

**“Community as a Window of Hope”  
The Story of an Emerging L’Arche Community**

by

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## **I. L'Arche and the Need for Community**

In the state of California, after adults with developmental disabilities turn 22, they “age out” of the school system. That’s when they lose the resources and programs provided by schools and the federal government through IDEA (Individuals with Disabilities Education Act) which ensures that each child with disabilities receives necessary support. Their caretakers, who are often the parents or single parent of an adult with intellectual disabilities, are left to care for their adult family member with disabilities themselves and often struggle to find appropriate adult care programs or homes.

“Here in San Diego county about 500 students a year ‘age out’ of the system, age out of educational services,” said Dr. Rebecca Laird, who is the president of the launch team for Friend Ship San Diego. “They’ve mostly been students who have been going to school, and by the time they’re about 22, there are no more services available.”

About two years ago, six moms of adults with developmental disabilities began meeting to discuss starting a L’Arche community in San Diego to address this concern. L’Arche (French for ‘ark’ and rhymes with marsh) is a worldwide federation of communities founded in the 1960s where people with and without intellectual disabilities live and work together as peers. The adults with disabilities, or core members, live with adult assistants in a spirit of faith and friendship, according to L’Arche USA. There are over 150 communities throughout 38 countries, with 21 emerging communities — Friend Ship being one of them. There is only one other L’Arche community in California, in Orange County.

‘Friend Ship’ is the name of a group that is working to bring a L’Arche community to San Diego. Their name was inspired by a drawing of a ship by Jack Medved, a 23-year-old with

autism. On his ship, called his Friend Ship, he writes down the names of everyone new he meets so he can “remember all the friends he was making.”

“I was making a list of all my friends. There were so many,” Medved said. “[I made it a ship] because of the play on words. There are many ways that ships have changed history. There was one with a crazy story, Noah’s Ark. Now that’s a story about caring.”

Caring is that Friend Ship is all about. What is different about L’Arche, Laird said, is it assumes core members are teachers, and communal life is focused on doing things ‘with,’ not ‘for’ those with disabilities.

Laird is the president of the launch team for the Friend Ship group. She, along with her husband Michael Christensen, has written three books on Henri Nouwen, a priest and friend of Vanier who spent the last decade of his life living in a L’Arche community in Canada. It was after a Henri Nouwen conference at University of San Diego (USD) in February 2018 that Laird received an email from a group inviting her to join and assist six families in discerning if they should work to bring a L’Arche community to San Diego.

Maria Nagy (Medved’s mom) is part of the group of six moms who began thinking about forming a L’Arche community. They all have adult sons with autism.

“For the families involved, all of us need a plan for our adult children,” Maria said. “For both the fullness of their lives, and for when we are no longer able to care for them. None of us are guaranteed that our kids are going to be in that [L’Arche] community, but we all know that whether or not they are in that house, they need the L’Arche community. We’re really building [L’Arche] for everyone, and it just needs to be in San Diego.”

Waitlists for intentional living facilities and group homes are often 10 to 20 years long. It is ultimately parents of those with disabilities who fight for resources and who create new housing models, according to Melissa Collins-Porter, who directed a documentary called “Aging Out” about the struggles families face in Southern California.

“One of the things we’ve talked about in the Friend Ship is that we know we can’t solve anything,” Laird said. “That the need to belong is big, and it’s perennial, and with each passing year more and more young adults will age out. What we hope to be is a sign, a place where we pay attention to what we feel called to do, create places and spaces of belonging.”

Friend Ship’s vision for L’Arche San Diego is to have an easily accessible welcome center, where activities and gatherings with the broader San Diego community would take place. Laird said after establishing the welcome center, the hope is to have a few residential homes or apartments throughout San Diego where core members live with assistants.

“Our hope for Jack is to establish community for him that outlasts us,” Maria said. “Where he’s a contributor and he’s connected, and he’s both giving and receiving from the community, which is what we all want from our communities. I think the hope for L’Arche is to build intentional community, people living and sharing life in all it holds.”

## **II. The goal of my project and what I found:**

The aim of my project was to tell the stories of a few families involved in Friend Ship who experience disability in San Diego. What I found through my interviews and research is that creating community for adults with disabilities is vital, not only to the adults themselves, but to the parents and those without disabilities within the larger community. Our lives are enriched by encounters with those with disabilities. Encounters with people who are different change us, and

that is what community *is*. I've found that community is messy—it is bound by vulnerability and time and place. Community *happens* in moments of love and communion. It is not an idea or an ideology, it is friendship that calls us to become vulnerable and human with one another. I thought I knew well enough what community was when I started this project back in September, but I'm realizing I have so much to learn. The incredible people with and without disabilities whom I've spent time with over these past nine months have challenged me to expand my imagination about what community, solidarity and love really mean.

