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TECHNICAL REPORT

Supporting independent living for disabled people

An evaluation of the
Foundations for Living Project

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Prepared for the Papworth Trust

The research described in this report was prepared for the Papworth Trust.

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Published 2008 by the RAND Corporation
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Executive summary

Over the last 15 years, both the demand for and suitability of residential care facilities for disabled people has been decreasing steadily, as Government policy has undergone a gradual shift towards enabling disabled people to live independently in the community. Against this background, the Papworth Trust identified the need for innovative ways to provide services for disabled people wishing to lead independent lives. The Foundations for Living (FfL) initiative is the Trust's response to this need.

FfL is based on the principle of providing a range of services, delivered through an inclusive community-based approach, to address disadvantages experienced by disabled people. The project includes three main elements:

- Housing and independent living – covering accessible housing, technical aids and personal care and support
- Community Learning Centre – covering inclusive education and training, support into employment, and accessible information, advice and guidance.
- Community Support Team – providing support and work with external groups to improve opportunities and access to services and employment

In October 2005, the Papworth Trust commissioned RAND Europe to support an evaluation strategy that would assess the successes and challenges of the Foundations for Living initiative, strengthen accountability arrangements, and provide lessons that can then be applied to other services run by both the Trust and other providers elsewhere in the UK and beyond (Stages 1 and 2 of the evaluation). This report sets out the findings of Stage 3 of the evaluation which has focused on evaluating the impact of FfL, and to examine interventions run by other organisations which are comparable to FfL (or to elements of it) in order to draw good practice lessons that are transferable both to FfL and the Papworth Trust, and to the wider community of organisations working on disability issues and social care.

Experiences of independent living: FfL and Papworth Everard tenants

As part of the evaluation of FfL, RAND Europe conducted a number of interviews with service users who had moved to Huntingdon from their own homes or from the village of Papworth Everard, home of the Papworth Trust, over the previous two years. These interviews aimed to shed light on clients' experiences of independent living, their views on the FfL programme, whether these views changed over time, and the challenges and opportunities faced by disabled people living independently. Interviews were also conducted with tenants who decided to stay in Papworth Everard, in order to identify

whether changes that were occurring in Huntingdon were paralleled in Papworth Everard and whether independence was influenced more by the individual than the intervention.¹ The key findings emanating from these interviews were:

- **Independent living is understood and experienced differently by different people** - Differences in people's understanding of what independent living entails can be said to account for much of why some Papworth clients chose to move to Huntingdon, and others decided to stay in Papworth Everard. The latter group did not feel unprepared for independent living or unwilling to experience it; rather, in their view they already were living independently in Papworth Everard, albeit in a different way than those in the larger town. The goal of independence in any intervention must therefore be based on a person-centred definition of independence, not a single pre-determined 'one size fits all' definition.
- **Independent living is a process** rather than an immediate outcome. The research shows that individuals who had at first struggled to adjust to a different way of living at the time of their move from Papworth Everard adapted to life in Huntingdon over a few months, and identified strategies for living independently. When evaluating any independent living intervention, it is important to look over a sustained time-period to understand the journey to independence of any individual.
- **The move to Huntingdon has been a positive experience** for the vast majority of tenants. They have learnt new skills, met new people, and feel both a greater sense of autonomy and generally happier than they had been prior to their move to Huntingdon. In general, increasing social interaction and opportunities for autonomy provides these individuals with a positive experience.
- **FfL tenants were initially concerned about the level of support they receive** - The levels of support when people first moved to Huntingdon were seen to be too low by several tenants. While people now feel more able to deal with various aspects of independent living without support, some still feel they need support with a few activities, for example with a big shop, or if something goes wrong in their flat (a burst pipe or the need to change a light bulb). Maintaining the balance in any intervention between support and independence is a difficult task, and can only really be achieved through effective monitoring and person-centred planning.
- **FfL tenants were very enthusiastic about having their own flat in the centre of town** - Most people especially liked: the space; choosing their own furniture; the privacy – 'having their own front door'; the proximity to shops and other amenities; the opportunity to cook their own meals and take more care of their own affairs. The privacy and autonomy of having their own flat is valuable in

¹ It is worth noting that during the process of FfL in Huntingdon, the Papworth Trust realised that service provision in Papworth Everard would also have to change to provide more independent living opportunities. Therefore, although those living in Huntingdon have clearly moved to a more independent lifestyle, those in Papworth Everard have not necessarily remained 'stationary' in terms of their independent living situation.

itself, and the town centre location allows individuals to take part in aspects of town life that had previously been unavailable to them.

