

The Argo Trust's residential home for young people with serious multiple disabilities is under way after more than three years of negotiation, much of it by one dedicated man.

Heading for Home

EIGHTY-FIVE Aro Street. The six-bedroom house which will rise on this messy site up a drive by the video shop springs from the desperation and vision of parents of the young people who will live there.

Their champion has been Peter McLuskie, a man who favours jeans and a denim cap, who's done a bit of this and that in life, worked with disadvantaged people, lived on the dole, taught prisoners how to cook, begun a law degree.

His skills and determination crystallised three years ago when his friends Cathy



DIANA DEKKER

and Tim Bollinger discussed with him the plight of Cathy's son Jason. Jason, needing 24-hour care, was living in a Waikato psychopaedic institution with no future under the Government drive for deinstitutionalisation. They wanted him close to home.

So the Argo Trust was formed, and named in honour of Jason after Virgil's Jason and the Argonauts. McLuskie, as if leaping to the Argo's tiller, has pushed, unpaid, for years to make it happen. On his voyage he has met enough bureaucratic obstacles to belie Government enthusiasm for community care for the deinstitutionalised disabled. The Argo Trust is having its wish fulfilled, but three years on, and only six children will benefit.

The trust was formed by word of mouth and invitation from a little group of parents and one guardian. All wanted their children - who have nearly all lived in psychopaedic institutions away from Wellington - in a permanent, safe place close by, run by people of like mind and with parental input paramount. They believe neither the State nor the IHC offer all of these.

"I think we're called 'disaffected parents' by the IHC," says one parent.

On the contrary, says IHC head J B Munro: "We welcome alternative providers. If the families of

He "looked the bureaucrats in the eye when they said it couldn't be done and said, 'It can be done'. I was never going to take no for an answer."

children with such handicaps are not satisfied with IHC services then good luck to them to do whatever they can." He is, he says, aware of criticism of IHC by one of the parents involved and IHC had been asked to provide help the Argo Trust could not provide by another. But he was not familiar with most of the children who would be in the trust's home.

The traditional first spade of earth at the site of the new house was heaved over on a wet morning last week by Mayor Fran Wilde, chairperson of the board of Community Housing Limited, a subsidiary of Housing New

Zealand.

But the real spadework has been done by McLuskie, in his third year of a law degree and tutoring part time in the commercial law department at Victoria University. He is only now being paid for six months "to bring the project to fruition".

The parents and the trust, he says, have been dedicated and highly supportive "and I have had the negotiating and political skills".

He says, matter-of-factly - and you can believe him - that he "looked the bureaucrats in the eye when they said it couldn't be done and said, 'It can be done'. I was never going to take no for an answer." He ploughed slowly through the process of finding the right bureaucrats and getting them on side.

His real breakthrough came when Community Housing became enthusiastic. That's where the land and money for the project, costing some \$500,000, are coming from. The Central Regional Health Authority, still negotiating with the trust, will pay running costs.

If most people are happy the house is going up, some of the neighbours in semi-gentrified Aro Street are not.

Community Housing manager Ross Sellwood sounds almost personally aggrieved when he talks about neighbourhood opposition to the scheme. Objection is bound to be fruitless - since the building is residential (neighbours successfully prevented the construction of housing units on the site a few years ago) and Housing New Zealand has carefully sewn up permission to construct it. Neighbours object to the inevitable increased traffic flow.

Nevertheless, Sellwood would like everyone to be happy about it even if "some of the neighbours are still a bit grumpy". The section has been an eyesore - "a rubbish tip" - and can only be improved. "For the life of me I can't see their reasoning. It's a real attack of nimby-ism - not in my back yard. Perhaps fear of different people, fear that we've 'done a number' on them and that we disregard the community. We own the land but the city council tells us what we can put on it."

Sellwood says the catalyst for the go-ahead was "Ministerial recognition that the provision of houses for people with disabilities was not proceeding with enthusiasm".

Will the expensive purpose-built Aro Street house, then, be the fore-runner for others or a token?

First, says Sellwood, "the house is inexpensive for what it is. Com-



HOME AT LAST - Scott Watling (left) and Stephanie Newman watch Peter McLuskie turn the first sods at the Argo Trust's new residence in Aro Street along with Cathy Bollinger (rear left) and Claire Stewart look on. Picture: PHIL REID

community Housing's preference is still to satisfy groups from within existing housing stock. If there's nothing appropriate, the next option is the open market."

Since there was nothing in those options satisfactory to the Argo Trust, there's likely to be nothing for other groups.

"I recognise the demand will come. We don't have a limitless budget. It's probably true if there was nothing suitable for this group there won't be for similar groups."

PETER McLUSKIE thinks there will be demand for at least three more homes similar to the Argo Trust's in Wellington alone. "There are 18 people needing 24-hour care going into the community from Kowhai Villa (a residence in Porirua) alone. In the wider picture the Kimberley Centre in Levin is due for closure. There's a need to accommodate a further 400 in the lower half of the North Island."

