'unhealthy' (Oldman and Beresford, 2010). About half of the sample was not satisfied with their current accommodation and, of these, over three-quarters aspired to move. It is clear that disability can be made worse by mainstream housing provision, and that more

inclusive provision can render the children and their families 'more able' and better equipped to deal with the disabilities they face. Inclusive housing has the potential to reduce effective disability and improve the quality of life of its occupants. Such a shift in housing provision would embrace the social model of disability.

Although a much larger and representative survey would be required to verify associations, it is possible to identify, in a preliminary way, the design features of a house that would ameliorate some of the care issues affecting the diagnoses. For example, strong commonality was evident for enclosed garden spaces, level access across the layout of the house, and extra space to accommodate a range of needs. Particular diagnoses require specific features, such as sound proof rooms for autism and GDD, whereas a greater emphasis on higher space standards was needed for the care of cerebral palsy and Down's syndrome.

Although both developers and planners recognised the issues of mainstream housing for families with disabled children, there appeared to be institutional processes and attitudes that had established inertia and inaction over this issue. Developers tended to be driven by the commercial imperative to realise a 20-30 per cent gross profit on housing developments and planners assumed that any deficiencies in the design of family homes would be corrected by post-build adaptation. Through a lack of an evidence base for disabled needs, planners did not possess the confidence to impose conditions or obligations or refuse planning applications to cater for these groups (without incurring costs against the Council at appeal). As long as a proven need or viable market could be demonstrated, developers were willing to provide a minimum percentage of inclusive accommodation (with most offering 5-20 per cent). At the

heart of the issue, however, remains the small space standards in the UK, which constrains the flexibility of houses to accommodate the various needs and demands of the occupants.

However, what does seem to be apparent from this study is that the current development and planning approach to housing provision for disabled groups in the UK is markedly dysfunctional and certainly not ‘joined up’. The scope for improved communication and collaboration to resolve misunderstandings and misconceptions between planners, developers and families is substantial. The housing needs of families with disabled children must be fully understood so that properties, despite their generally inadequate provision of overall floor space in the UK, offer much more of what is needed rather than what planners and developers think is needed. Such a shift in approach would more fully embrace the ‘collaborative’ or ‘communicative’ turn in planning encapsulated in the emergence of spatial planning and localism (Healey, 2005). Developers and planners might have to become more willing to accept subjective, qualitative and experiential data as part of the evidence base for policies and actions. Such an emphasis would be contrary to the underlying and fundamental reality of economic viability for developers.

One priority is the need for comparative investigations in other countries in order to pool ideas for both the design and delivery of more flexible and suitable homes for families with disabled children. Another priority is to establish a realistic and viable proportion of new developments that should be capable of accommodating disabled children based on cost/profit margin implications. A formal mechanism to ensure ongoing dialogue and collaboration is required to ensure that current issues are

addressed and that the future is more enlightened. While in the short-term there is little option but to retrofit homes currently occupied by families with disabled children, the ultimate long-term goal should be to increase the proportion of newly built dwellings that are designed with disabled needs included. Eventually, the housing stock could then have sufficient units to offer families with these needs. Nevertheless, the process of matching demand (ie. families) to supply (ie. the most suitable property) remains a challenge within an essentially supply-led system. Arguably, however, this planning challenge might be less daunting if this debate was broadened to encompass the quality of spaces in new homes more generally (CABE, 2010; RIBA, 2011; DCLG, 2013), including the case for the (re)introduction of minimum space standards, such as the London Housing Design Guide (Mayor of London, 2010). Such standards would contribute to residential environments better suited to the household needs of the twenty-first century, but balanced against the implications for land supply and affordability as well as redefining long-standing policies for urban encroachment and the protection of the countryside.

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