

"Care and Visibility: Modes of Agency in L'Arche"
Dr. Patrick McKearney, University of Cambridge
International Disability Rights Affirmation Conference 2018
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[2018/10/06 07:56] LV (lorivonne.lustre): Hello everyone.

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A little explanation about this service.

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Elektra Panthar

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The following initials in the transcription record will identify the speakers:

PM = Patrick McKearney

[2018/10/06 08:00] Gentle Heron: Good morning and welcome everyone to the second day of Virtual Ability's 2018 International Disability Rights Affirmation Conference.

The theme of our conference this year is "Taking Care of Us."

Our international presenters are approaching this theme from a variety of directions. Today you will learn about university research, policy creation, spiritual and journalistic support, among other topics.

I'd like you to keep an appropriate quotation by author Anthony J. D'Angelo in mind as we listen to today's sessions.

"Without a sense of caring, there can be no community."

Just something to keep in mind today.

Now over to Haubi to introduce our first speaker!

[2018/10/06 08:02] Strandhaubitze Resident: Hello and welcome to the International Disability Rights Affirmation Conference.

My Name in SL is Haubi, in RL my Name is Thomas and I am not a little pony. SL and RL are not far apart for me because I spend most time in my wheelchair at my PC.

I introduce Dr. Patrick McKearney, a Researcher at the University of Cambridge, UK.

He has published on care, disability, ethics, and personhood.

His previous research focuses on people with intellectual disabilities in the UK, in particular in a Christian charity called L'Arche, which is what he will presenting now. His future research explores the contrasts between this form of support and those in the South Indian state of Kerala.

He will talk about: "Care and Visibility: Modes of Agency in L'Arche"

Welcome Dr. McKearney, here is the Microphone.

[2018/10/06 08:04] LV (lorivonne.lustre): <<transcription begins>>

[2018/10/06 08:05] VAIPresenter1 Resident: (slide 1)

Introduction

My research is on L'Arche, an international federation of Christian communities for people with intellectual disabilities.

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A few years ago Melanie Saxon presented about L'Arche at this conference and she explained how the communities:

- Were founded by a Canadian Roman Catholic named Jean Vanier who was living in France in the 1960s
- He took two men with intellectual disabilities to leave the asylum they were living in to live with him in the countryside
- How this small house grew into a large community in France, where lots of people with intellectual disabilities lived with those who supported them: sharing work, play, prayer, and life together.
- How this community gave rise to more communities. There are currently around 150 L'Arche communities all over the world.

One of Jean Vanier's central ideas is that people with and without intellectual disabilities can form relationships with each other than will be transformative for everyone involved.

- It's not just about the person with disabilities receiving care
- But also about what they have to give

So L'Arche is a really interesting place where lots of different ideas about care, disability, and ethics come together in the same environment.

But L'Arche communities around the world put that idea into practice in a lot of different ways, and so they take a lot of different forms

- I recently came back from visiting one in South India, for instance, where the community receives no government funding and relies solely on charitable donations from locals.

- But I conducted research on one in the UK which receives extensive government funding via benefit payments made to the people with intellectual disabilities
- As a result, this community is regulated by the government according to all the normal laws that govern care homes in the UK

I lived in this community in Britain for over a year, and worked as a carer for that length of time too.

I also conducted lots of interviews with people, and visits to other community and organisations.

So through that research:

- I learnt a lot about how to provide care for people with intellectual disabilities in Britain.
- I also learnt more specifically about how L'Arche likes to provide that care differently from other organisations in the UK.

In this talk, I want to use my research on L'Arche to think about the relationship between care, agency, and visibility. That is, I want to ask:

- How do people appear to each other and relate to each other in L'Arche?
- I ask that question because I want to think more about what it means to be recognised and respected as a person while receiving care.

(slide 3)

The Invisibility of the Carer

By supporting them every day, I got to know five people with intellectual disabilities very well. They are Ruth, Martha, Rachel, Bob, and Sarah.

It's hard to be sure, but I reckon that they all have difficulty in thinking about their own well-being and flourishing:

- Many of them seem to have great difficulty in understanding how to get hold of the things that keep them alive – such as shelter, food, and healthcare.
- None of them, for instance, knows how to work a job to get money, buy things at the shops, or cook food to make it edible.

But it is the responsibility of government to ensure that the inabilities of these individuals does not result in their death.

And that is the reason they get disability benefits: so that government is funding carers to help these individuals do these tasks so that they do not die.

