

People with dementia's perceptions of resilience and the factors that strengthen resilience.

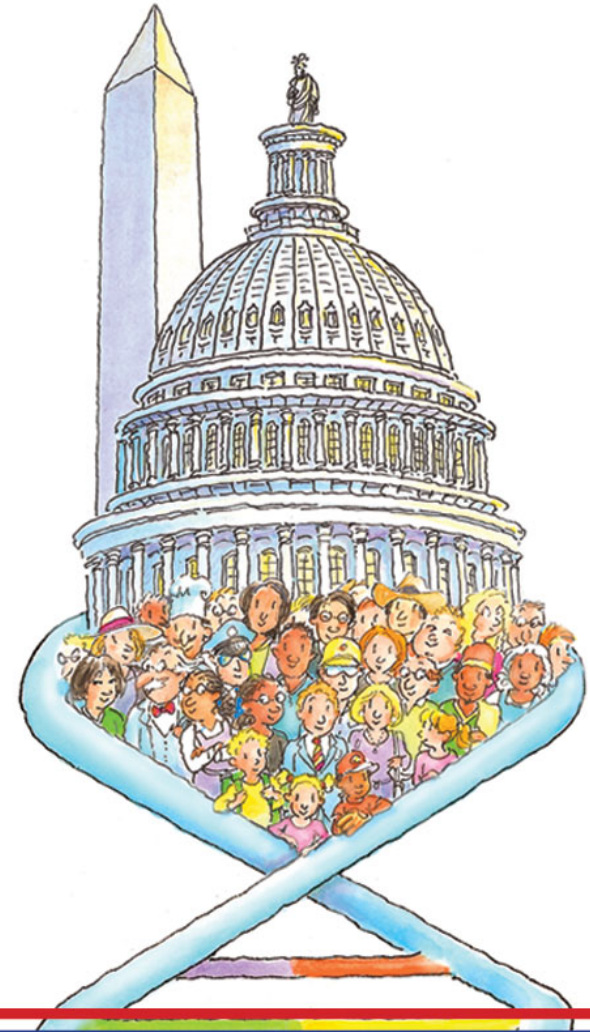
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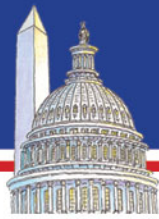
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Making Connections: From Cells to Societies



People with dementia's perceptions of resilience and the factors that strengthen resilience.

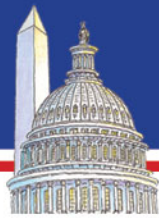
Dr Dympna Casey

&

Professor Kathy Murphy

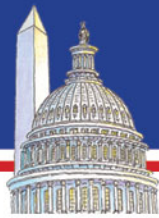


"Granted, the Board of Directors didn't think much of your proposal, but I think they'll be impressed by your resilience!"



