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Socially Adaptable Housing

New Housing Model for Families Living with Disability

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Abstract

In Australia, statistics collected in 2009 by the Australian Bureau of Statistics found that “four million people” are reported as having a disability, a figure that equates to 18.5% of the overall population (2009; p6). Statistics such as these are not by any means astonishing, even to members of the general public, and it is understood that these are only to increase significantly in our near future. What is particularly surprising however is, in the face of such statistics, the lack of new and creative responses to this demographic shift, particularly by the architecture and construction industries. The common response from a range of sectors seems to be the repetition of a series of models that offer limited, and often undesirable, housing options.

It is this against this backdrop, characterised by a lack of original options from mainstream practitioners and relevant government bodies, that the need has arisen to develop alternative models at a grass-roots level. This paper reports primarily on the work of the Living In group which comprises a not-for-profit organization, a pro-bono design practice group and a local university working together to design a more holistic, emotionally sustainable independent

living model of housing for families where a member of the family has a profound or severe disability. This approach recognizes the limitations of universal design in that it often does not "...meet all the housing needs that arise for people with moderate to severe disabilities" (Scotts, Margie et al, 2007; p.17). It is hoped that by examining the work of such a collective which is not driven by profit or policy, but rather born with the aim to address first and foremost individual and community need, that better insight can be gained into the real requirements of individuals and families as well as open up a view to new ways of fulfilling them.

Introduction

This paper examines the work of the Living In collective, which has formed to address the lack of suitable options for independent living for adult children with disabilities and their families. While the definitions of disability are far ranging and often divided around the notion of person-environment interaction, for the purposes of this paper we are looking at the very specific demographic of families who are living with, and caring for, adult children with severe or profound, mental and/or physical disability. In 2009 the Australian Bureau of Statistics reported that around 18.5% of all individuals in Australia suffered from some sort of disabling condition. The prevalence of families with children with disability is harder to quantify as the range of disabilities are categorised by such surveys statistically as follows: intellectual, psychiatric, sensory/speech, acquired brain injury and physical/diverse disability. However other figures, such as offered by the Australian Institute of Health and Welfare, estimated the number to be in the order of 700,000 (AIHW, 2007). The individuals with disability that the project currently focuses on experience a complex combination of both physical and mental disabling conditions.

Paucity of choice in living arrangements and lack of opportunity for independent living combined with a lack of market-state response to the problem is clearly mirrored in other developed nations, and as such it is hoped that there is an opportunity to share the learning of this collective and assist other communities who are seeking solutions to these problems. In conjunction with the specific group currently being designed for, many of the problems (and solutions) being addressed by this collective are shared by a wider community demographic, namely the ageing population. This demographic shift is resulting in increased survival rates for individuals with disability, and Hawkins highlights the interrelationship between these phenomena in the following statement, "Included in the ageing population are people with a disability, as the life expectancy of adults with a developmental disability continues to improve"(Hawkins, 1993; p.1).

The Living In collective, involves a non-profit community organisation, a pro-bono multidisciplinary design group and university researchers. The collective has been evolving over the last twelve months to the stage where it is presently working with the first of 52 families to develop design responses (which work in conjunction with social and financial support requirements) that suit their particular needs and aspirations. The local historical context and currently available options are vast topics in themselves that warrant further, more comprehensive study. This paper considers the conditions that have not only given rise but that continue to impact on and shape this unique project.

The Problem and its Origins

In 1994, The Intellectual Disability Services Council described a trend that has been mirrored around the world, albeit on differing timeframes and to varied extents:

“Since the early 1980s, there has been a move in Australia to close institutions for individuals with a developmental disability and accommodate them in small group homes, hostels, boarding houses, and independently supported accommodation within the community” (Baladin and Chapman, 2001; p.38.3)

Further momentum for this movement can be attributed to the UN charter convention on the rights of persons with disabilities (December 2006, ratified by Australia 17th July 2008), particularly article 19, (entitled ‘Living independently and being included in the community’) which states:

Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

In the process of large-scale de-institutionalisation in Australia, many individuals that were in the care of these facilities were offered a choice of social housing spaces as alternative to their previous accommodation. While this addressed the primary need for basic shelter, the matter of care was a significantly more complex problem to solve. The size of allocated care budgets dictated a need for many individuals to group together in shared accommodation, often with strangers, in order to afford the around the clock care previously provided. Government and privately run group homes sprung up and continue to be a common model. Other accommodation options available, which we will discuss further, include hostels, boarding houses and aged care facilities.