He sees his efforts as paving the way for further trusts to get purpose-built residences going expeditiously. "Once the ball is rolling it can't be stopped."

Wouldn't there have been economies of scale in building something even a little larger than a house for six? He says the size of the Aro Street residence was largely dictated by Government regulations which stipulate a maximum of six as desirable.

There won't be the "environmental alienation" which characterises larger institutions. Staff focus will be on a few clients, rather than dissipated.

McLuskie says the trust is in the process of recruiting staff - seven full time equivalents for six young residents who will come, mostly, from Kowhai and the Kimberley Centre in Levin. Staff will be directly accountable to parents and guardians though there will be external monitoring. There will always be a staff member awake at nights.

"This has been designed as their permanent home and services will develop as they develop throughout their lives. It will be a safe environment which will validate their existences as individuals with the maximum amount of comfort, stimulation and love."

'It has been a glimmer in the distance since then. I think if we hadn't had it, we'd all have committed suicide.'

Scott goes flatting

“WE'RE calling it 'Scott's going flatting'. That's how we talk at home. I couldn't tell you how excited we are. Every time I go past the drive I look up there at what's going on. I think his life will just begin there."

Meanwhile, Robyn Watling, with her husband Alec and Scott's two sisters, care for oldest son Scott, 16, at home in Karori. They have part-time help, through an IHC scheme, and Scott goes to the Puketiro Centre in Porirua for a week or so each month, but the days are otherwise interchangeably gruelling.

Scott is profoundly physically and intellectually disabled.

"He can't walk or feed himself, he has to wear nappies - he's incontinent - he has epilepsy. Do I need to go on?" She believes Scott recognises family voices, though he has hearing in only one ear. "It's debatable if he knows me," she adds.

Scott is the weight of a man. Reluctantly he allows his parents

to heave him on to a toilet chair "If he's dry that's okay, if he's wet we change the bed" - wash him, shave him, clean his teeth, dress him, balanced on the side of the bed, feed him and get him ready to go to Evans Bay Intermediate. Scott was the first profoundly disabled child in the state system here, his mother says.

Next year he'll go to Newlands College. He can't learn in the conventional sense, but his mother feels the contact with ordinary children is good for him - they're not beyond racing him round the playground in his wheelchair every now and again. When he is returned home, the physical heaving and constant attention begin again. Scott sleeps only fitfully and the family is used to broken nights.

Robyn was told, when Scott was two, that he could be kept at home, with help from the Puketiro Centre, for as long as the family was able to cope, and then there would be a bed available for him. That time came several years ago, but then Puketiro was no longer

taking new residents. "We felt extremely let down," she says.

Three years ago the couple heard of the plans for the Argo Trust. "It has been a glimmer in the distance since then. I think if we hadn't had it, we'd all have committed suicide," she says candidly. It has still, however, been "the most frustrating period of our lives".

She looks forward to Scott being given much more of the care he needs in the Argo Trust home. She looks forward, too, to having more "quality time" with her son when the family is released from the constant grind of feeding, changing and bathing him. She'll visit him every day.

She'll also be able to have more quality time with her other children. Every family outing now has to be geared around Scott, his needs, whether the destination can cope with a wheelchair - "whether he'll fall out!"

"The other children have missed out on a lot. It will be the beginning of our life and of his."

A home for Jason

JASON BOLLINGER did not live to move into his Aro Street home. His needs were the catalyst for it, though, his name inspired the trust's name and his ashes will be scattered there. His mother Cathy and her husband Tim were at the early morning ceremony to mark the start of building.

"I felt a little empty when I left," Cathy says.

Jason died at 16 just a few months ago, at a psychopaedic hospital in Waikato, from which his parents had long known he needed to be shifted. The options were having the totally dependent young man in their own home, or having him fostered under an IHC system. They found both unacceptable and that's when they approached Peter McLuskie and the idea of the Argo Trust was conceived.

It's now more than three years

on, and Jason did not make it home.

"He just couldn't hold on any longer," says his mother.

Tim Bollinger says a little more bitterly - "my personal bitterness" - he believes Jason, "threatened with eviction" from Tokanui, would have thrived if he had been able to shift into the house earlier, but negotiations took years.

"I can't help feeling he was a victim of the system in a way. I'm surprised the Government espoused the idea of putting such people into the community without thinking it through, making it easier for parents. It took us three years and we are all actively committed parents."

"These kids are the lucky ones. Not all parents are so committed and take the initiative."

"The system is faulty, government bureaucracies very badly coordinated and we had to work through several changes of hous-

ing and social welfare policy.

"So many different reports that had to be written, work repeating itself. The Government was willing to spend money on reports. Jason has never seen the benefit of them but a whole bunch of social workers has been paid."

Tim is still active as an Argo trustee. Like Cathy, he's happy for the other parents.

Jason was the eldest of three children. He recognised her, though his severe disability, she says, made him like a three-month-old.

Trust leader Peter McLuskie says the trustees see the home as a memorial to Jason.

"The home was the Golden Fleece, the great treasure we finally achieved. He's still very much present in everyone's thoughts even though their ship has come in without him."