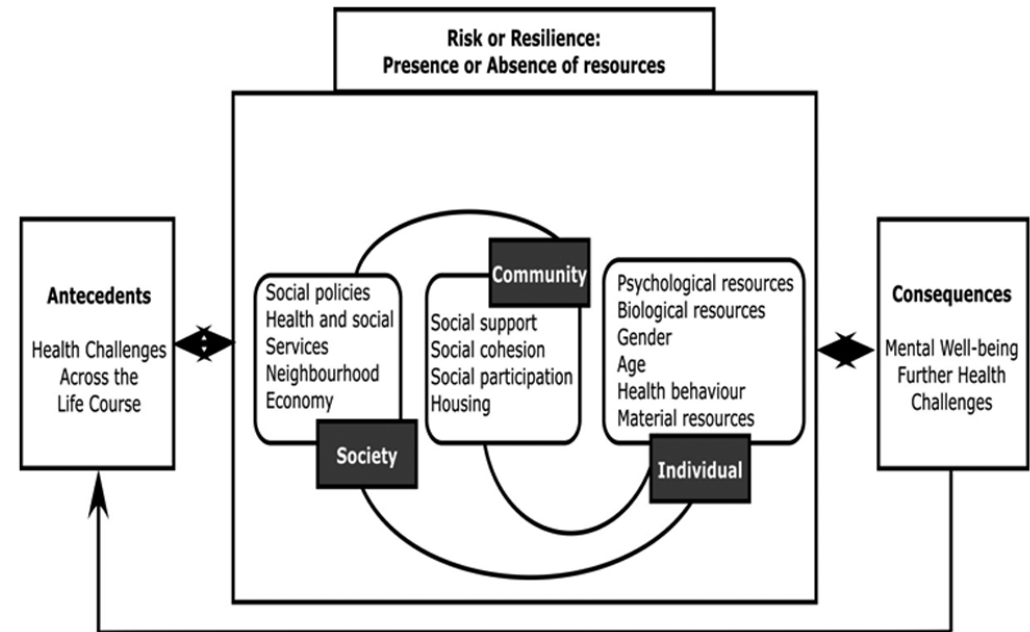
Background and why important

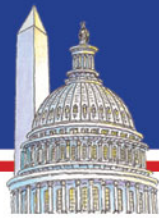
- Participation of people with dementia in family and civic life is diminished by cultures of exclusion and stigmatization.
- Building resilience has been identified as a strategy that may help foster social inclusion of people with dementia within communities.
- Resilience refers to one's ability to 'bounce back' and cope in the face of adversity.
- However despite the recognized potential of resilience theory, the extent to which resilience exists or can be cultivated and nurtured in people with dementia is still relatively unknown. **Dementia is seen by some as negating the ability to develop resilience.**



Resilience Framework (Windle 2011)

- Windle (2011) defines resilience as ‘the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma.
- ‘behavioural process’ built on strengthening personal attributes and external assets such as supportive relationships and community resources
- to increase the person’s ‘hardiness’ to remain psychologically and physically healthy (resilient) in the face of adversity.

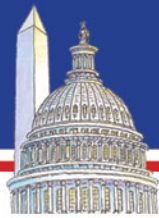




Aim: to explore people with dementias' perceptions of resilience and the factors that facilitated or hindered their capacity to develop resilience.

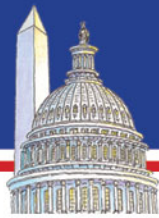
Methods:

- A descriptive qualitative study
- 1:1 interviews with 6 people with mild to moderate dementia living in the community in Ireland.
- The CORTE interviewing framework (Murphy et al 2014) was used to guide the interview process.
- This guide consists of four main areas; gaining COnsent, maximizing Responses, Telling the story, and Ending on a high. This process maximizes the meaningful involvement
- All interviews were tape recorded and transcribed verbatim.
- Transcripts were analyzed for themes using the constant comparative technique and Windle (2012) resilience framework was used to guide the analysis.
- The criteria identified by Lincoln and Guba (1985) were used to ensure and maintain rigor. Ethical Approval was obtained from NUI Galway.



Demographics

Participants	Gender	Age Range	No. Years with memory loss	Highest level of education
020914	Female	60-69	1-3	Second Level
WS320069	Female	60-69	1-3	RGN/RGM
010914	Female	60-69	1-3	Degree
080414	Female	70-79	4-6	Technical Vocational
040414	Male	70-79	4-6	Second Level
WS320070	Male	70-79	1-3	Masters



Findings :Perceptions of resilience

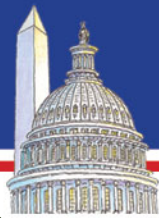
Most participants felt that resilience had to do with :

- It's, kind of, coping, is it, yea, with, with my lifestyle, I suppose, really and, and the memory loss as such. (080414)
- “...for me anyway, is that you continue to fight...” (040414)