Working with Thomas Feiner, a film student with intellectual disabilities for the video portion of my project, has taught me to pay better attention to what I'm doing and to slow down. Working with him has also forced me to confront and break down deeply harmful (and violent) notions I once held that those with intellectual disabilities were in any way 'less capable.' Thomas is an incredible cameraman and video editor, and I have been time and again impressed by his maturity, skill and talent with a camera. And many thanks to Adam Lanser, his film teacher, who has given me an example of true friendship and solidarity with those with disabilities.

My life has been radically changed through my friendship with Jack Medved. I met Jack when I was paired to be his buddy at a Special Needs Family camp last summer, and my life has not been the same since. My friendship with him has given me a platform and passion for sharing the stories of those with disabilities—to break down the fear and avoidance that so many (including myself) may hold against those who speak differently, behave differently or think differently. I've learned that difference is what makes us human, what gives life meaning, and

encountering Jack's differences and sharing with him my own differences has been life-giving and life-changing, even in the difficult and frustrating moments.

This project does not seek to 'solve' any of the problems that families who experience disability face, just as Friend Ship San Diego does not seek to 'solve' these problems either. My goal in this project was to examine what community means and if we can find hope in community, especially for those with disabilities. I can say that I have found hope through the specific moments and encounters—the laughter, the small accomplishments, the conversations, the hugs and tears shared with those with and without disabilities that I interviewed, with Thomas and Adam, with professors—these specific moments of love and solidarity is where hope is found, not in overarching, far-off ideas. Hope is found in the here and now, which is also where community is found. So I did find that community is a window of hope, though not in the more 'ideological' way I was thinking.

L'Arche is a sign that we can love each other. Community calls us to respond with a "Here I Am" to the one we encounter—to the presence of God we encounter in our disabled siblings in Christ, and in everyone. It's a way of being that, as Jack said, you "think about everyone you love, and everyone who loves you. And that lets the love flow out like a bright light."

### **III. The Story of Ethan & May Marr**

Ethan Marr, 24, was one and half years old when his parents noticed a delay in his speech and language. May Marr, his mom, took him to the doctor, who referred them to a psychologist, who diagnosed Ethan with autism.

May said it was difficult to get appropriate services for Ethan through the school district in San Diego, so she went back to school and got a degree in Special Education so that she could “know what quality service is and tell [the district], whatever you are providing is not good enough, or not appropriate.”

“I had to do a lot of, actually, teaching or sharing the methods and strategies with teachers and therapists at that time,” May said. “And not until we discovered [Ethan’s] talent, which is music and drawing, when he was in middle school, that’s when we took that route, focusing on his talent rather than just on academic... with music, it didn’t really take a lot of effort. He was able to grasp the skills very quickly.”

Ethan loved playing instruments in his high school orchestra and was plugged into music programs throughout middle and high school. After Ethan turned 22, however, May said it was like starting over from scratch in trying to find services for Ethan.

“I thought everything was fine until after he graduated from high school, that’s when I found out the lack of services that they provide,” she said. “It almost felt like someone just pulled a rug out from under me.”

Ethan was placed in an adult transition program after he graduated high school, but May said it operated “more like an adult daycare than an education program.”

“I had to pull him out and try to find something on our own,” May said. “That’s where the community of L’Arche came in.”

May joined the group of five moms who were all searching for a community for their adult sons.

“Before then, I didn’t really think about where he’s going to live, [what] his adult life is going to be like until there were no appropriate services out there for young adults,” May said. “And it was like, oh wow, what are we going to do? And at that time, what if, when he’s like 40, 50, what’s going to happen at that time when we’re not around? That’s when I really started the whole process again, like when he was two years old and starting with, what is autism? I have to do my research all over again and try to figure out what’s out there for him so that he could learn and become a contributing member of society. ”

What attracts May to the L’Arche model is the ‘doing with,’ not ‘for,’ those with disabilities. Many of the adult programs May looked into were teaching the adults “to be dependent rather than teach them to be independent.”

“I could feel that the staff [of other adult homes] care, [but] they are there as a caretaker, to help them but not so much as giving them the opportunity or helping them to be independent,” May said. “I think as a result, our young adults aren’t getting the respect that they deserve... I feel strongly that a community [must be] inclusive, that they treat everyone equal, with the same respect.”

The Marr family is not religious, but May said what she likes about L’Arche is the “inclusive community of love” and that “everyone is very caring and loving and spiritual.”

“It’s not like, ‘oh, you have a disability so you can’t do a lot of things,’” May said. “I think with L’Arche it’s different. Everyone there is like, it doesn’t matter what skill or talent you have, you are a unique individual, we do things together, we live together, and you as an individual have a talent to contribute, and we’re going to embrace that and we are going to



celebrate that. That's why we chose the L'Arche community, also for an environment like that for Ethan, to be in his future too."

