

The Good Life: visualizing the complexity of supported living for people with disability

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ABSTRACT

This paper outlines the development of an interactive visualization tool, 'A Good Life,' which emerged out of a collaborative project between design researchers and practitioners from the University of Technology Sydney and Northcott, an Australian disability services organisation. Northcott provides supported accommodation services for people living in group homes (up to 6 people) with moderate to severe intellectual and physical disabilities requiring 24-hour support.

Supported accommodation provides housing for marginalised and vulnerable people, often with limited resources. Working in this environment can be challenging but also rewarding. However, residents face even greater challenges because decisions made by others primarily determine their quality of life. These decision-makers can include family members or long-term support workers who have a deep understanding of the resident, allied health professionals who interact with the resident regularly but have a limited perspective, and government officials who lack a personal relationship with the resident but formulate policies that consequently have a profound effect on them.

A significant issue for people with disability is the lack of visibility or understanding regarding how decisions affect their quality of life. To address this issue, the tool visualizes how decisions can restrict or enhance opportunities for people with disabilities. Additionally, it seeks to improve levels of communication by better expressing the will and preferences of the residents.

Keywords: Visualization, disability, care, decision-making

1 INTRODUCTION

In Australia, 5.2% of individuals with disabilities receive support from the National Disability Insurance Agency (NDIS) and reside in supported independent living (SIL) accommodation, also known as group homes [1]. The ongoing Australian Disability Royal Commission has shed light on the significant shortcomings of group homes in meeting the needs of residents [2]. One of the central concerns is the lack of choice and control experienced by people living in group homes. Respondents, including family members, professional bodies, advocacy organizations, individual advocates, government agencies, and service providers, have identified that individuals have limited choices regarding living arrangements, support providers, and housemates [3]. These limitations can affect people's ability to exercise their will and preferences. While we acknowledge the flaws in the group home model, many people are living in these homes, and meaningful change at a structural and systemic level is necessary.

Northcott is one of Australia's largest not-for-profit disability organisations, offering services in both metropolitan and regional

areas of New South Wales (NSW) and the Australian Capital Territory (ACT) [4]. The organization provides Supported Independent Living (SIL) services to almost 500 people. Residents living in these group homes typically require 24-hour support. They often have varying levels of intellectual and physical disabilities, ranging from moderate to high. In Northcott's case, a significant portion of them are non-verbal, requiring alternative supports for communication. It's worth noting that while residents in SIL often live in group homes, this is not always the case. They can also live alone.

Supporting people with disabilities in group homes is complex. The driving force behind this work is the application of Person-Centred Active Support Principles. These principles focus on a strategy that enables all individuals, regardless of their cognitive or physical limitations, to exercise choices, partake in meaningful activities, and foster social connections [5]. Even though the Person-Centred Active Support model provides well-defined guidelines for optimal approaches to greater levels of inclusion, independence and choice, translating these into practice within group home environments can sometimes present challenges [5], [6]. The overall support system involves multiple stakeholders, including frontline support workers, house managers, allied health practitioners, safeguarding committees, CEOs, policymakers, government ministers, friends, families, and guardians. Although the overarching goal is to provide high-quality support, each stakeholder's priorities and decisions may not always align with the needs of the resident [7]. These priorities can range from meeting basic needs, ensuring safety, financial stability and considering work conditions to realising individual preferences and promoting enjoyment. Furthermore, the operational complexity of the system is compounded by the diverse expertise required, the need to define roles and responsibilities, and the presence of regulatory frameworks, often leading to conflicting priorities [8].

In addition to the complexities described above, support teams face the challenge of managing vast amounts of information. This includes familiarising themselves with policies, procedures, individual profiles, and organisational details. They must also acquire knowledge about how each resident communicates, their typical and atypical behaviours, dietary requirements, medical needs, and various other information crucial for ensuring residents' general health and safety [9]. While this focus on health and safety is essential, it does not necessarily capture what truly matters to the residents or what constitutes a meaningful life for them. This information exists but can be difficult for new or casualised staff to access and absorb quickly, and it often gets lost amidst piles of paperwork or within poorly designed IT systems [9]. Consequently, supporting a resident in realising their will and preferences becomes difficult when this vital information remains unrecorded or obscured.

Defining what constitutes a meaningful life for individuals residing in group homes raises important questions. For instance, is

it sufficient to meet basic needs such as cleanliness, nutrition, safety, and rest? Or is a meaningful life based on individual choices and preferences that require more ambitious support requirements? Different perspectives on quality of life exist, depending on the observer's viewpoint. For instance, a support worker may have their understanding of what it means to provide the support that leads to a high quality of life, which may differ from that of a parent advocating for their child or a senior staff member responsible for ensuring the organisation's compliance with regulatory requirements related to risk and safety.

This paper demonstrates how creating an interactive visualization tool can empower individuals with disabilities to effectively convey their preferences, which can often be obscured within these multi-stakeholder support environments. The tool introduces innovative techniques to improve communication by incorporating diverse qualitative approaches to information visualization. It builds on research that shows how the quality of life is dependent on developing a good culture in the home, one that supports choice, autonomy and independence [8], [10]–[12]. It also responds to the principles outlined in the United Nations Convention for People with Disabilities, which emphasizes the importance of promoting self-determination in one's lifestyle and upholding the quality of life.