From 2001, researchers Baladin and Chapman observed that “In Australia, the majority of people with a developmental disability are now living in the community” (2001; p.38.1). In other countries the phenomenon has also been clearly visible, for example in Scotland, Hogg observed that people with a developmental disability are now a “well-defined population” who are “living in the community and are likely to remain in it” (2001; p.137).

Faced with the demise of the institutional care setting, families raising children with disabilities began to choose, or equally importantly feel obliged, to continue to provide 24-hour care within their family homes. These families, while receiving varying levels of government funded assistance, eventually find themselves trapped in a cyclical situation borne of a ‘needs based assessment’ system. Simply put, those individuals who are currently

receiving adequate family care are not seen to be ‘needing’ the level of outside care provision that would enable them to live independently. In extreme cases, in order to break this cycle, parents have found it necessary to abandon their children in order for them have a chance at independence. Queensland Shelter, a local disability housing coalition in Brisbane, has termed this a ‘crisis response mentality’ (QLD Shelter, 2010). Many of those who avoid this path and provide care for the full extent of their lives are still faced with equally sudden and harsh transitioning for their children when they either are no longer able to care for them, or pass away. While current funding and support packages are notably more generous and flexible than previous decades, ultimately attempts to plan and execute a smooth transition to future secure and independent living are frequently thwarted with the current systems in place. Researchers such as Matthew Janiki have noted parallels of this phenomenon in other countries such as the US and have reported that “.....there is a low expectation that families – who are the primary carers – will be able to continue to provide care for all of the older adults who will need care” (1998; p. 4).

An Australian study, entitled ‘Service and Support Needs of Australian Carers Supporting a Family Member with Disability at Home’, undertaken in 2009, highlights this dilemma and notes that “if the family home is not realistically a “home for life” for the person with disability, it is reasonable to propose that transition planning commence early so as to avoid “crisis placement” (Burton-Smith, 2009; p.245).

Current Alternatives Available in Brisbane

The overview below is not intended as an exhaustive description of all accommodation and care options available but rather an outline to give the reader a more complete perspective on the project discussed within this paper.

- **Institutions:** Currently in the South East Queensland region there remain a small number of facilities that could still be classified as institutions. One in particular, the Basil Stafford centre has a public and chequered past. In 1995 the Criminal Justice Commission conducted a review of the centre and some serious findings were published from the investigation. It was documented that “a number of unlawful assaults were perpetrated by staff at the Basil Stafford upon severely and profoundly intellectually disabled persons residing there (clients)” (Criminal Justice Commission, 1995; p.15). The overall recommendation from the report was to “close the centre at the earliest possible opportunity”, however the centre remains in operation to this present day.
- **Aged Care:** The Senate Community Affairs Reference Committee in 2005 predicted the number of young people living in aged care facilities to be close to 6,500. In 2006, the Council of Australian Governments signed a 5-year agreement aimed at reducing the number of young people living in residential aged care, with funding of up to \$122 million from the Australian Government to be matched by state and territory governments (AIHW, 2009a; p.170). Of those who participated in the program, 555 people were identified by the government as benefiting from the project. Clearly the difference between an estimated 6,500 individuals and the number listed as receiving aid is not an insignificant proportion.
- **Young Care:** Unique to South East Queensland, an organization was established in 2005 entitled Young Care (Young Care, 2010) which has the aim of creating more age appropriate accommodation for young individuals with high physical care needs who are wishing to avoid aged care facilities. Funded through a combination of

