

## Developmental Disabilities and Intentional Communities: Creating Lives with Meaning

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### Abstract

**Background:** Contemporary social policy fosters social inclusion of persons with developmental disabilities. **Methods:** This paper advocates for the “intentional community” approach based on an evaluation of Botton Village, a UK intentional community, in addressing challenges being encountered in Ontario in implementing social inclusion.

**Results:** Challenges such as long wait lists, lack of meaningful engagement and access to adult services and unmet health care needs continue to persist in current integrated communities.

**Conclusions:** This paper suggests intentional communities have the potential for creation of lives with meaning for adult individuals with developmental disabilities and for their caregivers.

**Keywords:** Intellectual disability; Social inclusion; Community development; Meaningful occupation; Residential supports

### Introduction

Early in the 21<sup>st</sup> century most jurisdictions have closed traditional institutions for persons with developmental disabilities and now promote services and supports designed to achieve “social inclusion”. A social inclusion policy is directed at integrating persons with developmental disabilities in local community services, thereby avoiding the risks of isolation and neglect observed during the institutional era.

Ironically, as clearly articulated by Austrian psychiatrist Viktor Frankl [1], contemporary communities often struggle to satisfy their members’ “human needs”:

“No doubt our industrial society is out to satisfy all human needs, and its companion, consumer society is even out to create ever newer needs to satisfy; but the most human need – the need to find and fulfill a meaning in our lives – is frustrated by this society. In the wake of industrialization, urbanization tends to uproot man from traditions and to alienate him from those values that are transmitted by the traditions.... More specifically, such phenomena as addiction, aggression and depression are, in the final analysis, due to a sense of futility” (p 140).

Frankl’s observations should give pause to those responsible for providing services and supports for vulnerable persons in local communities.

This paper explores social inclusion from the perspective that simply providing for persons with developmental disabilities in mainstream community services fails to afford them with lives with meaning. It suggests that establishing so-called “intentional communities” can involve significant benefits for persons with developmental disability and for their caregivers alike.

### What is a life with meaning?

This section explores Frankl’s formulation of a life with meaning as recorded in his book “Man’s search for ultimate meaning [1]”. Since Frankl’s professional work was not focused on persons with developmental disabilities, observations made by Jean Vanier, the Canadian who founded the L’Arche movement will serve to supplement Frankl’s important contributions.

For Frankl, a life with meaning involves forgetting one’s self, be it through a cause higher than one’s self, or loving a person other than one’s self; he calls this “self transcendence” (p 138). In addition to doing creative work or caring deeply for another person, Frankl also addresses contending with “a fate that can’t be changed”, no doubt linked to his personal experiences in a concentration camp during World War II:

“Facing a fate we cannot change, we are called upon to make the best of it by rising above ourselves, in a word by changing ourselves. And this holds the three components of the tragic triad – pain, guilt and death – inasmuch as we may turn suffering into a human achievement and accomplishment; derive from guilt the opportunity to change for the better; and see in life’s transitoriness an incentive to take responsible action” (p 141).

So how can Frankl’s important insights find useful application for persons with developmental disabilities and for their caregivers? To address this challenge, we can consider Jean Vanier’s lifetime experiences in caring for persons with developmental disabilities, particularly his reflections as recorded in his 1998 Massey Lectures “Becoming Human” [2].

There seems little doubt that Frankl would agree with Vanier’s admonition to caregivers:

“It is not a question of performing good deeds for those who are excluded but of being open and vulnerable to them in order to receive the life that they can offer; it is to become their friends. If we start to include the disadvantaged in our lives and enter into heartfelt relationships with them, they will change things in us” (p 84).

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Received November 23, 2016; Accepted November 25, 2016; Published December 01, 2016

Citation: McCreary B (2016) Developmental Disabilities and Intentional Communities: Creating Lives with Meaning. J Ment Disord Treat 2: 131. doi:10.4172/2471-271X.1000131

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So Vanier suggests that providing service and supports for persons with developmental disabilities can create a life with meaning for caregivers, wherein the caregiver forgets himself, does creative work, relates intimately to others and often, at the same time, addresses “fates that cannot be changed”. Beyond these considerations, however, Vanier also notes, having clearly described the frustrations of contemporary society, that persons with developmental disabilities: “will call us out from our individualism and need for power into belonging to each other and being open to others. They will break down the prejudice and protective walls that gave rise to exclusion in the first place”. (p 84)

Accordingly, persons with developmental disabilities can be seen to represent a path to a life of meaning with obvious benefits for both the individual with disability and for their caregivers. In the next section contemporary approaches to social inclusion are outlined, including consideration of how these approaches have yet to fully acknowledge opportunities to create lives with meaning for those involved.

## Methods

### Contemporary approaches to social inclusion

This section examines contemporary approaches to social inclusion utilizing information available on experiences in Ontario where social inclusion legislation was introduced in 2008 [3] and where three remaining traditional institutions were closed in March 2009. As will be seen the “intentional community” approach has received little attention in Ontario to date.

Ontario’s social inclusion act assigns major responsibilities to the province’s Ministry of Community and Social Services, an arrangement prevalent across Canadian provinces even if other levels of government and other provincial ministries have important roles in providing care [4]. The Ministry of Community and Social Services is responsible for application centres (DSO’s) tasked with determining the eligibility for services for adults, for direct funding agreements to support individuals, and for funding of local service agencies across the province. Transfer Payment Agencies (TPA’s) provide a range of services and supports needed in each community including residential, activities of daily living, case coordination, community participation, as well as selected “professional and specialized services (e.g. psychology, occupational therapy, social work)”. Residential support services include intensive support residences, support group living residences, host family residences, and supported independent living residences. Note that “intentional community” approaches are not listed but presumably could be added in a final category “other, as may be prescribed”.