Now, it would be possible for carers to do this by just forcing the people with disabilities to do certain things. Carers could, for instance:

- Buy whatever food they choose and just force it upon people
- Or keep them safe by never letting them out of the house

But people with intellectual disabilities also have equal rights in British law, so carers are not allowed to do this.

- Instead, they have to cater to these people's needs, while not coercing them.
- It is important, in other words, that they do not stop the people they support doing what they want to do

(slide 4)

Let us take the example of Bob to look at how carers try to do this:

- Bob knows that he wants toast every morning and can say that quite clearly
- But he has no idea how to get hold of money, or how money works. So he cannot buy toast, or a toaster for that matter.

- So, Bob's carers do all this for him. They buy the toast, and think over the very long term about where the money will come from to enable this to keep happening. Then Bob can still have toast every morning.

What carers try to do in this circumstance is not be someone who has opinions about what Bob should have.

- Instead, they try to be more like Bob's servants – carrying out his orders so that he gets what he wants
- They aim, that is, not to be a person that Bob has to negotiate with but rather a reliable part of Bob's world that he can trust will do what he wants
- They try to be not someone with their own desires, but simply someone who mediates Bob's desires
- They do not aim to appear as another character on the stage of Bob's life, but rather to be someone working behind the scenes.
- They aim, that is, to be invisible.

I wonder if it might be worth thinking about this in terms of prosthesis.

- If you have a missing leg then you can use a prosthetic leg to enable you to walk.
- This object might even start to feel like a part of you. It does not have its own desires, but just helps you achieve yours.
- Bob does not have a fully functioning mind, and so carers use their own minds to help him.
- When they do this well, they do not impose their own desires but just help Bob achieve his.
- Could we talk about them as mental prosthetics?

In some instances, it's really hard for carers to play this role for Bob.

- When new carers arrive, they don't know how to support Bob very well at all.
- They don't know what toppings he likes on his toast, or how he likes his bath run.
- Every time a new carer comes he loses a lot of his connection to his world.
- And so he often doesn't trust new carers.
- It will be a while before he will go out with you, because he doesn't feel safe if you don't understand him and how he interacts and what he needs.
- So carers – due to their own inabilities and Bob's lack of trust in them – can't play the role they want to: of someone who just mediates Bob's desires.
- Instead they appear very visibly on the front stage of Bob's life: as an interfering and unreliable presence.

In this context, carers in L'Arche focus a lot on training Bob to be able to do things regardless of how good his carers are.

- Bob was afraid of doing new things quite often, and so it always took a while to figure out how to do something new with him.
- I managed once to get him out to watch football at a local pub.
- I was told to write down exactly what I'd done so that other carers could follow it
- This way, any carer would be able to help Bob go to the pub.
- That would mean that carers could more easily disappear, and Bob could keep on doing things he enjoyed without the varying ability of his carers getting in the way.

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Sometimes, though, it's even harder for the carer to disappear in this way. Take the case of Martha.

- Martha loves to go out to the local café to get a slice of cake, and so she asks to do this a lot.
- But if carers said 'yes' to Martha every time that she asked then Martha would be extremely unhealthy.
- Martha doesn't realise this.
- But carers have an obligation to keep her healthy.
- So they are left with a conflict: should they do what Martha wants, or what is best for her health?
- If they don't do what Martha wants, then they will appear as interfering presences in her life.
- But if they do what she wants, then they will not be taking responsibility for her health.

At one point during my research, the carers had lots of different opinions about this:

- Some thought she should be free to do what she wanted and so said 'yes'.
- Others thought that this was neglecting her and so said 'no'.
- This meant that when people said 'no' to Martha, it seemed like they were being particularly mean to her.
- And when they said 'yes' to her it seemed like they were being particularly nice.
- So this made Martha's carers appear very strongly as individual characters in her life.
- It was their decisions, not hers, that made all the difference.
- This made her very anxious.
- She clung to those carers who said 'yes', and got very attached to them.
- She started to really dislike those carers who said 'no'.

So at one team meeting the carers got together and tried to fix this – to find a way to be invisible even in the face of this conflict:

- They agreed that if Martha ate cake once a week then this would be healthy enough.
- So every Wednesday, they would give Martha the choice about going out to get cake.
- If she said 'yes' then they would take her.
- If she said 'no' they would not force her.
- If she asked at any other point during the week they would say, 'yes you can go out to the café on Wednesday if you would like'.