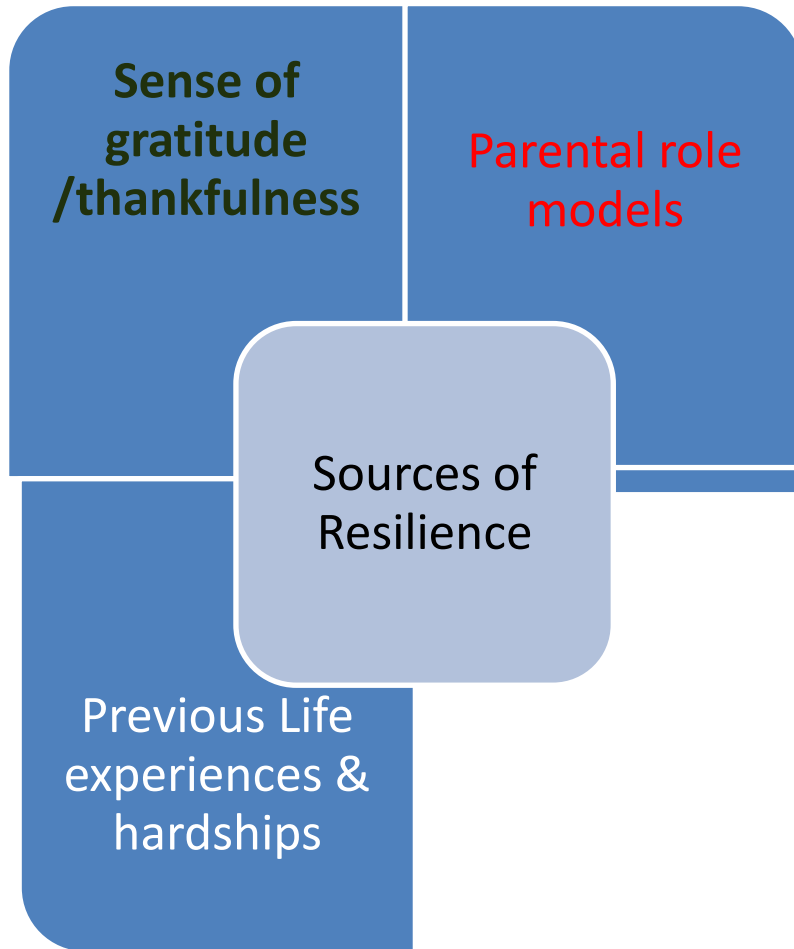
“That you can remember things, is it, I don't know.” (020914)

- “I'd say I have a bit of, you know, that (*resilience*) in me alright. I'd say that I wouldn't be put down very easily”. (WS320069)
- If I'm partially honest, if I'm fully honest – partially I am and partially I'm not, (010914)

When it was fully explained that resilience was about 'bouncing back' in the face of their memory loss, most felt that they were resilient to some extent



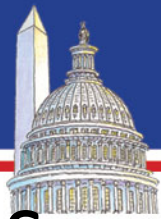
Sources of resilience



- Ah yea, well see we've been lucky enough. We've been able to, to travel the world...great friends over them years...and had a great time...You know, great memories, like, you know., Well, what I remember. (080414)

I was lucky I suppose really, getting through life, I had nothing, I had nothing major now, you know,... (W320070)

- Mom was a social worker through the Blitz in Manchester. And she had to leave home at 14, because her mum had died, and she had to go working, to make money, and then go to England to support her sister....And I always think of what she has gone through, and what she has done, you know...It gives me the strength (010914)



Previous Life experiences & hardships

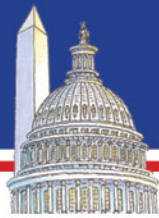
- you know... I had my ups and downs, my first wife... died about twelve or fourteen years ago and I've – the lads were actually, I've three, three sons...that was, that was tough at the time. She was ill for a good while...
- **Q But you had to be the strong person in the family?**
- Well in a sense of I was out earning and arranging, I mean most stuff... (WS320070)

Q Where did you get that spirit from?