government funding and private philanthropy, Young Care has gained much media attention locally and as it grows rapidly is currently looking to extend past the local region into neighbouring states. As well as being able to reside with other individuals of similar ages to themselves, Young Care strives to provide more desirable living options. Pro-bono design involvement from local architects and designers has resulted in facilities that have features and aesthetic attention to detail normally not found in other high care facilities. While these facilities are undoubtedly a significant improvement on the aged care facilities that would otherwise be an alternative, a main difference between the Young Care and the Living In model relates to the scale of the development. Young Care developments currently comprise of a number of living units closely co-located with areas of private as well as shared facility. This co-location helps in the sharing of care costs across the site, similar to the group housing model. The Living In model, in contrast, works at a more individualised scale, seeking community placed solutions which deal with each family and their needs in a standalone manner.

- **Group Homes:** This model of care provision currently houses a significant proportion of the local population of individuals with severe physical and intellectual disability. Typically in a group home, two to four people sharing a house are supported by a team of Residential Care Officers who provide day-to-day assistance and support. Advocates claim that group homes represent a type of ‘forced co-habitation’ (Qld Shelter, 2010) that contravenes the mandates set forward in the UN charter convention on the rights of persons with disabilities, certainly there are very real issues associated with this model, which include the potential for violence and unwanted behaviour of residents toward each other.
- **Social Housing:** Similar to other housing options, both public and private providers (non profits) exist in the social housing world. Housing options range from boarding rooms through to 5 bedrooms houses and apartments. This form of housing is purely accommodation and as a rule does not include any form of care. It is important to note that as families with children with disabilities often have reduced income due to many factors such as one or more parents acting as full time carers, this form of accommodation may be necessary (AIHW, 2009a).
- **Hostels and Boarding Houses:** Services provided by these businesses range from basic accommodation, through to the provision of meals and in some cases limited support with daily activities. Some of these private organizations also have a dark past in the local area with early service providers being renowned for taking advantage of the vulnerable nature of the residents. Recent reforms have resulted in the closure of many facilities, but the standing of each still varies greatly between reputable groups through to some that are known for their less than desirable practices.
- **Private Homes:** As touched on earlier, a sizeable percentage of families with children with disabilities have raised their children into and through adulthood within their family home. The Australian Institute of Health and Welfare estimated the number to be in the order of 700,000 in 2007. While the rate of home ownership is high in Australia (Kendig and Gardiner, 1997), levels are considerably lower for individuals and families living with disability (Queensland Shelter, 2010), which in turn reduces choice and control over accommodation. It is families within this category that the project outlined in this paper focuses on.

- **Respite:** The main form of care available to families caring within their homes for children with disabilities is respite care. Options for respite include, residential respite care, in-home care of a short (few hours) or longer (few days) duration, host family respite, flexible and/or vacation care respite and centre based day care (AIHW, 2009b; p.24). One ongoing problem that has been acknowledged by families and government alike is the ‘under utilization’ of respite services. In Australia’s Welfare Report in 2009 it is noted that “...few carers report that they have used these services. For some carers this may indicate a lack of appropriate respite services” (p. 188). This view is also supported by family advocacy groups (Queensland Shelter, 2010).

The Project: Up Close

Against this historical and social backdrop, a growing number of families have been faced with the decision of needing to prematurely abandon their children in order to ensure that the state finds suitable alternative living arrangements. Many of these families are aware that this is something of a ‘no-win’ situation, in so much as the perceived advantage of a smoother transition that time might provide (as opposed to the emergency accommodation scenario involved in doing so at the same time as the death of parent) can be negated by the fact that the family often needs to claim, and prove, a state of crisis in order to be eligible for such measures. Certainly, as touched on previously, the dominant options of aged care or co-habitation with strangers (who often have disparate needs) are not seen by many families as viable alternatives, and it is in this climate of lack of suitable options that the Living In project has been growing.

As noted earlier, the project is being undertaken by a collective involving the community service provider (who is also the builder), a group of pro-bono designers, and a university research team. The research team provides both an ethical and conceptual framework for informing the consensus design process as well as also playing a role in enhancing the criticality and rigor of the project seeking a credible and enduring level of engagement and outcome. PhD students embedded in the project focus on certain aspects, for example, policy, design, sustainability and so on, considered chiefly from an interpretivist position while adopting particular methodological lenses (for example, grounded theory, phenomenology) relevant to the questions being asked. In all, the project is regarded as a case study adopting an action research frame-of-reference. Action research, by definition, is an approach that focuses on action and research simultaneously and in a participative manner in order to bring about change, ultimately at the social level (Gray, 2009; p. 313).