Ethan is the drummer in "Jungle Poppins," a band made up of musicians with and without disabilities. May said the Marr family's life currently revolves around drumming and playing in gigs, including performing at BellyUp in Solana Beach and the Casbah downtown.

"Friendship means doing things with my friends," Ethan said. "I like to go dancing with my friends at the BellyUp."

The Marr's Del Mar home is full of Ethan's colorful drawings of cities and maps of places he's been or wants to visit. There is a large drum set in the middle of their sunlit, bright living room. May said she's happy that he's found a sense of community in the band and has been able to share his talents with a wider range of people in San Diego that might not otherwise encounter those with disabilities.

"I'm hoping that Ethan, one day, would be able to live in one of the [L'Arche] homes and just celebrate life together with everyone," May said. "To dance together, do music together, cook together, and just live life and socialize together. Just like we do when we have friends, we go out and do things together. It's the together that we're doing, not the 'I'm here to help you do this.' L'Arche is more of a, 'let's do it together.'"

#### **IV. The Story of Jack Medved, Maria Nagy & Marko Medved**

Jack Medved uses his love of animals to connect with others. That's part of what community means to him—it encompasses the animals and the earth as well as family and friends.

“Community means things we have in common, to help keep things in peacefulness and harmony,” Jack said. “And that means a group of us working together for our care for the world, including conservation, to protect and save the environment and all the creatures of the world. It’s our sworn duty.”

Jack was diagnosed with autism at age three when Maria Nagy, his mom, and Marko Medved, his dad, were living in Boston. He started backing away from social experiences and lost a lot of language and hand use, Maria said.

“I think early childhood intervention is the apex of services, and that stops at three years old,” Maria said. “You continue to have different services through the school-age years, but the saying is that you fall off a cliff at 22 [years old] in terms of services, and that does ring true. We’re probably in the best situation we’ve ever been in for young people experiencing disability in their adult programming, but it’s just a total reduction in what you need to really experience the world in the way that you need in terms of support and community.”

Marko said that as Jack progressed in school, it became increasingly difficult to get appropriate support for him. In elementary school, “there seems to be a lot of cooperation and willingness to help... That seems to get harder and harder the more you progress through high school. It becomes more of a fight and the resources become more constrained and you have to get more formal about everything. Now we’re at the stepping off point where now we’re not in the school system anymore, we’re forging our own path and trying to figure out what resources that will bring.”

Maria and Marko are now struggling to create community for Jack, 23, now that he has “aged out” of the school system. This desire to find a healthy community for Jack is what attracted both Maria and Marko to the L’Arche model.

“I think what’s appealing about the L’Arche model is at the most basic level... it is good to be human together,” Maria said. “The people who are there are there because they care about each other, they are vested in each other.”

Maria and Marko want Jack to be able to practice his independence in a safe environment. The family’s small home in Coronado has an apartment attached to it, which Marko said they live in because it would “be a great place for Jack to have some independence yet be connected to us,” but what that apartment doesn’t have is “this sense of community.”

“On a basic level you’re looking for someplace that they can plug in, that they can have a meaningful job,” Marko said. “Where they can feel like they’re living their own life, that they can walk around safely in a community.”

Jack’s love of animals is how he creates community and makes friends. Maria said she has witnessed how encounters with Jack change people.

“What makes Jack unique is what makes everybody unique, it’s what’s in your heart and what you carry when you take in the world and how you express that,” Maria said. “Many people who experience autism have a particular focus of interest, and for Jack it’s animals. He memorizes, reads, researches, draws, takes in every animal fact he can, and then tries to find ways to share it with people and connect with people through animals.”

Jack said people call him the “great animal-loving expert.”

“As much as Jack can articulate about animals or geography or different topics impacting the environment and science, what’s also unique is the way he struggles to remain regulated in a world that comes at him a little bit more intensely than other people,” Maria said. “While he can sit and talk to you and tell you Latin names of animals and genus and species, handling some of the everyday world is a little bit hard for him on other venues.”

Living life with Jack means “everyday is a challenge in a different way... certain days can be amazing, and other days can be, ‘how are we going to get through to the next day?’” Marko said. “And so that requires that you have even greater faith and get tighter as a family so that you can work through it.”

To both Maria and Marko, the family’s involvement with the special needs community in San Diego has helped them recognize that “[Those with disabilities] are just beams of light,” Marko said.

“They [those with disabilities] bring us together. They’ve brought us together stronger in the body of Christ, you know, we are the church. And so in this case they have helped us in our local community create this bond that is stronger than we’ve had without them,” he said.

Maria’s hopes for Friend Ship San Diego are that it would grow beyond just living and being together, but truly grow into a model of inclusion to remind people that everyone has unique talents to be shared and respected.