The aim of this was that:

- It would restrict the times that Martha could get cake, to keep her healthy.
- But it would make that restriction uniform so that Martha wouldn't see it as something that particular carers were deciding to do.
- And they hoped this would make them appear less as interfering presences.
- It would also mean that on Wednesdays Martha would have a genuine choice about going to the café.
- On Wednesdays, it would be Martha who had the final word and not the carers.
- It would not be the carers' decisions that would determine what Martha did, but Martha's decisions that would determine what the carers did.

- On Wednesdays at least, therefore, they could go back to being mental prosthetics – objects and not subjects.

Sometimes though even this very limited form of disappearance was impossible.

- Martha often doesn't like to bathe.
- But carers think that if she goes too long without bathing then it will be unhealthy for her.
- In this case, their problem is not that to keep her healthy they have to ignore Martha's desires.
- Instead, they think they have to try to make her do something that she doesn't want to do.
- This means they have to appear front-stage as characters in her life, trying to persuade and encourage her to bathe her.
- Sometimes Martha finds this kind of attention quite fun.
- But at others she finds it extremely intrusive and troubling.
- And carers don't like doing it too.
- They know that it is, in many ways manipulative.
- Even if they also think that it is necessary to do it.

So, in the context of care, invisibility is really important to people in L'Arche. Carers aim to appear only as objects that people with disabilities can use, not as subjects – even if this is not always possible to achieve.

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Appearing to Others

In most care organisations in the UK, invisibility is the rationale of the whole relationship.

Carers try to be as invisible as possible in the hope that the people with disabilities they care for:

- Will become more independent
- Will get out into public life outside of the caring relationship
- Will form genuinely reciprocal relationships there

The idea is that, if care is invisible and as minimal as possible, then the world will open up to people with disabilities – so that they can be agents who can form relationships with others.

The aim, in other words, is that carers will stay invisible and 'backstage' in the house.

That way, people with disabilities can interact 'front stage' in public – appearing to other characters, and interacting with them.

Things are normally not so simple:

- People with intellectual disabilities often struggle to become independent of their caring relationships.
- Even when they do, it is often very difficult for them to get recognised by others.
- There is a lot of stigma against them.
- 'Normal' people often do not know how to interact with them and how to form relationships with them.
- The result is that most people with intellectual disabilities have very few friends outside of the contexts in which they are cared for.

Carers in L'Arche level a lot of critiques of this approach to care. They think that L'Arche is an example of a better way to do this.

- In L'Arche, carers do not try to push people with intellectual disabilities into the outside world.
- Instead, in L'Arche, carers try to create a new kind of community around the care home.
- The way they do this is by not trying to play down the caring relationship and make it disappear.
- Instead, they try to take advantage of the fact that people with intellectual disabilities have such intense relationships with their carers.
- So instead of trying to create new relationships outside of care,
- People in L'Arche try to transform the caring relationship itself into a friendship.
- If they are successful, then people with intellectual disabilities will automatically have loads of friendships without having to leave the caring relationship.

In order to achieve this, they need to get carers to look at people with intellectual disabilities not primarily as people who need to receive care, but as people who can give something back.

- Carers in L'Arche tell lots of stories about the people they support that emphasise their best qualities.
- And they are trained to think about these individuals as having particular 'gifts' for openness, warmth, spontaneity and so on.
- They are taught, also, ways to interact positively with these individuals,
- So they learn how to overcome fear of them and instead play with them.
- And they are taught to re-interpret difficult behaviour, such as hitting other people, as actually signs of a positive intention – like wanting to reach out and connect to others.

All of this makes the person with disabilities visible to the carer: not as someone in need, but as an agent with something to give – someone they can form a relationship with.

The other thing they need to do is to train carers to stop being professionally invisible carers and instead make themselves appear.

- So they teach carers to get in touch with their own vulnerability, with their own need for connection and relationship.
- They also teach these carers to see looking to receive something back from the people they support as something good.

They hope, then, to define the relationship between the person with disabilities and the person who supports them as not just about care – but also about friendship.

They want it to be a place where people with disabilities and their carers appear to each other and so can form intimate relationships with one another.

I know of many very powerful examples of when this works:

- Rachel, for instance, has a very deep friendship with Elina who has been caring for her for over 20 years now.
- Peter also has a really strong relationship with Bob, whom he has looked after for 5 years.
- And during my research Martha and I also came to be friends – genuinely enjoying each other's company and laughing a lot at each other's ridiculous jokes.

There are also many moments during the year when this comes together at the level of the community too.

- The most obvious example of this is Christmas.
- All the carers and the people with disabilities share their Christmas day together.
- And they may invite some of their family and friends too.
- During this period, carers work far harder than normal doing loads of support work,
- But they also really enjoy it.