2 METHODS

We drew on a range of traditional (desk), ethnographic (interviews and focus groups) and design-led methods (diagramming, mapping, prototyping) (UTS HREC REF NO. ETH22-7604). These methods enabled us to build a better understanding of supported living and laid the foundation for the initial design prototype. Importantly our work is directly informed by the lived experience of service providers and residents, as well as literature on what makes a good group home. This includes the role of culture within the home [6], [11], [13], the principles of Person-Centred Active Support [14], as well as the work of philosopher Joan Tronto and others that explore the characteristics of care practices [7], [15]–[18]. The prototype was developed through the following stages: problem scoping and definition; consultation, and visualising and prototyping.

3 PROBLEM SCOPING AND DEFINITION

Initial research involved observations and interviews with staff. We also surveyed and analysed analogue and digital de-identified client records and other organisational paperwork, which was kept in the homes and in the central office. This enabled us to define better the problem being presented to us in collaboration with Northcott staff.

3.1 CONSULTATION

In the research process, consultation played a critical role in enabling us to access the expert insights of staff. This consultation encompassed various methods, such as conducting interviews and focus groups with Northcott staff from various levels of the organisation. We spoke to frontline workers and coordinators, risk and compliance assessors, financial managers and members of the Executive. These insights provide a clearer picture of staff challenges and the difficulties of supporting residents to realise their will and preferences.

3.2 VISUALIZATION AND PROTOTYPING

We created diagrams and maps of supported independent living environments in response to these initial findings. This approach aimed to enhance our comprehension of information and how decisions flowed within the context. Subsequently, these

visualizations were communicated to Northcott. They served as the cornerstone for the development of multiple design prototypes.

4 FINDINGS

We identified three key factors that added to the complexity of supported living at Northcott: Multiple layers of decision-making, costs and gaps in funding and tensions between risk and choice.

4.1 MULTIPLE LAYERS OF DECISION-MAKING

Amongst the competing priorities of support providers, the day-to-day life of the person living in a group home can become lost, moved from the centre of the decision-making process to the periphery. During our research, we noticed that it was difficult for most people to understand how the priorities of others and the resulting decisions affected individuals. Most people viewed the system from their perspective. Let's consider Steve's support worker, who is constantly trying to strike a balance between handling Steve's risk profile and safeguarding his quality of life, all while addressing the need to be more efficient. Steve is 32 years old and has physical and intellectual disabilities. While he enjoys rugby union and baking, he dislikes showering. Typically confined to a shower trolley for expediency and safety, Steve finds this process stressful. Despite the trolley being quicker and safer, Steve prefers showering in a chair for the sake of dignity, even though it's slower and riskier and requires more support. This tension between risk and efficiency is common. Not only does it affect Steve's quality of life, but it also reduces his ability to express his preference for showering more independently and with dignity.

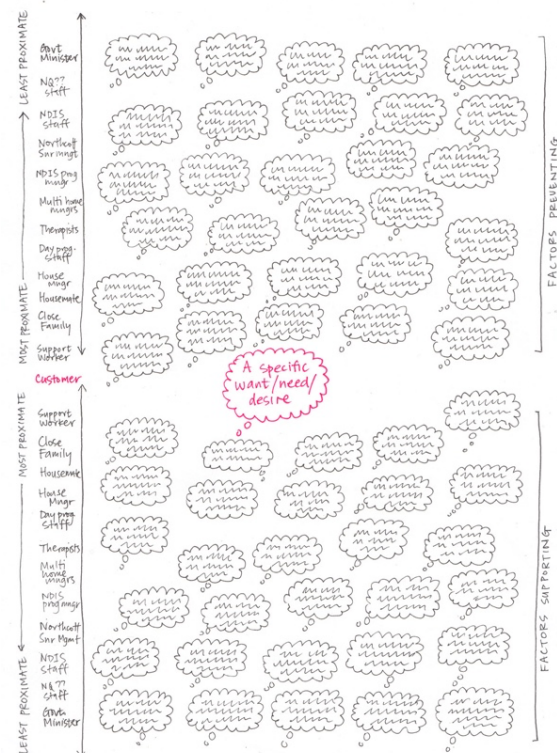


Figure 1: visualizes the layers of people involved in either preventing or supporting a resident's needs.

4.2 COSTS AND GAPS IN FUNDING

Many people living in supported living are individually funded by the NDIS. However, tensions between how the scheme is structured, assessed and implemented persist, particularly for those living in group homes [19]. For example, if a client is assessed as

requiring 1:2 support (one support worker, two residents) and all the other residents of the home are out of the house for the day, Northcott has no choice but to provide a support worker at a 1:1 ratio. The client's NDIS funding will cover the cost for half of that support worker, whilst Northcott must bear the cost for the rest as it's impossible to roster half a support worker. *Figure 2*, visualizes how activities are either possible or not possible due to gaps in funding. As we will discuss, this line between possible/not possible, that is, which activities a resident is able to do (or not do) due to decisions around cost, is a key feature of our final prototype.

