

“It just looks like a field to anybody else”:

*Interdisciplinary perspectives on the role of the
neighbourhood for people affected by dementia*

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Linking dementia and neighbourhoods

- ▶ Neighbourhoods and design/ dementia friendly communities
 - ▶ Discourses of localism/the 'Big Society'
 - ▶ A shrinking world
 - ▶ Therapeutic landscapes
- 

“Building more dementia-friendly communities will take time. The Alzheimer’s Society will take the lead, working with members of the Dementia Action Alliance to create a formal dementia friendly recognition process that will make villages, towns and cities accountable to people with dementia and their carers through local Dementia Action Alliances. They will identify what villages, towns and cities need to do to be recognised as dementia-friendly. Only villages, towns and cities that meet their criteria will be granted dementia-friendly community status.”

(DoH 2012)

A shrinking world...

“A ‘shrinking world’ tends to lead to an overall decline in independence as places such as town centres become ‘no go’ areas, and even shopping locally often becomes dependent on being accompanied by a carer”

(Duggan et al 2008)

“Outside spaces can be anxiety-provoking (for both carers and people with dementia) leading to constraints on previous levels of outdoor activity”

(Brittain et al 2010)



About the project

Research questions

- ▶ How do carers for people with dementia use their neighbourhood and what does it mean to them?
 - ▶ How can carers and people with dementia be supported locally?
 - ▶ How can engagement with the community help in designing for the needs of people with dementia and their carers?
- 

About the project

Sample

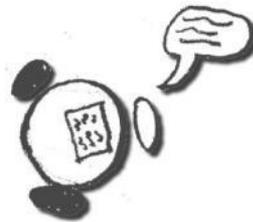
- 12 women / 2 men
- 10 Carers / 4 Ex-carers

Methods

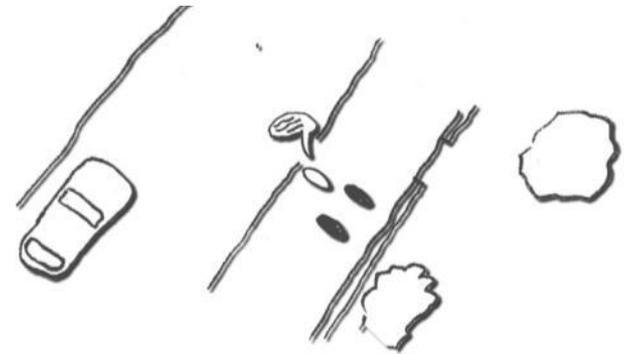
1. Discussion groups
2. Social network 'maps'
3. Walking interviews
4. Mobility diaries



1.