Examination of two reports published well into the implementation of social inclusion would suggest there are very significant problems in meeting the residential and related needs of adults in most communities across the province. “Ending the wait”, the initial report of a housing study group published in 2013, identified 12,000 individuals waiting for a place to live and listed three key barriers to success: uncertainty of funding/funding sources to ensure sustainability, the extent of investment of time and resources by families and meeting the highly individualized needs of the participants. The study group made several recommendations in a “Three year action agenda” stressing new funding, immediate attention to adults being cared for by senior parents, and a “communication strategy study group” to help individuals and families “become more familiar and more comfortable with developing opportunities”. The report was forwarded to a Select Committee on Developmental Services formed in 2013 that held 14 public hearings, receiving 140 presenters and over 300 submissions.

The Select Committee report [5] concluded “that individuals and families who need developmental services and supports are in crisis” listing amongst many concerns:

- Long wait lists
- Repeated, onerous invasive assessments
- Abrupt termination of children’s services at age 10 and school-based services at 21
- Unmet health needs due to inadequate primary and dental health care, and
- Serious lack of services and supports in northern remote, and First Nations communities.

Amongst the Select Committees 46 recommendations were the establishment of an inter-ministerial committee to implement 45 recommendations including “fast-tracking” the “Ending the Wait” suggestions.

Where might “intentional communities” be represented in this unfortunate scenario? Sadly, apart from a March 2016 newspaper report on a forum on affordable housing we have discovered little evidence that the intentional community approach (to be described in the next section) is on the Ontario agenda [6]. In this report representatives of Reena, an organization that provides support services to children and adults in the Toronto area described the development of a new intentional community for 84 people in Vaughan, Ontario. Reena carefully planned this initiative over 10 years, their CEO noting, “I know that whenever we’re not the property manager, people get treated terribly... That’s why we get involved in building. I don’t think anyone else in planning housing even gets to that part of the population”.

In summary, at least to date, in Ontario there are major unsolved dilemmas in addressing the challenges of social inclusion for adults with developmental disabilities. And there is little experience, even little awareness, of the potential of the intentional community approach in creating lives with meaning for persons with developmental disabilities.

## Results

### Intentional communities

This section reviews an important 2009 evaluation of 15 individuals residing in an intentional community located in the North York Moors National Park in England [7,8]; the aim is to illustrate the special contribution of intentional communities in promoting social inclusion for adults with developmental disabilities.

Botton Village, part of the Camphill Movement, serves 132 adults with intellectual disability in a cluster of farm and domestic buildings; the village has 300 community members (members with disabilities and co-workers) in over 30 households. Employment is provided by five biodynamic farms; a creamery, bakery, food centre and meat store; and various craft workshops that generate income for the village. Amenities in the village include a store, post office, bookshop and gift shop, recycling workshop and a coffee bar. A Village Hall is a meeting point for social groups and events. Because nobody receives a wage, members are able to work full time while still being eligible for public welfare benefits; people’s financial needs are met on an individual and cooperative basis irrespective of the work done.

The Camphill Movement manages 90 intentional communities in 21 countries in Europe, North America, Africa and India; the communities “create a life for those unable to find a place in the outside

competitive world, but can avoid becoming an asylum in which people lead passive and regulated lives if men and women whose intelligence is according to test standards supposed to be inferior, will live and work with others of normal intelligence but will not regard this as a barrier between them”.

The 15 individuals (10 men, 5 women) selected for interview were asked about how long they had lived in their household, what role they played in it and their likes and dislikes about home life. They described very active lives in which they were able to enjoy leisure time while also having responsibilities that enabled them to contribute toward their household. Residents described a wide network of friendships; these were almost exclusively with other adults with an intellectual disability. Respondents said that the good things about living in the village were: having a job within the community, socializing with friends and knowing a lot of people, living in the countryside, knowing your neighbours, living with people who are supportive and caring, having the coffee bar and living alongside families.

The authors of the evaluation, although acknowledging their research is limited by a small sample drawn from a single community, highlight key factors in explaining the high levels of resident satisfaction:

1. The absence of the overt subordination of residents to staff,
2. The facilitation of friendship with other people with an intellectual disability,
3. High levels of meaningful employment, and
4. A sense of community.

In contrasting the pattern of organization and how it differed from most other services, they noted other services were challenged, as in Ontario, by uncertain funding, reliance on short-term contract staffing arrangements, and staff “alienation characteristic of industrial process work”.

And finally, it is recognized that there is a wide range of personal preferences among adults with intellectual disability and “it is unlikely that the kind of intentional community offered by Botton Village would appeal to all”.

## Conclusions

This paper considers an apparent role for intentional communities in achieving social inclusion for adults with developmental disabilities.

The important observations of Viktor Frankl and Jean Vanier are integrated to focus attention on the lives of 15 adults with intellectual disability resident in a UK intentional community, part of the world-wide Camphill movement.

It is concluded that the intentional community approach has much to offer in jurisdictions like the Province of Ontario that, having closed its traditional institutions in 2009, continues to struggle in implementing a policy of social inclusion. Indeed, the intentional community approach may be of particular utility in relation to serving northern, remote and First Nations individuals, i.e. those highlighted as particularly underserved in the 2013 report of the Select Committee on Developmental Disabilities.

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