- From... I'd say it was family kind of. Do you know? We were family, there were Seven of us that were in it, you know... I mean that gives its own dynamics...It has its own, it has its own, what would you say about it now... It does its own thing, like you know, but ... We had a shop at home, you know?

Q Mmm, what kind of shop?

- It was, it was, well they sold everything. Everything. When my father died... You know... But... And we'd be told off if somebody would come in and knock on the counter, whatever, 'who's that?' and you didn't know them. You were supposed to know everyone, you know? And, what else?.. I worked in Dublin first of all, I trained there as a nurse....Seventeen when I left home, that's right..
- **Sister : And there were times you didn't come home for nine months. You know, it's like you were in America.**
- Yeah, nine months, you'd be a year before you get your holidays...the way it went, you know? It never bothered me, like, you know, I just took it and went with it and that was it, you know? (WS3200069)

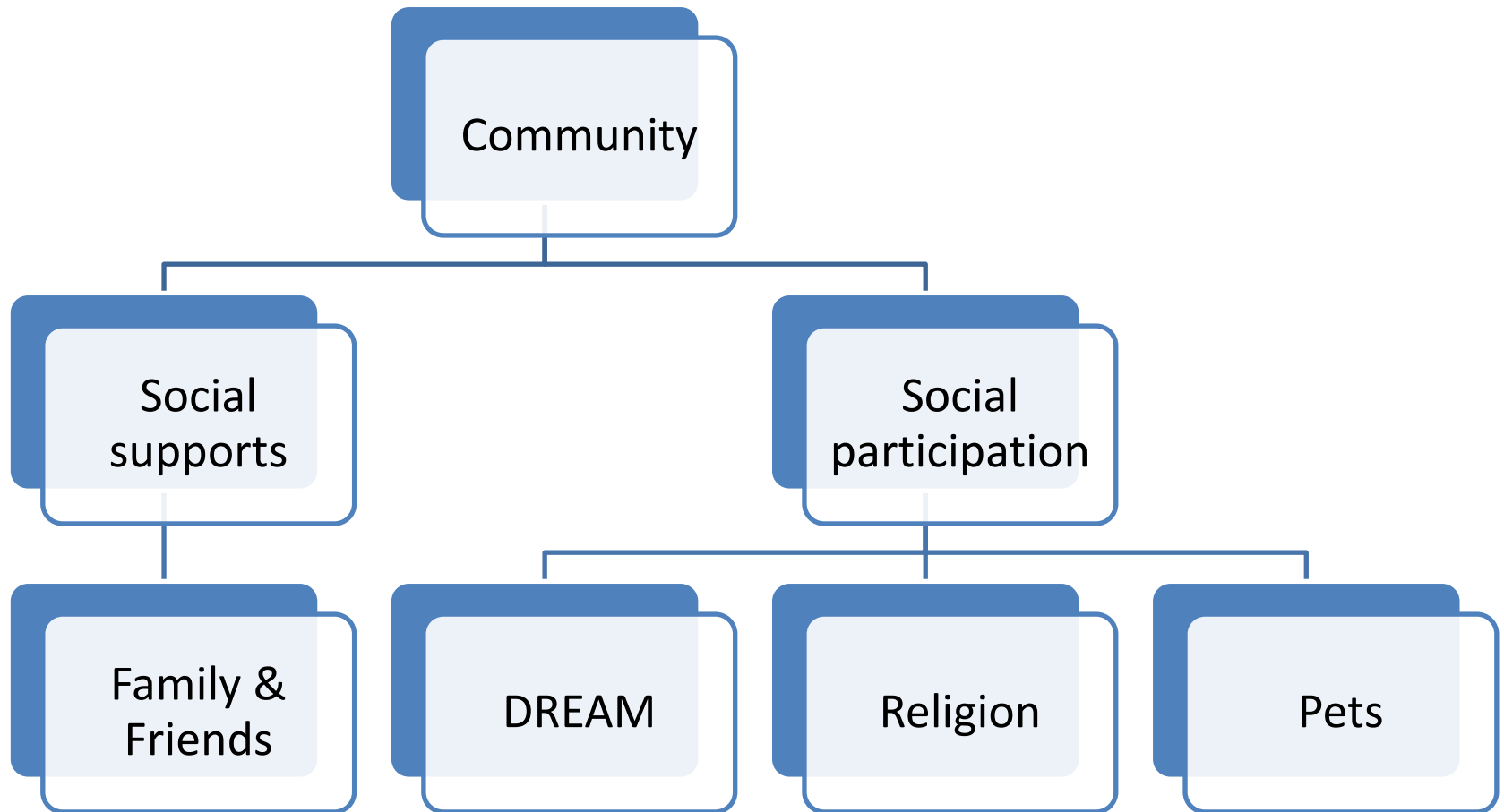


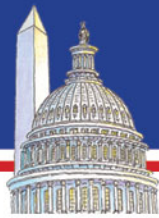
Previous Life experiences & hardships

- **A lot of hardships in your life X?**
- Oh yes, I had but it's terrible, this terrible thing you're trying to, mama, mama, mama speak to me, speak to me, speak to me. And this was me and she was, blood everywhere, my mother.... Evelyn (*sister*) was the same, you know, whatever is, Evelyn had, had, had definitely cancer. And I went over to the UK... Doctors and that, eh specialists.
- **Q:The consultant, yeah?**
- ...he, he was a gentleman too. He, he told me, he says, the most she going to be only two weeks and two months. And that, that, that spurred me. I'm going to fix up this, this little house that could make her happy. Which, I did. And I had to rebuild this, that and the other. Particularly, the electrics and so on. But it was, it was great, I was trying to work during the day.
- **Q:And look after her then?**
- Every night, every, every night that she was coming home, that she'd have something to cheer her up. But I never believed it, that it would actually, actually happen. Well, you might be aware but you wouldn't give in... (040414)