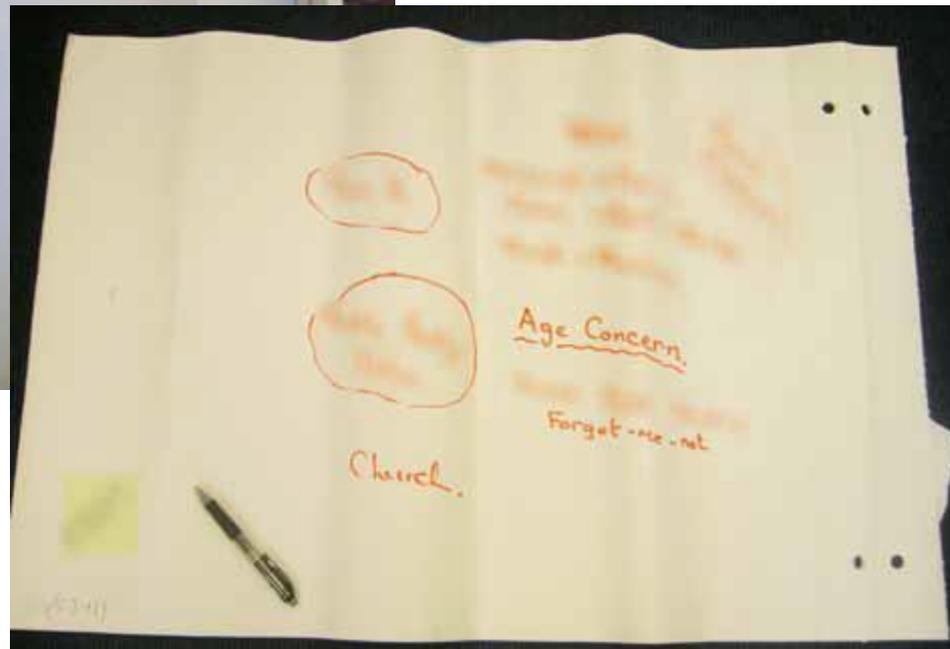


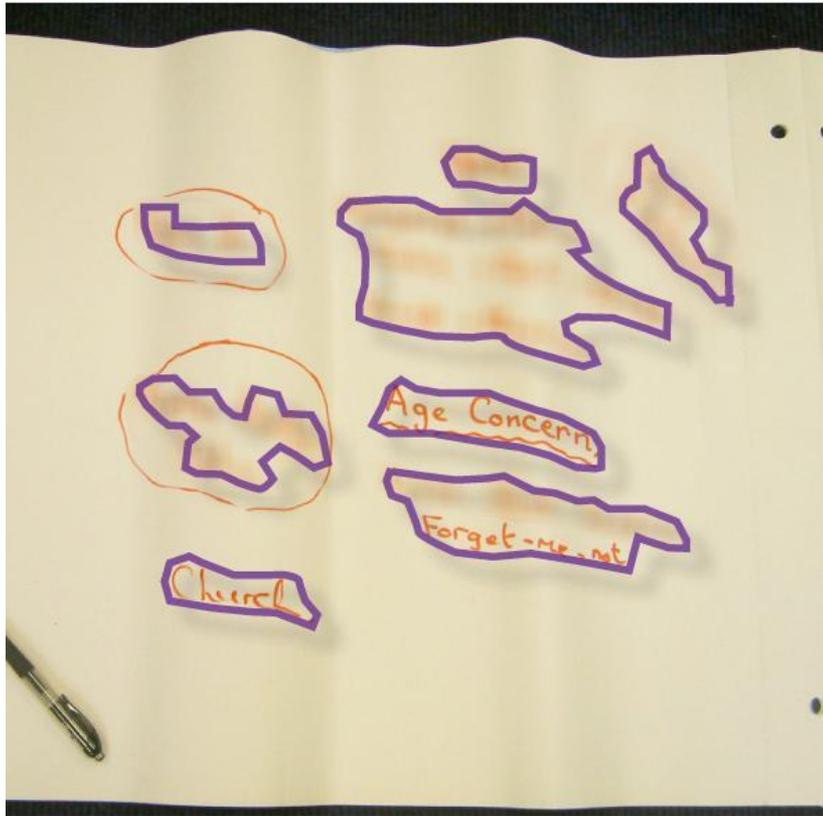
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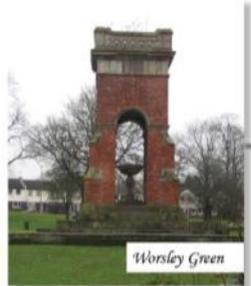
Social mapping





- Cared For
- Carers
- Careworkers
- Family
- Old Friends
- Neighbours

Walking interviews





Changing meanings of family

- ▶ *“family don’t interfere. You’ve probably come to the wrong person really because I’m sure there’s a lot of other families where a lot of people, the carers, whose family pop in each day”* (male carer 1)
- ▶ *“To be honest with you... because it wasn’t life threatening I didn’t have to get on the phone and shout ‘[son] your dad’s dying, come up and see him’ because he lives... 200 miles or so away... [son] saw him for the first time for a long time [last] Christmas... and I think it was the first time he had seen his dad and spent time with him... I think he was a bit upset”* (female carer 2)

Changing meanings of home

▶ The home as ‘prison’

For people with dementia... *“John doesn’t go out as much now because the last time he did he decided that he would go for a walk, ‘I’ll just go round the corner’. The corner is right down the road. John doesn’t stop. John goes on. So about five hours later... I have to phone the police”*

(female carer)

For carers... *“It’s when you go home. Then you feel isolated and you think there’s no one but you that’s in this situation and you’ve got to keep telling yourself ‘oh no, I was out this afternoon’, or ‘I was out yesterday’. Or ‘I’m going out tomorrow or the day after and am meeting people who are in the same situation”*”

(discussion group)

The importance of the neighbourhood

- ▶ Neighbourhoods as ‘therapeutic places’
 - ▶ What are neighbours for?
 - ▶ Hidden support
 - ▶ Neighbourhoods and collective capacity to care
- 

Neighbourhoods as ‘therapeutic places’



It just looks like a field to anybody else

Neighbourhoods as 'therapeutic places'

It's one of our favourite walks, not very far. We just go... onto the canal and we walk along just around. Look at the boats and it's the same summer and winter because it's always a nice scene... I'm hoping we might see cygnets. There were some cygnets last week so that was quite nice.