The stated aim of the collective is to provide a “world’s best practice model of universal design and adaptability that is the impetus and basis for government and community to enact their hopes for an inclusive society enshrined in human rights and disability legislation worldwide”.

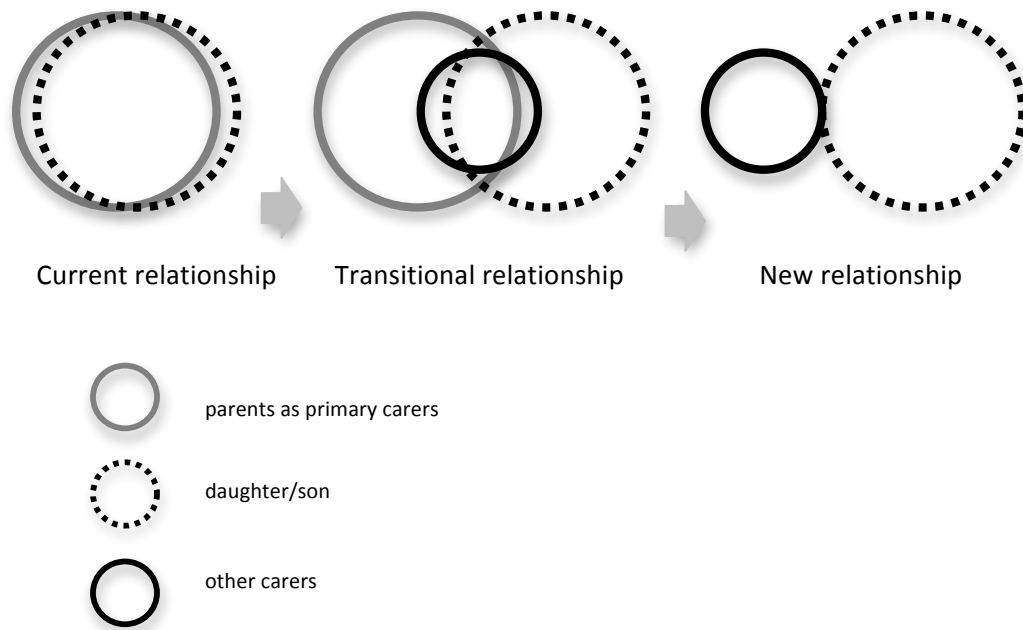


Figure 1. Relational Model of Transition towards Independent Living

Essentially, the collective has been developing a new design model which is based on two interconnected or co-located dwellings; the dwelling for the adult child being essentially ‘a home for life’, and the adjacent dwelling which, in the eventuality that the parents pass away or require care themselves, can be put to a number of uses which allow the child to remain in the home (see Figure 1). This design facilitates, amongst other options, the parent’s home to become a residence for a carer (or carers) after the parents are no longer able to care. Another variation of this model that is being investigated is the option that the parent’s home could also be rented privately to provide income to fund the continuing care of the child after they are no longer able to care themselves.

Most importantly, the model works towards supporting a stable family to transition through these inevitable life stages. As well as this it aims to actively promote the development and movement toward the highest level of independent living that each child is able to obtain. For families who have worked for decades to teach children behaviours that developmentally for others are learned by the time they are five, there is an acute awareness that time is one of the most significant factors in successfully working towards independent living. Certainly, trying to undertake this kind of change during times of high stress or crisis, are clearly not advantageous to a successful outcome.

At present a site is being selected for the first family and the brief development process is well advanced. In addition to this current client family, there are 51 other families associated with the community organization who are interested in working with the collective to provide a more inclusive and independent living option for themselves and their family member. While the project is in its infancy in terms of design and construct, what we are looking at in this paper are some of the current opportunities and challenges faced by this collective, in the hope that they can help others who are tackling this complex issue.