Factors that facilitated resilience





Social supports –Family and Friends

And how did you manage to go back (*playing cards*) ? What happened that made you go back?

My friend made me

Q She knew (*about the memory problems*) , and she made you?

Yea, yea, yea she was the first person, I lived next door to her on xxx Road when we came here thirty-six years ago, and when her children were young I used to often help, and we are best buddies, best best buddies

Q So that support that you got from her was crucial for you to go back and play the games?

yeah (010914)

I mean (*wife's name*) is really, let's say, my memory, if you're talking about what I needed from a carer, Rita is...She keeps me in touch with everything and, you know, if I forget something she'll say 'oh, you know, you've said you'll be doing this', so that, I can forget things like but she's there to, to kind of keep an eye on me, now if I was on my own it might be a bit different, but having someone like (*wife's name*) around, you know, it's not, it's not a problem for me at all, at all.(WS320070)

there's four sisters...And we meet up every Wednesday afternoon.

Q:Every Wednesday?

A:Yea with...

Q:And where do you meet?

Here or in their houses, you know, we, kind of, go around.

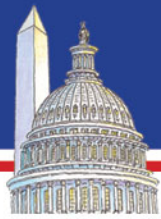
Husband: Different houses, they go around...

Q: Okay, so that's, that's something you look forward to?

Oh Lord, yes, yea, yea. (080414)

Q You were talking about your very good family and the strong relationships there. Have they been important in helping you to cope with the memory loss Mary?

Oh they have yea. You know. They're there to hear you when you're not feeling so good like, you know? (WS320069)



Social participation- DREAM

... well the DREAM group there's no problem because everybody is expected to have, by going there you're acknowledging, but there's no sort of embarrassment about it... (WS320070)

Do you think that kind of, I suppose group, do you think that will be helpful for you to help you.

Yeah well you see everyone is in the same boat.

Husband: And if you like a person.

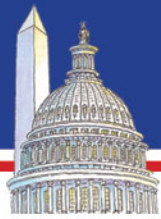
A More or less.

Q: Yeah that's true.