- **The relationship between tenants and staff is an important determinant of success** - FfL tenants felt that generally they were partners in the support relationship, with staff taking on board their views. By ensuring the staff-client relationship is positive, the Trust can provide a positive experience for clients, and move towards a more individualised service.

Bringing FfL to life: collaboration with 'development stakeholders'

As part of its remit to understand the development and ongoing successes/challenges of FfL, this evaluation aimed to gain insights into the views and experiences of 'development stakeholders', i.e. partners who were engaged in the process of designing, developing and implementing the initiative (including local council, housing developers, support and care service providers, and others). These interviews were undertaken in order to gain insights into the Trust's relationships with stakeholders in the process of bringing FfL to life. These insights provide useful lessons about managing and optimising relationships with key stakeholders in order to improve the effectiveness and efficiency of the intervention. The key findings from these interviews were:

- **Understanding of and familiarity with the aims and mission of the FfL project ranged considerably among stakeholders** - While some indicated that they understood the aims of the initiative when they became involved with it, others said they did not know much about it at first, and only learnt about its mission and aims over time. In spite of these differences, when asked how they would describe the aims of FfL there was a considerable degree of correspondence between the different descriptions offered. Most people understood that FfL aimed to enable disabled people to live independently within a mixed community. Developing a shared understanding of the aims and objectives of a collaborative project can contribute to steer the project more effectively.
- **Most stakeholders viewed their participation in the project and their relationship with the Trust as productive and positive** - A few explained that communications were handled fairly informally, which worked well. Others had more formal communication channels with the Trust, for example through regular meetings, but even within these there was a degree of flexibility that meant these channels could respond to changing circumstances and emerging pressures. A number of interviewees suggested that improved communications at the early stages of stakeholders' involvement with FfL, about the project's aims, mission and objectives would be useful.
- **Involvement with FfL can raise disability awareness among development stakeholders** - While several of the interviewees stated that their organisations already had disability awareness and accessibility policies in place, others said that their involvement with FfL had a positive impact by stimulating further awareness of disability issues.
- **Positive perceptions of the project can strengthen collaborative relationships** - Stakeholders' commitment to the project are in part informed by their views on

whether the project has been effective. Moreover, positive reviews of the project can contribute to developing a network of collaborators for future initiatives. While most interviewees did not, at the time of the interview, have substantial evidence to support their conclusions, the majority were of the opinion that FfL was a successful initiative, informed partly by their own involvement and partly by feedback from other people. Regular feedback to stakeholders and collaborators on the outcomes of any intervention can help to reinforce these positive relationships.

- **Community learning centre management views** – As a new service, the staff team at the community learning centre are still learning about the role of the centre in Huntingdon. The need to understand the views of their own stakeholders (from the regional college to the general public and the Trust’s own clients) has been prioritised in order to ensure that the centre fulfils its potential. This kind of needs analysis is something that can be a powerful tool in providing a service that fits well with the community it is designed to serve.

Lessons from other community-based interventions: Case study findings

The research team conducted case studies of organisations that provide similar interventions to those in FfL. The findings from these case studies can provide learning opportunities for the Papworth Trust and the case study organisations themselves. The case studies selected in this research are not restricted to disability interventions, since the aim is to learn from good practice in adult social care in the fields of accessible housing, community learning, support and independence, and a combination of the three. The case studies for each area (chosen in consultation with the Papworth Trust and independent experts in the field of social care) are **Habinteg** (accessible housing); **Idea Store** (community learning); **Optua** (support and independence); **Foyers** (integrated services). The key lessons arising from the case studies are:

- **Planning for sustainability from the outset of a project is crucial to ensure its continued success** - The challenges of longevity and sustainability stand out from all case studies, which involve external funding. For new projects it is possible to create a wave of enthusiasm that brings funders along with a new idea and a new way to address problems. However, maintaining the enthusiasm and interest of funders proves to be far more difficult and when interventions are no longer a ‘flagship’ this can lead to deficits in funding.
- **Stakeholder involvement is another necessary element to ensure a project’s success** – The issue of stakeholder engagement in interventions is linked to that of sustainability. The Paine’s Mill Foyer, Habinteg, Optua and Idea Store all have a number of stakeholders with whom they must interact in the long-term in order to produce a useful and integrated service.
- **The Community Learning Centre in Huntingdon (Saxongate) can learn from the experiences of the Idea Store** in providing a resource for the whole community – Three of the key attractions of the Idea Store that draw people into the centre are the availability of computers for internet and other uses, the library (which includes fiction, non-fiction, educational and reference books as well as magazines and newspapers), and the café. The interviews and focus groups

