

# Sandra wants peace of mind over her boys



Sandra Smythe with Richard, left, and Daniel at home in Frankston, south of Melbourne, yesterday

STUART McEVOY

The needs are immediate for a mother who has spent decades as a carer

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WHEN Melbourne couple Sandra and Graeme Smythe's only son Richard was born with Down syndrome they knew the road ahead would be tough.

Then they went and made it tougher, falling for and fostering another Down syndrome boy, Daniel, then aged three.

Both "boys", as Mrs Smythe calls them, still live at home. Richard is now 43, Daniel 31.

It's emotionally draining, exhausting, relentless, but, as carers of disabled children around the country know, it's what you do.

Mrs Smythe, 61, says she has to scratch around to access services for Richard. She's trying to get him into a cooking class for a day or two a week and he works in supported employment on two days and takes some art classes.

She watchfully welcomes the Rudd government's announcement to engage the Productivity Commission to conduct a feasibility study into disability insurance.

But she worries that the discussion will revolve around long-term issues when her concerns are more immediate — better respite so she and Graeme can have the occasional holiday, and organising accommodation that would cater to the boys' needs if anything happened to her or her husband.

"As far as the NDIS goes, you do get so cynical at my age, you're almost hesitant to believe it. I also worry that any system they do get in place will be too late for us," Mrs Smythe says.

What she is hoping for is an aged-care-like facility that could cater to the needs of Richard and Daniel, allowing them some independence but also social interaction beyond their parents.

Mrs Smythe says she has worked to make sure her two sons stay together if anything happens to her or her husband.

"But that dream is slowly disintegrating."