Q: So you say this is a favourite walk.

Yes. Well I don't find there's an awful lot of places we can walk. ... I don't do it on my own because [he] comes with me, because I can't really leave him on his own... There's memories for me and [he], I tell him all about the past and you know, so he's involved with it... It gets all things, you know, all things -I don't know, memories for him. It brings him out and he just gets talking about things. I think when we're walking I don't know whether it just helps, but he seems to cotton on to things. You know, I'll say 'oh do you remember this at such a time or do you remember these sorts of trees' you know on holiday and different things... I jog his memory I think because then he starts talking about when he was a little boy and where they lived. ... When my mum was alive we used to walk it all the way through, cut through this football field. We used to do that with the children and grandchildren... It just looks like a field to anybody else, but it is nice... I think it's quite beautiful really.

(female carer)

Getting out and about in the neighbourhood

- ▶ *If she sees it's nice and sunny she might want to go out for something to do... there's a coffee shop where we go in and the girls take a big, they love [xx] you know, they think she's great you know, always seeing to her, and she wouldn't know them in the street but there she could*

(Male carer)

- ▶ *“Quite a few people go in [the pub]... That are [disabled] in some way or another, you know, not all with dementia, other things as well, and the staff there are, you know, they're very considerate with them”*

(discussion groups)



Getting out and about in the neighbourhood

- ▶ Leaving the home as breaking with routine
 - ▶ ...but with 'organised spontaneity'
 - ▶ Maintaining independence and the need for 'planned risks'
- 

Getting out in the neighbourhood: the importance of opportunity

- ▶ For carers...

Q: *What stops you from getting round to [coming here] ?
Because whenever we meet we're drinking coffee and eating
cake.*

R2: *Or we're delivering the men and just come here.*

Q: *You're delivering?*

R2: *We're delivering the men to their club, lunch club, and
then we escape.*

Q: *You escape?*

R2: *We've got like four hours on a Friday.*

R: *We could bring a flask with us.*

(female carer)



- ▶ For people with dementia...

*We've got the cricket club further up which is very functional,
very good, Dave is still a member because he enjoyed cricket,
he's not able to go up, but he likes to be a member still, so it's
there in his mind that when he feels like it he can go.*

(female carer)

Getting out in the neighbourhood: Issues of mobility

Without the car I think I would have killed him or walked out... I've got the relief of being able to say 'fancy going out... come on, let's get in the car and go for a ride'. And I think 'I've left the house', I've left the washing and the ironing, especially the cleaning, get in the car and go out... it didn't mean you were a prisoner in your own home, it didn't make it so that 'you've got dementia. You can't go out. You don't know where you're going'

(female carer)

We don't do such long walks as we did, but yes we still like walking... I tend to take the car so far now because he doesn't walk as well as he did so we do shorter walks

(female carer)

"Ed's condition is causing a bit of a rift because (our son) doesn't think I'm handling it properly, because I still, you know, Ed still goes out walking, and that and (our son) thinks I'm letting him be in danger but there's no way I can keep him in anyway"

(female carer)

Neighbours and neighbouring

- ▶ Neighbours as ‘intimate strangers’
 - *Courtesy and consideration*
 - *Knowing from a distance*
 - *Issues of ‘disclosure’*
 - *A watchful eye*



Neighbours and neighbouring

Yes his sister knows.... And my friend in Preston. That's it.

Q: Okay but that's it... so you've not told your neighbours?

No not really no, no actually.

Q: I know it's a personal question but can I ask you why you've ...

Well, the reason why is because I don't want them to spread it all over the place. Just leave him as he is.

(female carer)

[Neighbours] will say hello to her but none of the people in the road, they all, they don't know what to do. That's the nicest way of putting it. They don't know what to do... we don't have anything to do with them really

(male carer)

Neighbours and neighbouring

Rob's been great next door in the way that he doesn't moan.

Q: What do you mean he doesn't moan?

Well about noise of anything. And I said to [my son] if your dad starts getting up in the middle of the night [and making a noise], and Rob's got to go to work in the morning then I'll have to see about having him in a home because it's not fair on them

(female carer)



Neighbourhood roots

Yes fifty years now, and the couple across also have and next door, so it's a nice community, we're all very friendly but not imposing, we've all had sort of jobs and work, so we've learnt that yes we're here for each other, but not always popping in and out of each others houses as such, we've got our own privacy which is a good thing, but if any help is needed then they're there for you... There's a lot of older people that have been here for many, many years, so those again are always the caring people because they know your history, and they've known our children, and they ask about them and they understand the situation

(female carer)

Neighbourhood roots



He was becoming more and more lonely... his neighbour died and one or two of his friends died or they moved away to live with family or near family.