indicated that these three facilities create an open, welcoming atmosphere which attracts a wide range of users. The Idea Store believe that by attracting numerous users in the first place, many of them will then opt to also participate in some of the other activities offered, such as courses and cultural events. This highlights the importance of strategic thinking about the mix of services that an organisation such as Idea Store or Saxongate needs to provide to attract, retain and engage a wide range of users and creating an appealing, inclusive learning space within the community.

- **Habinteg provides interesting lessons about the management of an integrated housing project** -The management of the project is overseen by a designated employee who lives on/near the site, whose role is that of site management (not care or support). Residents who have higher support needs value having a close point of contact available in the development. In spite of social activities such as coffee mornings and Christmas dinners, which the site manager helps to organise, some tenants felt that independent living in the community often comes at the expense of reduced interactions amongst tenants. This sense of having reduced opportunities to intermingle with other tenants in independent living arrangements was also brought up in interviews with FfL tenants. While not necessarily part of the stated remit of independent living initiatives such as FfL and Habinteg's, it might be worth considering the importance of providing spaces to facilitate social interaction as part of the 'integrated services' available to tenants.
- **There are interesting lessons to learn from the experience of Optua homecare with support service provision** -The links between Optua homecare and the other sectors of the organisation (such as care) are formalised, leading to learning within the organisation. Since the Papworth Trust, and in particular FfL are looking to provide a similar wide variety of services, we would stress the importance of a formalised method of communication between disparate activities.

Conclusions

The study has shown that, overall, Foundations for Living tenants are very satisfied with their move to independent living in Huntingdon. Many of the tenants have learnt new skills, enjoy the town-centre location and proximity to shops and other facilities, and relish having their own flat. Most report that the move to Huntingdon has exceeded any expectations they had prior to the move.

The value of co-locating the community learning centre in Huntingdon with the housing is less clear-cut. There has been a positive uptake of the facilities and courses at Saxongate by local businesses and individuals. However, tenants have tended to use Saxongate for informal support and social contact rather than for accessing formal learning courses. Similarly, the impact of co-locating accessible affordable housing with private housing is still unclear.

The research also shows that the scheme might not be suitable for everyone. The interviews with people who decided to stay in Papworth Everard reveal that different people have

different understandings of what independent living means. Many of those who stayed in Papworth Everard reported that they already feel independent in the sense of having a significant sense of autonomy in decision-making.

The study suggests that there are a number of challenges which merit further consideration. A number of suggestions based on the findings from the interviews and case studies emerge which aim to act as a springboard for discussion and planning within the Papworth Trust (and other interested organisations). They are not exhaustive, nor are they prescriptive; rather, they are intended to stimulate thinking about ways to improve, expand or strengthen existing service provision by responding to some of the challenges raised through this research.

- Prior to the move to independent living, it is important to ensure that service users have a robust understanding of what independent living entails, and the types of support and assistance they can access (particularly in the more challenging first few weeks and months)
- It would be valuable to review the role of the Saxongate Community Learning Centre, in terms of its role within the Foundations for Living initiative and within the wider Huntingdon community
- To look at how Saxongate can most effectively respond and adjust to the needs of the community, including attracting groups who are not currently using Saxongate, through careful monitoring and review.
- For future initiatives, to ensure early involvement of key ‘development’ stakeholders, and the provision of full information on the aims, objectives and mission of the project and the Papworth Trust

As the Papworth Trust continues to look for opportunities to develop other independent living schemes, the findings from this report and other learning activities undertaken by the Trust provide an invaluable knowledge base on which to build future initiatives. Similarly, policy and social changes encouraging the move towards independent living for disabled people mean that the findings and suggestions in this report can be used by other organisations as part of an evidence-base for the provision of services of this nature. In addition, in the context of an ageing population and its concomitant likely increase in the demand for accessible housing, the ability to deliver effective, efficient and sustainable independent living services takes on new relevance.

As this report aims to show, helping disabled people live independently requires coordination and collaboration among a number of diverse stakeholders. Recognising the importance of consultative, open and responsive project development is paramount to enable disabled people have greater access to housing, education, support, transport, employment and leisure opportunities within inclusive communities.