Husband: If you like a person you're going to get some satisfaction out of it.

A: Ah they're all very nice, (020914)

- ...He's the one person believe it or not I'm totally, I feel totally on his level. I never thought about that until now! You know some days we have the chat on our own, and there's a lovely, sure they all are, they're lovely people, and there is a girl called xxxx and I told her...They'll do a lot for society, what they're doing, and I'd like, you know, I can not, I'm not capable of being able to help them, but I admire so much what they have done, and I hope that the group will get bigger (010914)



- **Religion**

I'm involved with the Jesuits alright. I'm a Eucharistic minister over there. But that's just to...Kind of. more it's the weekends and that.

Q:Okay, okay, so that keeps you connected with, with the.

With the church.

Q:With the church?

And we go to mass every morning, as well.

Q:So religion's very, something that's very important to you?

It is, yes, oh it is, yea.

Q:And then from what you said earlier, it helps you cope, so that gives you a, a inner, inner strength?

Strength, it does really, it does, it kind of, whenever I'm kind of, if I ever happen to get down, or worried about something. I say Lord, please help me, be in my corner, you know. So it does, the Lord does.(080414)

- **Having a pet**

- And it probably sounds silly, but that dog paves the way for a lot of things for me. Having a pet, it helps you...I feel sorry for her, she hasn't been down to see any dogs, she's a very friendly girl, so I take her to xxx beach and she knows the nice ones!...And they go to her. And the people then will speak to me. And it's called the "Dog Romp" you know, so I go down there, I know I'll see somebody, I don't know them, but I know their dog, and likewise...So I'm looking after her, so she is my focus, when I leave the house she is my focus, and there is interaction with people that I never thought...yea there is interaction with people that know me, as me, not as what I was...

(010914)

Q: So would you know a lot of the neighbours now, or are there many of them you don't know?

A: Yea, well there are still a few that we, kind of, when we got married and came (*husband's name*) was always here anyway with his mum. But eh, we, we, there are still a few that we're, they're there but there are a lot of the houses. rented... And so you wouldn't know those people.

(080414)

Community

No longer a sense of community

Never really engaged in the community

Q... you've moved here only three months ago but maybe if you'd been still in your own place. Do you think that would help, do you think if you'd more connections with the community?

Well, the, certainly, on that side of the fence, in relation to where I was. They wouldn't say hello, or goodbye..

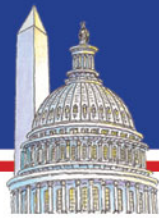
Q: You didn't know your neighbours that well?

A: No. I didn't take the opportunity, anyway.

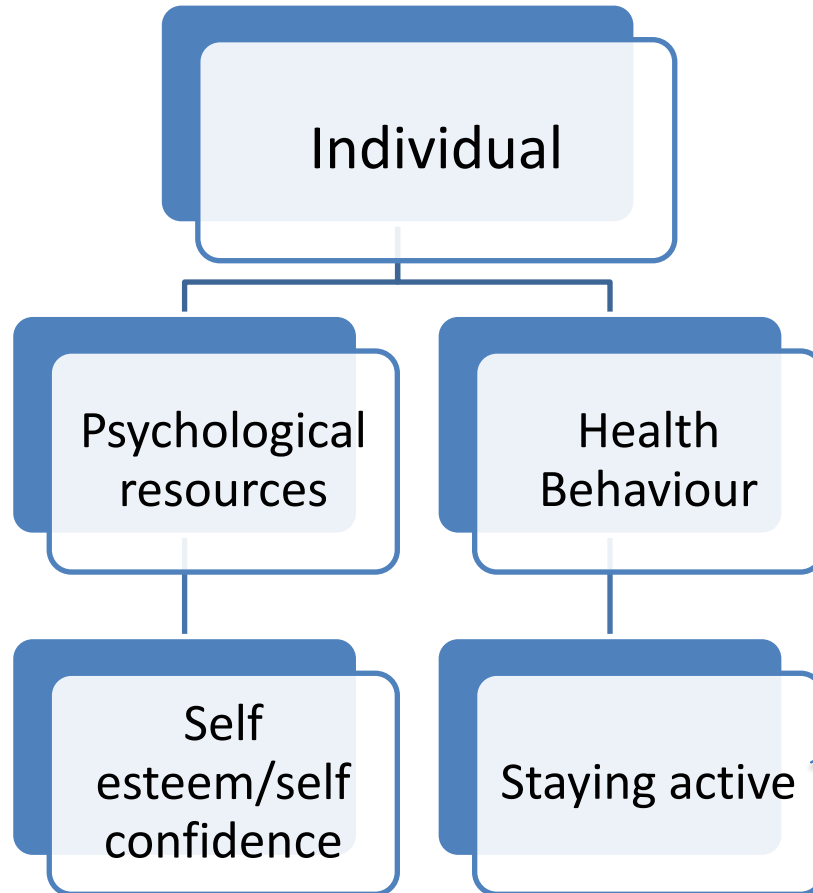
Q: How long were you there for, were you there quite a while were you?