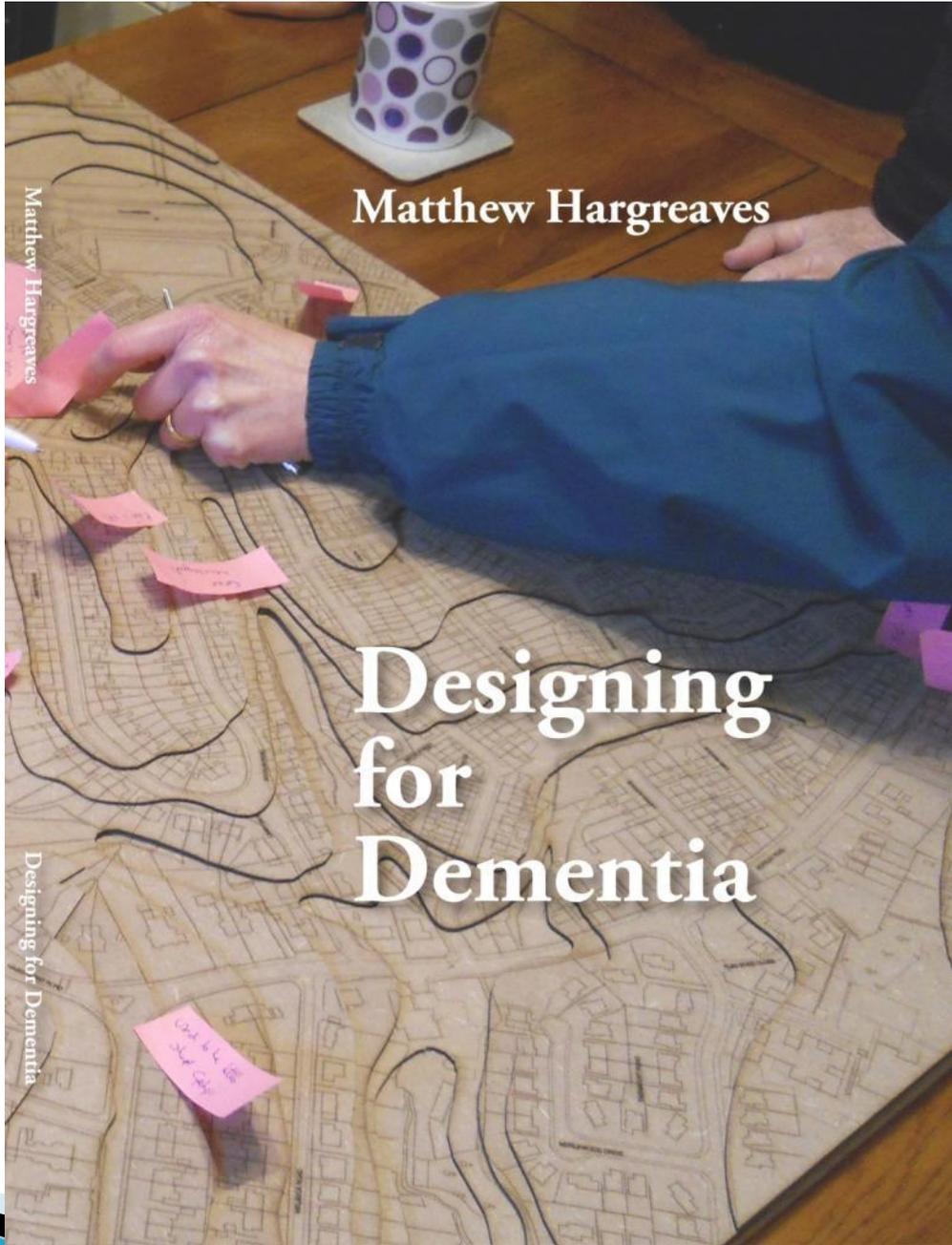
Q: People of his generation?

His generation... They were a different set of people that were moving in, because again they were building apartments and new house, so it wasn't the village that he had [moved to] twenty, thirty years ago and he just said to me I can't stand another winter here, I've not seen anybody all week.