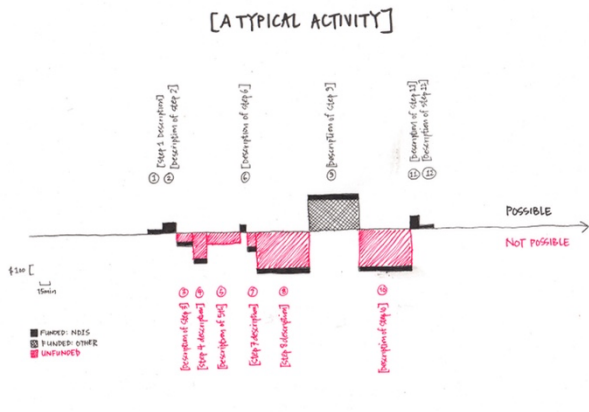


Figure 2: visualizes how activities are either possible or short due to gaps in funding.

4.3 TENSIONS BETWEEN RISK AND CHOICE

Our research revealed that one of the key tensions in supported living is the relationship between risk and choice. Whilst risk may lead to undesirable outcomes, avoiding risk entirely limits choice and the potential of a full life [20]. Whilst many support workers understood the concept of the ‘dignity of risk’, that is the ‘dignity afforded by risk-taking, and the subsequent enhancement of ... quality of life’ in practice [21], supporting a person with a disability to have the autonomy to take risks is not straightforward.

Let’s take the example of Amelia’s support worker, who constantly has to balance Amelia’s risk profile and independence, as well as the need to be efficient. Amelia loves coffee. At around 3 o’clock she will often ask for a coffee or go into the kitchen and try to make it herself. Her support workers struggle to assist her at this time of the day. Following is an example of the issues a support worker juggles in this scenario: “Amelia always wants to make it herself but by the time I wait for her to ‘help’, it will take half an hour. I don’t have that time. The others will be home from the day program soon and then it will all kick off if we don’t get straight into our usual routine. And if she helps, she could burn herself and then I’ll have to write an incident report. I could get into trouble. I also worry that if she has a coffee now, she’ll be up all night. If she won’t go to sleep, the night shift will be angry because they’ll have to deal with it. But I guess it’s her choice.”

Figure 3 explores two key ideas. First, that the relationship between quality of life, risk and cost are constantly related. Second, is that people perceive these tensions differently. The triangles are the same activity explored by different people.

It became clear that managing the relationship between risk, cost and quality of life is a complex and ongoing aspect of working in supported living. Showing how these different priorities impacted the residents became core to the visual tool we developed.

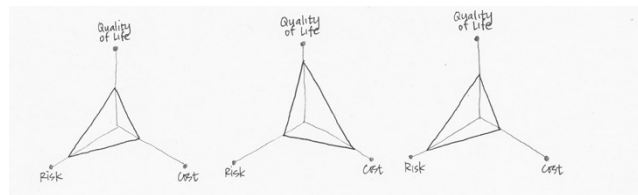


Figure 3: explores two key ideas. First, that the relationship between quality of life, risk and cost are constantly related. Second, is that people perceive these tensions differently. The two triangles are the same activity being explored by different people.

5 THE PROTOTYPE

The ‘A Good Life’ tool operates in various ways. Primarily, it portrays a resident’s daily life by illustrating their activities. Inside the dotted line, you can observe the activities ‘Steve’ (a fictional resident) engages in over a week. These include tasks like sleeping, eating, attending day programs, and playing board games, among others. The size of the bubbles indicates the time allocated to each activity. Beyond the dotted line, you’ll see activities that Steve desires to engage in but currently doesn’t, such as attending a football game.

Another feature is the *colour* of the ‘bubble’, providing different perspectives on the activities. For example, selecting ‘risk’ from the dropdown menu reveals the varying levels of risk associated with activities—the darker shades indicating higher risk. The activities can also be viewed through lenses of cost, complexity, or enjoyment. Activities lacking colour indicate tasks critical to Steve’s support but not involving him directly—these are carried out by his support workers, such as cleaning and laundry.

Another tool function allows disability providers to gain a clearer understanding of how their decisions impact a resident’s life. For example, adjusting the slider to prioritise risk reduction lessens the occurrence of high-risk activities. This is evident from the absence of dark bubbles in Steve’s life, within the dotted line. Unfortunately, this also means the activities Steve loves are outside the dotted line, and his life is now confined to essential tasks like showering, sleeping, and eating which does not lead to a fulfilling life.

Similarly, if the goal is to minimise costs, the resident’s ability to engage in activities beyond the basic essentials like eating, sleeping, attending day programs or going to the doctor is limited. However what if a resident likes feeding ducks in the park or watching movies with friends, these activities might not materialise due to associated costs that often fall outside the coverage of the NDIS. The tool also includes a feature known as the support slider. By adjusting this slider to the left or right, you can visually observe the amount of support allocated to a resident and its direct impact on the variety of activities available to them.

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