This is the L'Arche model in action: people with disabilities do not try to escape the caring relationship, but rather find in it potential friends

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But it does not always work at all.

- Some people with disabilities, like Ruth and Martha, sometimes hit their carers.
- I wonder if this happens most often at the times that their carers are not being invisible.
- When carers are clearly interfering in their lives, telling them not to do something or trying to persuade them to do something, they often seem to get very frustrated. These moments make it very difficult for the caring relationship to transform into a site of friendship:
- Carers are not sure, to start with, if that would be a good idea: for what the people with disabilities seem to want and need is not a friendship but a more invisible carer.
- Carers also find it very difficult to see the people they support as potential friends at this time.
- They struggle to make themselves even more vulnerable before those they support.
- And they also struggle to see these individuals as people they want to be friends with.

So these moments are often very tense:

- Carers and people with disabilities feel very visible to one another (because they are in conflict).
- They also really desire to be more invisible (because it would protect them better).
- But they feel some pressure to remain visible – because that's what the L'Arche model is based on.

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Conclusion

L'Arche offers us a way to reflect on some really big issues in the support of people with disabilities.

- How can people with disabilities be best supported to realise their desires and to stay healthy?
- How can people with disabilities be cared for and also interacted with as friends?

Both L'Arche and the mainstream model have not figured out answers to these questions.

In drawing attention to these issues, I think this example also raises some much bigger questions about what respecting other people means.

- Does it mean not getting in their way, but simply being alongside them in the most supportive way?

- Or does it mean being a visible 'Other' to them?

Or does it always involve a very complicated combination of these things?
 Does a full human life necessarily involve a range of relationships on this front?
 How can they be combined together, and how do they need to be separated?
 How does relying heavily on care, as all of the people with intellectual disabilities I worked with did, change this?
 When we talk about treating people with disabilities as equals, what do we mean?
 What are we hoping for?

[2018/10/06 08:43] Rhiannon Chatnoir: Thank you! A very thoughtful look at the care / caregiver process through the L'Arche process

[2018/10/06 08:44] iSkye Silverweb applauds: APPLAUSE!!!!

[2018/10/06 08:43] LV (lorivonne.lustre): PM: Thank you very much

[2018/10/06 08:43] Elektra Panthar: ((Paul McKearney's e-mail: pm419@cam.ac.uk))

[2018/10/06 08:44] Reginald Odoi Esq. (vaipresenter8): Wonderful

[2018/10/06 08:43] Gentle Heron: Thank you so much, Dr. McKearney!
 You said you were going to Kerala to contrast with your time at l'Arche in the UK.
 Will you please come back and tell us about that experience?

[2018/10/06 08:43] Elektra Panthar: PM: I'd love to!

[2018/10/06 08:44] LV (lorivonne.lustre): PM: Questions?

[2018/10/06 08:44] Mook Wheeler: COMMENT: Your talk points out the paradox of invisibility -- it can be both a place of safety, and also a place of risk: carers in the (traditional) care system seem to be safer when they are invisible (they don't stand out as the 'mean' carers who say no), but at the same time, these invisible carers don't invite an extension of respect from their care recipients because they remain 'objects' to them, and not 'subjects'. This actually leads to a question I have....
 QUESTION: 'Visibility' is a social construction, always bound up with power, legitimacy, 'otherness' and the dichotomy. Ideology informs what we 'can'/'cannot' see, and *how* we see. The disabled individual is historically one of the most unseen/sub-seen subjects. I note that l'Arche at once upsets this positioning (residents acquire agency, legitimacy, community, visibility and a voice), and -- necessarily-- re-engages with it (residents are supervised by 'able-bodied' staff, regulated in their activities and decisions, identified as a group distinct from the carers, etc.). This is a wobbly see-saw, even for l'Arche. How do residents and carers negotiate what is essentially a paradox -- 'private' political agency and a 'public' form of dependence'?

[2018/10/06 08:46] Elektra Panthar: PM: That's a tremendous question, Mook
 It's one of our biggest difficulties

I agree with you, I was trying to show that invisibility gives both carers and people with disabilities a sense of safety

But also they want to be seen more

L'Arche seems to be a solution to this but some also see as a too strong of a co-dependence

L'Arche brings these problems up in a different way

People are continually experimenting with different solutions at L'Arche

There are also different 'schools' of thoughts, and so there are often debates about these topics

I hope that answered your question

[2018/10/06 08:49] Mook Wheeler: thank you for that

[2018/10/06 08:50] Gentle Heron: [08:48] iSkye Silverweb: The carers at l'Arche have to be exceptionally skilled, perceptive, able to shift smoothly between invisible and visible modes. That's a really, really tough and unique skill to have.