A: Five year.

(040414)



Factors that facilitate resilience



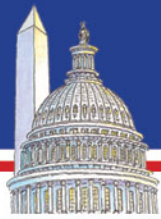
Q: So exercise is something that's important for you everyday to.

Oh, very much so...

Q: To do. And you, and you, you enjoy that?

Oh yea, yea.

Husband :Oh I notice very much, like you know, that eh, she's much better after, after, eh, we go for a walk. And she comes home then and she's, eh, a lot sharper (080414)



Self esteem/self confidence

Being positive; having a sense of humour; a sense of purpose; fighting spirit

Well, generally, I do try to have a positive attitude because I know that if I. If I think negatively about something, I'll say, well right, that's going down the wrong road, you know. And I do try to think positive and himself, as I said, is great support. To think positive, you know. So I, I do feel, definitely, thinking positive, yes. (080414)

Q Another thing that people say is about sense of humour and how important that is?

A good laugh will do you any good, do you great good. (WS320069)

...I think it is, I think it's important, yeah, I mean you have to have something that's going to interest you from day to day, whether it's, and in any part of your life, you really need something, but yeah, it is yeah, important form e to have things to do (WS320070)

And do you believe in persevering with things x

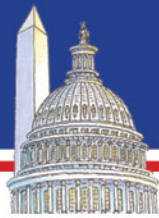
I do.

So you've a fighting spirit have you.

Yes.

Q Have you always been that kind of a person.

I have, but this is the worst thing ever. (020914)



Factors that hinder resilience

Individual

Psychological resources

Personal competence & Control of environment

What's the most difficult part for you xx?

See the thing about work, that gets you out...

And you work, you do something productive?

You do, you can.

And that's the worst part of having...your problems with your memory now, is that you can't do that?

I can't do it, no. I, it seems that I can't but I want to. I, I, I, I'm a broken human being, you know. (040414)

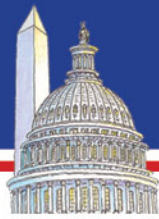
No, now I used to read a lot, like, and I enjoyed reading but I'd given up on the reading. If I could get that back again I'd be very happy. (WS320069)

Doing the baking, actively doing something, cooking the dinner...

Ah no I'm not able for that anymore.

Q You're not able for that...

Husband: they (the children) wouldn't expect her. Ah they wouldn't, in fairness, they'd be bringing us out ... (020914)



Conclusions

- Most participants understood resilience and feel they are resilient
- Learning from life experiences, parents as role models and a sense of gratitude seem to be important resources for resilience
- Foundations for building capacity for resilience at
 - Community level include social supports and social participation, relationships matter
 - Individual level- self confidence, belief in self, staying positive, having a sense of humor, and a fighting spirit and staying active
 - Society stigma and attitudes
- Most feel they have the capacity to be resilient and building resilience matters.