Challenges and Opportunities

Walker (1998) suggested that the support and care provided to people with a developmental disability “is more driven by expectations of dependence rather than the goals of inter-dependence”. Michelson and Tepperman, in studying caregivers note that, “Housing, like other built environments, offers opportunities and constraints for the realization of different patterns of behaviour” (2003; p.592). Certainly the advent of the project saw eager participation from designers based on the belief in the power of the built environment to help support the social goals and aims such at the heart of this project.

As the project unfolded however it soon became apparent that the built environment was simply a small part of a much larger overall nested system of ‘interacting elements’. Cantor and Little’s 1985 ecological model of ageing, if nothing else, begins to illustrate the large number of contributing factors at play in care-giving scenarios.

Paradoxically, the goal of independent living at the heart of the Living In project is one that has been born, in part, due to the dominant government funding structures that are in place. Families are aware that true independent living may be a dream never fully realized with their children, due to the amount of care required, however in order for them to secure a suitable “home for life” for their children (Burton-Smith, 2009; p.245) and the appropriate levels of care that this requires, they are forced to strive to replicate an ideal of independence. This point alone illustrates how intrinsically larger social and political ideologies and practices influence what might at first glance appear to be a simple building project.

If past architectural examples such as the famous urban housing project Pruitt-Igoe have taught us anything, it is that design alone cannot solve complex social and political problems. Much as one might wish it to be otherwise, the reality is that building projects such as these are intrinsically linked to the historical context in which they are born and all that is incumbent with that. One can build the physically ideal model of ‘independent living’ but without adequate funding and larger system supports behind it there is little guarantee of success. This is not to discourage the pursuit of new and lofty ideals, it is simply a reminder that projects such as these are multi-dimensional and as such need to be approached on a variety of levels simultaneously.

One particular advantage that this project does have over other similar ventures is the relative positioning of the key players. Being neither aligned with policy makers or profit driven gives the collective has the ability to approach the inherent challenges from a unique vantage point. It also allows a greater degree of flexibility to adapt the approach to suit the situation at hand. This contrasts significantly to the rigidity often integral to government and commercial projects, which are forced to adhere strictly to political or economic criteria. Flexibility of approach also is mirrored in the built environment, where a major lesson emerging from the project is the need to design in the ability to adapt a home to a wide range of possible futures.

Like many others who have led the way with socially innovative projects, the collective quickly became aware that it may be required to design for a political and social future that does not currently exist. Greg Dees captures this notion well when, in writing about the phenomenon of social entrepreneurship, he points out that “to create significant and long lasting changes, social entrepreneurs must understand and often alter the social system that creates and sustains the problems in the first place” (in Goldsmith, S, 2010; p.27). Each major group in the collective has a particular vantage point that teaches the others about not only what is, but more importantly what is possible. The insight that families and the not-for-profit community organisation have into the political systems that they have engaged with for decades greatly informs the design teams process. Similarly, the designers are able to discuss the potential for the built environment to support or challenge behaviours and interactions, in

ways never before considered by the families. This leads us to finally reflect on the significant lessons learnt to date and consider what the future holds for this project.

Current Challenges and Lessons Learnt

In a 2002 article entitled, Restorative Home Environments for Family Care-Givers, Gowri Gulwadi posits that “The house itself can be considered a system with physical and social characteristics whose synergy creates a holistic experience of the place called home” (p. 198). To take this a step further our project highlights how houses that are the sites for care giving are intrinsically part of larger social and political systems, and as such are not only homes, but potentially workplaces, share houses and even to some extent institutions.

To use the example of the first house within this project, it is unclear yet how the funding bodies will react to this proposed model of independent living, and as such all involved are acutely aware of the need to design in a way that facilitates a range of functional models. If an increased care budget is not allocated to support the client living more independently, there is an understanding that a need may arise to share the accommodation (as has been necessitated in other group home scenarios). Given that the different futures are potentially so disparate the main aim of the design team has been to strive for the pinnacle of ‘adaptable housing’, housing which is not only physically adaptable but arguably more importantly, socially adaptable.

