

Intentional Communities

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I'm going to touch on intentional communities, which are bit of 1/3 rail sometimes in in discussion of of residences. You know, intentional communities have all kinds of been around with us for many, many years. So, you know, they've got this here is a, is a, in fact a monastery in Germany, which is an intentional community. So we the obviously the religious communities have been intentional communities for thousands of years. People of the same belief with the same ideals coming together to create their own intentional community. For those of you too young to know or to remember, these are hippies. Back in the 60s, there was a movement to go back to the land and to create communes living on the land.

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And for most of them, they realized fairly soon after starting that living off the land is really hard work. And now they're all working as accountants back in the cities. Is it better to be in an intentional community than to be in a single room occupancy hotel? Yeah, maybe this is an intentional community for people who with developmental disabilities, who are transitioning out of school life, family life and into adult life. So there's all kinds of intentional communities. So this is Jean Vanier, who died last year and who was the person referred to in the the launches internal report. But he said, you know, we don't have to be saviors of the world. We're simply human beings unfolded in weakness and in hope, called together to change our world one heart at a time.

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That's the point that he started from in creating the large intentional communities, very much spiritually and religiously driven to do something good for the weakest people in society. And that's AI guess that's a praiseworthy motive, but is it what we need? So when I think of the terms belong, So does somebody belong in an institution? You know, we, we want these, these people don't belong here. They belong over there. Or do they belong? Is this where you feel you belong? That this is a community that I'm part of and that I'm I'm welcomed in and simply does somebody feel that they've been put into a home in the same way that as anybody aging might not want to be placed in a nursing home?

{ 2:57 }

Have they been put into a home or is this really their own home? Is this community gated or literally or or virtually, is it planned? So planned communities that include a broad mix and broad diversity of people and enterprises and shops and offices and everything else are a way to go to create more housing. Planned communities that are essentially a collection of cul de sacs with keyhole cul de sacs of housing with no sidewalks, not particularly what people want. So what does the person really, really want? And how should we be looking at intentional communities generally?

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Should we still be looking at them as if we're doing something wholly inappropriate, wholly in the sense of sanctity or, you know, which is sort of makes us feel good or are we doing it because this is what people want? So in looking at intentional communities, and I've certainly not seen every single intentional community that's out there. I've I've seen a bunch, but not certainly not every single one. So, but not those I've seen. What works is when there is a commonly held and defined intention. What are we doing this for? Why are we doing it for what you know, why are we doing this at all? There is a high concentration of communal activity. So it's a community. You come together a lot more than you might do if you were in a non intentional, just a regular community. You do more things with other people that you live with or live adjacent to than you would if in a typical town or village. Everybody does some work.

{ 4:54 }

So when I hear that somebody person with the developmental disability doesn't want to work, I think we need to reframe that. Sometimes they don't want to do a job that they're not ready for or they're frightened or well, they're worried about. But everybody should work. And an intentional community will also include people who are volunteers, life sharers, people who live in the same house as somebody with a disability that who might need some help on a day-to-day basis. They're integrated into their local community. That doesn't mean that you have to be rural and integrated. You could be urban and integrated, but be part of the general community, not separate, not be gated, not be segregated, not be congregated away from the world. It's not an escape from the world. And what works is also when there's clarity around the funding most intentional communities. And I'm not talking about just people with DD.

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Most intentional communities fail within a short period of time, relatively a year or so, because they figured they didn't figure out the funding properly. They expected people to contribute more, they expected the cost to be lower than they turned out to be. Most intentional communities are like small businesses and anybody who's ever run a small business knows it's very hard and most small businesses don't last very long. And the same is true with intentional communities. So the things that work, having a really strong intention on a strong ethos about what you're doing, What doesn't work is somebody says, well, it's, it's a way to create more housing that does. That's just not it. It's not a, if the sole reason is to have housing, then it's not going to thrive if it is a failure and commitment. If people say, well, you know, I, I thought that this was going to be something where I, I really wanted to live in the country and, and work in agricultural work. And I really don't want to do that.

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Or if, if they are a life sharer that said, you know, I, well, I've, I've had second thoughts about this that doesn't, that's not going to let it go. And if the person who is

in the intentional community, a person with developmental disabilities, is in the intentional community because their parents think it's the right place for them, you need to make sure that it's what they think too. Because they're not going to be committed, they're not going to be a volunteer, they're not going to participate in communal activity. They're not going to work eventually if they move to having only paid direct support professionals.

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And we've seen this happen a couple of times in New York of late, where what began as an intentional community with volunteers and life sharers, perhaps those life sharers were recruited from church organizations or from people seeking visas in the United States who were able to obtain a visa on a religious exemption. But over time, those people have moved on, and now it's only paid direct support professionals, working shift work. It's not very different to just a regular IRA failure to adapt to societal change. So I saw an intentional community that had essentially arisen in the DE institution, the first wave of de institutionalization in the 1920s based primarily around one particular diagnosis. And they hadn't changed over the years. They, the people that they supported had in fact changed a great deal because medicine and medical advances and social advances had changed the context and and the of their lives and and their health generally. But the organization had failed to adapt to the fact that they were now living in the 21st century.

{ 8:58 }

So they were having great difficulty in adapting, failure to adapt to funding. So as we move to more self-directed funding, organizations or institutions that used to be funded at a top down level on it capitated basis and no longer able to get that funding and are having difficulty adapting and on their governance, so who runs what? So if an intentional community is meant to have the involvement of all the people who are members of that community, if it starts to get too paramedical in its structure, it's not a good sign. And the state's not crazy about intentional communities either at this point. Not that they don't already fund quite a few and are open to others, but their primary concern is about regulation and funding.

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So how do they oversee this in a Medicaid context and including HCBS waiver requirements? Not just the HCBS standards settings as standards, but the HCBS waiver requirements. They know that research that we have points to best practice being for smaller or integrated settings, and they are obliged to abide by the precautionary principle, which essentially says if you have science showing that there is a preferred course of action, that's the preferred course of action you need to take until such time as convincing other evidence emerges to make you change your mind. But if you have something that says best practice is smaller settings, that's what you need to encourage.

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New York State has a really disastrous history in terms of not just Willowbrook, but before Willowbrook and, and since as I think I mentioned earlier on, you know, we

have a, you only need to open the paper on a fairly annual basis. You'll see some scandal of abuse, neglect, if not in New York and somewhere else in the United States that will give you great pause. And New York State's OPWDD is well aware that the history in New York State's not been a good history that we have. They need to guard against it and they're not going to let it another Willowbrook happen on their watch.

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