(female carer)

The neighbourhood as built form





Matthew Hargreaves

Designing for Dementia

Matthew Hargreaves

Designing for Dementia

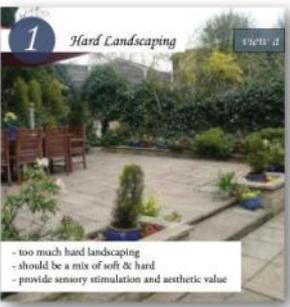
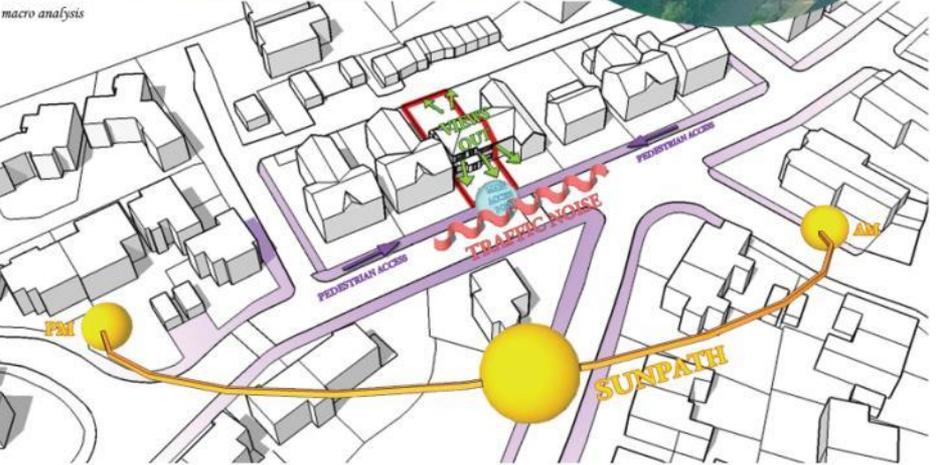


My intervention is to create an informal, comfortable space where anyone in the neighbourhood can drop in and chat to other neighbours, and relax. I wanted

the space to feel as homely as possible, so the design is based around this house on Hazelhurst Road, which is currently for sale.

