

'IT'S NOT ABOUT TICKING BOXES, IT'S ABOUT LIVING LIFE'

'SURPASSING anyone's hopes', 'excelling', 'a joy to watch', 'endless potential', 'big positive change', 'a lot happier'.

This is what staff and family members have to say about some of the former residents of St Raphael's Residential Centre for people with intellectual disabilities in Youghal, Co Cork who have moved from the centre and now live in their own homes in the tranquil seaside town.

Care assistant Bernie Fitzgerald has seen, first-hand, the transformation in the lives of the gentlemen who lived for many years in St Raphael's.

She notes that it's the simple things like going out for a walk, helping to prepare their own meals, meeting the neighbours or going down the town to do some shopping that are making a real difference.

"Jerry [O'Callaghan, one of the residents] goes out for a walk, out past the gate and down the road. We might pass a particular neighbour every day and he'll wave and say 'hi Jerry' and Jerry will say hello back. It's the small things that are making such a big difference. It's not about ticking boxes, it's about living life and he's excelling here and has surpassed anyone's hopes."

Bernie's colleagues also see the huge difference in Jerry and how he communicates since he moved into his new home. Although Jerry is non-verbal, he is very capable of communicating his needs and wishes, through sounds and gestures. He smiles and laughs a lot more now and appears to have gained a lot more confidence. He will gesture where he would like to go and what he likes to do. He loves having his own vehicle outside that he shares with the three gentlemen living with him and will get the keys and bring them to staff when he chooses to go out.

"Watching Jerry discover all these things is a joy to watch really. He loves the freedom he has now in the house and he's only been here four months, the potential is endless," says care assistant Ken Dempsey.

Elaine Walsh, CNM2, adds, "Life has changed so much since he has moved out. He now has a job, he works every Saturday, and is in charge of the upkeep of the grotto. Rain, hail or sunshine, Jerry will do it. He knows he is in charge of the grotto and he really enjoys it."

Deborah Harrington, Project Manager, explains that the work in St Raphael's to support Jerry and other residents move from congregated settings to live in their own homes in the community comes under the HSE's 'Time to Move on From



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Congregated Settings' policy, (part of the wider Transforming Lives reform programme of disability services nationwide).

"This isn't just part of a national strategy, it is part of an international strategy and best practice and all the research will tell you that people should 'lead ordinary lives in ordinary places'. And as part of that, we have received funding to purchase and develop houses in the community for people to do exactly that – live ordinary lives in ordinary places."

St Raphael's, which opened in 1904, was originally a psychiatric institution. It was designated as a residential centre for people with intellectual disabilities in the early 1990s. Michael Taunt, a nurse in the Centre, highlights the limitations of the congregated, hospital-like settings of St Raphael's.

"It was basically just looking after people's

basic needs. The physical care was very good but that was all that it was limited to," he says. "The bedrooms would have had 20 or more people living in them. Most of the people who lived on the ward had a physical disability so they had to contend with narrow corridors in their wheelchairs and there wasn't a lot of room."

The house where Jerry lives in Youghal is the third new home in the community for former residents of St Raphaels.

"The transformation in the quality of life for residents since the move to their own homes in the community is significant. We have three houses open at the moment. There's a fourth to open in December with another three to four houses planned thereafter," reveals Deborah Harrington.

"This is not just about a move out of St Raphael's, it is a move in terms of changing the model of support for people with a disability. We are moving away from an institutional model of support to a social model of support. The basic tenet of that is to be person-centred and to support the needs of the individual and their choices about where they live and how they spend their time. We've been very lucky in that staff have really embraced the change and we've had great support from families and from the community to assist us in that."

As part of this transition to community living there is a lot of engagement with the residents, their families or advocates as well as with staff. The process is about ensuring



that any move enhances the quality of life of the resident and that their views, and that of their families, are heard.

Families of the residents were understandably initially apprehensive about the move into the community but they have been won over by the changes they have seen. One such family member is Margaret Lyons. Margaret reveals that her son Sean is so much happier since he moved to his own home. Sean communicates non-verbally and can prompt staff about his needs. Staff are supporting Sean to now explore new things and to become more independent. Sean's family visit regularly and he loves to relax with them at home or go for a spin in the car with them.

"Since Sean moved here I have seen great changes in him – he's a lot happier in himself. When he came to St Raphael's first, he was banging and was a danger to himself and staff members. He could lie down and bang his head and he had to be slightly restrained for his own safety and the safety of others, but all that has changed. He is completely changed. It's brilliant," she smiles.

Donal O'Mahony and Catherine Ryan, the nephew and niece of Finbarr O'Leary, who has been in care nearly all of his adult life and was in St Raphael's for over 50 years, have also been won over by the visible changes in Finbarr.

Finbarr refers to his house as 'home'. When asked, Finbarr will comment that he is very happy in his new home. He loves to

greet visitors, open his own front door and show visitors his room and all the lovely photographs he has framed. He is very much involved in the running of the house, helping with the weekly shopping and helping around the house. Finbarr's family are a big part of his life and visit regularly.

"I suppose we were all nervous about his moving here because he was in care for most of his adult life but he seems to have taken to it like a duck to water. For example, today he is helping out doing stuff in the kitchen, and he loves to be out and about and meeting people and he's definitely getting to do a lot more of that. It's definitely a big positive change," explains Catherine.

And it's not just the residents that are enjoying the change. Kim Twohig, registered nurse, intellectual disabilities, says she loves coming to work.

"It's different for the staff too because when you are working in an institution, the staff are almost institutionalised too, without even realising it. But now it's so easy going here, you still have your duties to do but now you are in a family home setting. I just love coming to my job every day," she says.

"Now what I love about it is that while you still need to have some forward planning, we do plan on a day to day basis. For example, if it's a sunny day, we'll go down to the beach, we could have our dinner outside the front, or do whatever the gentlemen would like to do on any given day. We can bring all that into play and go about our day."

TRANSFORMING LIVES

'Transforming Lives' is about the fundamental reform of our disability services and working together to ensure that people with a disability are at the heart of, and involved in, our decision making. A key part of this reform programme is supporting people with a disability to choose where they want to live, who they want to live with and how they spend their time.

A video, which captures Jerry, Sean and Finbarr's transition to community living with the support they need, demonstrates that this kind of move can literally 'transform lives'. St Raphael's Centre is one of 19 centres nationally that has received funding to enable them to develop homes for people moving from congregated settings.

Nationally, €100 million is being allocated over six years under the Disability Capital Programme to enable this to happen. During 2016-17, €40 million of this funding was allocated and there are currently 87 houses being developed which, when completed, will be home to almost 300 people.

Further information and video can be found here: www.hse.ie/timetomoveon

 ABOVE LEFT: Finbarr O'Leary and Kim Twohig, registered nurse, intellectual disabilities, at a new community house in Youghal, Co Cork. Finbarr and three other men recently moved from an institutional setting to live in their new home. ABOVE RIGHT: Sean Lyons and Yvonne Dalton, CNM1 at the kitchen table at the Sean's new home. ABOVE: Finbarr O'Leary in his bedroom at his new home in Youghal. FAR LEFT: Finbarr O'Leary and Kim Twohig. PHOTOS: BRIAN LOUGHEED