This lesson is certainly one that can be applied to communities on a larger scale. Having moved away as a society from previous decades where a single family may build a home and reside there for life, today any given home may over its life accommodate individuals with a whole spectrum of abilities and needs. This being said there has never been a better time to start working towards a housing industry future that embraces the principals of adaptable design.

Increasingly, evidence is showing that when invested early in a building project only relatively minor additional costs are needed to create adaptable housing. As far back as 2001, Baladin and Chapman pointed out that sums as minor as an “additional 5 percent” can be all that is needed in building adaptable housing and few would argue with the statement that these “are more than made up for by the cost benefits to the community” (2001; p38.14). Margie Scotts et al also point out that “incorporating good architectural design into adaptable housing has assisted the uptake into their private housing markets” (2007; p.15). Certainly this aim is at the heart of the Living In project.

Another issue currently being tackled by the collective in this project is the concept of ownership. While the research team explored in the early days of the project the importance of notions of ‘home’ as opposed to simply housing, it is clear that a sense of propriety and control over ones own space is closely linked to the ability to form bonds and create a home in the truest sense (Cooper-Marcus, 1995, Dovey, K, 1999). The desire to create spaces that are truly considered to be ‘homes’ is currently relating somewhat uncomfortably in the project with some of the economic realities at play. Due to factors such as land availability and cost of building, it is clear that many families which have provided 24 hour unpaid care to adult children with disabilities have done so at the expense of financial security, and as such building one of a kind housing such as this can appear untenable. This fact alone raises further questions. If the not-for-profit community organization is unable to raise sufficient funding to build and maintain these properties, how do families attain a feeling of ownership that is so integral to feeling ‘at home’ and importantly a sense of security that allows them to relinquish care of their children with a feeling of safety and hope?

As touched on earlier, this model is also fundamentally tied to the dominant funding models in place and as such all are aware that the ideal of ‘independent living’ requires a great deal of government support. In the absence of being able to accurately predict how this model will be received by governing bodies, practicality dictates that the collective may be pressured to consider the option of ‘co-habitation’ of more than one individual with a disability until such time as adequate financial support is provided to allow this dream to be properly realised. As such there is a real danger of necessity dictating the replication (in some way) of existing models (group housing) and by doing so reducing the chances of true change being enacted.

Another challenge faced by this collective that is unique to the pro-bono process is the scarcity of time available. With most participants engaging in full time work and also balancing their own social and familial commitments, carving out productive space with which to engage with the process is a constant challenge. This, however, does bring some minor positives. The notably slower progress of the project creates an extended incubation and design process in which a myriad of outside forces and interactions have the opportunity to inform and contribute to the work. Whilst being less single-minded and fast paced, it also opens doors for a more organic and receptive progression.

The other rare advantage that this project has with donated professional architectural and design services, is that it brings a diverse grouping of designers with both commercial, residential and institutional backgrounds together to solve this design challenge. It is this range of different perspectives and experiences that enriches the process rather than diminishes it. Many commercial or government projects draw specifically from a pool of individuals with considerable expertise in the relatively narrow field of disability design, without recognizing the double edged sword that this may bring. While familiarity with the territory may be considerable, such immersion may also be a barrier for individuals in thinking outside their past experience and in the end be an obstacle to the creation of new and innovative solutions. This is not to honour relative inexperience over extensive familiarity with a subject matter, but more to entreat each individual that is part of such a process to consider deeply their own particular vantage point and lens, through which they view the problem, in order to be able to begin to find new and creative solutions to very old problems.

Conclusion

In summary, while this project is not seeking to offer perfect all encompassing solutions to the complex problems faced by families raising adult children with disabilities, it does have the ability to contribute a unique and novel perspective on the problem and propose potential solutions not currently seen elsewhere in Australia. This opportunity to explore solutions outside of the models currently in play is one which at the very least we hope can help provide others who are currently wrestling with these issues a chance to consider the situation from another point of view and ultimately serve as a reminder that we all have the potential, and indeed the responsibility, to work toward a better future.

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