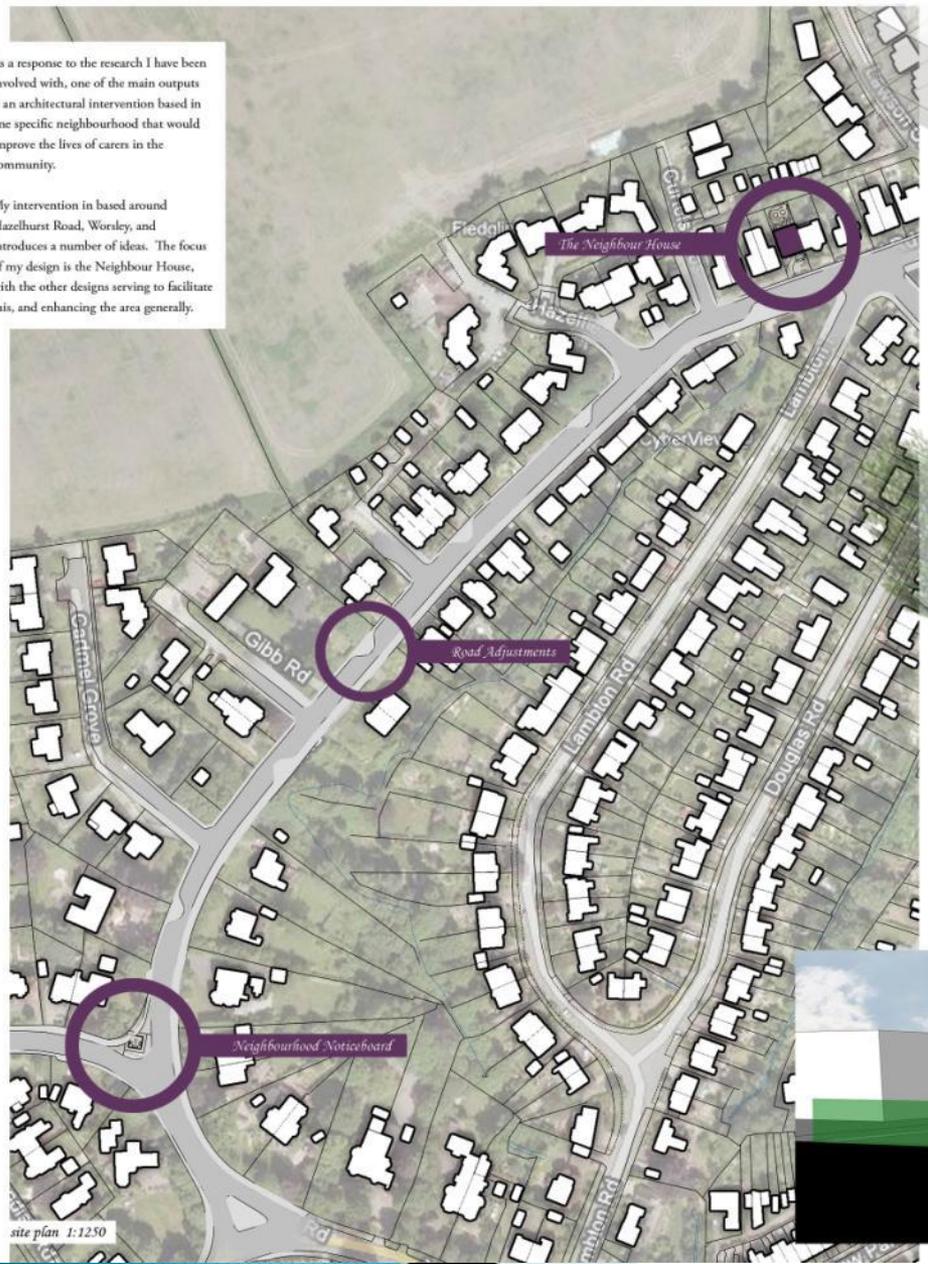


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As a response to the research I have been involved with, one of the main outputs is an architectural intervention based in one specific neighbourhood that would improve the lives of carers in the community.

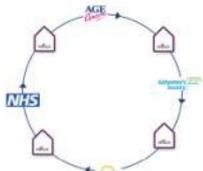
My intervention is based around Hazelhurst Road, Worsley, and introduces a number of ideas. The focus of my design is the Neighbour House, with the other designs serving to facilitate this, and enhancing the area generally.



Accessible W.C.s



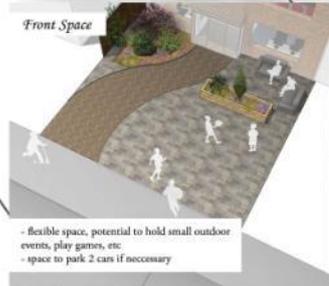
Office Space



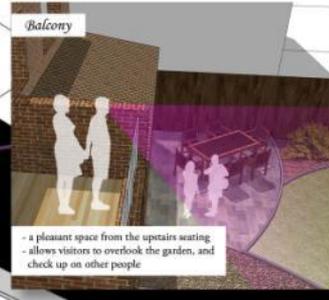
office to accommodate the needs of workers from various organisations. Generic workspace, fit use of computers/laptops, tele-communications



Front Space



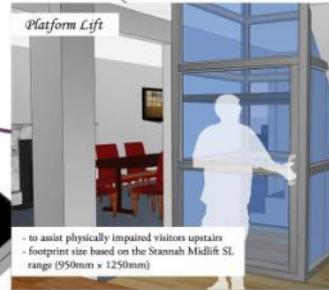
Balcony



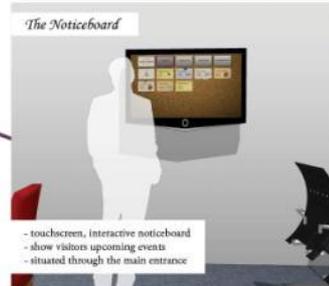
Sensory Garden



Platform Lift



The Noticeboard





existing



proposed

One of the main features of my intervention is the introduction of the Noticeboard. The aim of the Noticeboard is to share information between neighbours, bringing people closer together, within and across communities.

It can be accessed in 3 ways:

1. *Touchscreen Noticeboard (in the Neighbour House entrance)*
2. *Online*
3. *The Neighbourhood Noticeboard*



Physical Model 1:50



Connectivity

PC Internet Access



- purpose made website accessible
- links direct to the Noticeboard
- ideal for home users

The Neighbourhood Noticeboard



- situated at various street interventions
- gives the Noticeboard physical presence
- ideal for people without internet access

Neighbourhoods, dementia care and policy implications

- ▶ Neighbourhoods are not fixed spaces
 - ▶ Dementia care operates in the spaces in-between the home and institutional spaces
 - ▶ Recognise the embodied and sensory ways that people engage with neighbourhoods
 - ▶ Dementia friendly communities are not simply about maintaining (physical) independence but about supporting identity and a sense of self
- 