[2018/10/06 08:50] Elektra Panthar: PM: A lot of that is through informal learning, general socialization

[2018/10/06 08:50] Gentle Heron: How do they do that?

[2018/10/06 08:51] Elektra Panthar: PM: They don't find it easy, it is actually tough to inhabit though

It's difficult to navigate the different nuances of behavior depending on circumstance - for example, when one of the residents is being violent because in distress

There's no clear guidance how to balance being supportive or protective - corrective

[2018/10/06 08:53] Gentle Heron: Too many people without disabilities are fearful of interacting with people with disabilities. Shakespeare said, "Things done well and with a care, exempt themselves from fear." Do you see this lessening of fear as part of the l'Arche model?

[2018/10/06 08:53] Elektra Panthar: PM: Elina for example think it's ok to debate with persons of disabilities, and young people look up to her, but it's also difficult following her example

It's a key part of L'Arche model

It puts people in contact with people with disabilities and gives them mind opening that lets them interact with them in a better way

L'Arche provides a safe space for people to meet each other and get to know each other

Young carers pick up that there are deeper meanings to one's behaviour and to navigate how to react to it

[2018/10/06 08:55] Gentle Heron: [08:54] Shyla the Super Gecko (krijon): You provide a good picture, but I wonder, how do the paradoxes faced by the disabled person affect them? Are there any impacts beyond the anxiety and fear of change. The switch between visible and invisible, how does it impact the care recipient?

[2018/10/06 08:56] Elektra Panthar: PM: It's complicated to give a full answer to this The switch is a normal part in our lives - so it's not unusual for PWD to meet carers and 'see' them.

Sometimes it's challenging and it confuses them

Some might get attached to their carers in an unhealthy way - the fact that there aren't clear boundaries between carer and friend might bring to this confusion and fear

[2018/10/06 08:58] Shyla the Super Gecko (krijon): thank you

[2018/10/06 08:58] Gentle Heron: [08:55] Youri Ashton: A lot of people tell stories about people with disabilities alright, unfortunately always without knowledge about the subject or really understanding what is going on

And Youri, he was talking about experienced carers interacting with newer less experienced carers, I believe.

[2018/10/06 08:59] Youri Ashton: Oh sorry, I completely missed your reply Gentle. And no, I mean people in general

Differences between generations may also be part of the issue

[2018/10/06 08:59] LV (lorivonne.lustre): GH: I think what you are saying is true of all human relationships Patrick.

[2018/10/06 08:58] Elektra Panthar: PM: I'm reluctant to speak on their behalf, but this approach is both helpful and complicated

It's one of the more controversial aspects of L'Arche

L'Arche is interested in giving PWD a public voice, and L'Arche wants to have a strong public presence

It's important to be aware of the context. The PWD is always present, and the carer talks directly to the PWD

They don't address the hearer directly

Do the carers really know what's going on in the PWDs' heads?

The carers say they know the person well, they're not trying to speak FOR them

They emphasize the quality of the PWD

I took from it a sense that I might never know PWD, that this person might always surprise me

It made me feel more comfortable with being surprised

It made me think that I need to pay closer attention to PWD and their voices

The paradox is that sometimes the carer needs to talk on behalf of the PWD

[2018/10/06 09:03] Gentle Heron: [09:01] Mook Wheeler: OBSERVATION: The carer<>care recipient relationship provides a really visible example (no pun intended) of how human rights are a constantly shuffling binary -- enabling one group's rights in any matter is usually the lessening of another group's rights in the same instance -- a shuffling to and fro across that line. We always want human rights to be clear, solid and permanent, for e.g. as listed in the UN Declaration of Human Rights, but they may actually *have* to be in a constant state of dynamic uncertainty in order to work.

[2018/10/06 09:05] Elektra Panthar: PM: I'd like to point about how optimistic organizations think they can navigate this boundary

In general the organizations are sceptical about the success in achieving this.

L'Arche is more optimistic, but it's also more difficult

[2018/10/06 09:07] Gentle Heron: I love your thinking we need to change from defending to trusting. Thank you again Dr. McKearney. We certainly want to hear more about your work in l'Arche as your research continues.

[2018/10/06 09:07] Elektra Panthar: PM: Thank you, it's been a pleasure to speak with you

[2018/10/06 09:08] Elektra Panthar: <<transcription ends>>