“When we talk about L’Arche it sounds so literal, just in the living together, but it’s really recognizing the humanity between each of us,” Maria said. “God’s spirit is imbued in every one of us, and we all have value and that goodness and humanity that we share. So much of our lives are enriched by those encounters.”

## V. Exploring Disability Theology and the Meaning of ‘Community’

### What is ‘Community’?

Encounters “with those who experience disability change you,” Maria said. “You cannot spend time with Jack and not be changed. We’ve seen people change the entire track of their lives from these encounters.”

Community is encounter. What can be dangerous about the word “community” is the possibility it has to become less about individual encounters between human beings and more about an ideology of an institution, nationstate or religion, allowing for assimilation and exclusion-from. What I’ve learned is that we should constantly examine the ways that we think about or imagine community so that it does not fall into an ideology. Philosopher Jacques Derrida writes that community is “a word I never much liked, because of its connotation of participation, indeed, fusion, identification: I see in it as many threats as promises” (Caputo, “A Community Without Truth”).

To re-think community is to re-think identity. “What alerts and alarms Derrida about the form of association described by the word ‘community’ ... is that while the word sounds warm and comforting, the very notion is built around a defense that a ‘we’ throws up against the ‘other,’ that is, it is built around an idea of inhospitality...” (Caputo, *Deconstruction* 113). The notion of ‘we’ and ‘other’ must be constantly re-examined in community, for ‘community’ itself can be a terrifying thought to the ‘other’ that is excluded. To re-think community is to return for a moment to the encounters that Maria speaks of with those who meet Jack. To think of community not as an all-encompassing ideology that subsumes difference into sameness, but instead as an event that happens to us in moments of friendship and love—in fleeting moments

of vulnerability among human beings who meet heart to heart, the “light shining between them,” as Jack says. Philosopher Jean-Luc Nancy writes in *The Inoperative Community* that love is known in its singularity—it is the knowledge of encounter and relation. Though love’s address is always singular, “the other that demands our response is always the community. Its address bespeaks a need, but also an invitation and a perpetually renewed, perpetually deferred (or perpetually relayed) promise: Community without community is to come, in the sense that it is always coming, endlessly, at the heart of every collectivity.” Community is not produced, “one experiences or one is constituted by it as the experience of finitude” (Nancy 31). To think of community in that way—as a sharing of vulnerability, finitude and promise—and to deconstruct the idea of community as one of ideology, is to begin to re-imagine the possibilities of justice and peace in our world. The community “to come” calls up a certain generosity for a gift of “‘community without unity,’ at ‘loose ends,’ ... as an identity that begs to differ with itself. Community. Hospitality. Welcome to the Other. Justice. Come” (Caputo, *Deconstruction* 124).

### **Common Identity in Imago Dei**

For those with disabilities and their caretakers, the isolation after aging out at 22 is real and scary.

“This is the year Jack is stepping off the cliff as they say,” Maria said. “We’ve really seen that fostering, finding, supporting community encounters for him is absolutely critical. It’s just much more natural to be isolated with special needs, than it is to be in community.”

Community, as relationship focused on particular human beings, resists this very loneliness, unbelonging, categorization and isolation of the modern human condition and offers a different way of being with one another. The common narrative we hear in our world is extreme

individualization and competition that rewards progress, which for people with disabilities, and for everyone, means constantly being told in different ways that ‘you are not good enough, you are defective, you don’t belong.’ This ‘immanence’ is what already is: exclusion—exclusion from schools, jobs, churches, even the architecture of our cities seeks to exclude and erase those with disabilities. Transcendence, however, is the hope that is always pushing toward the possibility of what could be—a community that becomes human together, that lives, eats, works, laughs, mourns, celebrates and suffers together, keeping those with disabilities at the center. L’Arche is a tangible sign of what ‘could be’ in the world. Nancy writes that “Community is, in a sense, resistance itself: namely, resistance to immanence” (Nancy 35), and community must always push against its own limits into a possibility of a community ‘to come’ in which all are welcome, in which each life is respected and celebrated.

True community is that which “does not lie beyond the lovers, it does not form a larger circle within which they are contained: it traverses them...” (Nancy 40). The transformation toward identity found in *Imago Dei* liberates us so that we might become human together. This “secret sauce” of L’Arche, the “doing with,” is “relationship: meeting people, not through the filters of certitudes, ideologies, idealism or judgments, but heart to heart; listening to people with their pain, their joy, their hope, their history, listening to their heart beats” (Vanier). Community is found in heart beats. Community can no longer be thought when it is imagined as that which gives meaning to the “lovers,” as Nancy says, instead of the lovers giving the community its meaning. We do not so much produce community as community happens to us in fleeting moments of love, communion and vulnerability with one another, a transcendent moment in which we encounter the *Imago Dei* in each other. “To love someone is to reveal to them their

capacities for life, the light that is shining within them” (Vanier, *From Brokenness* 16), and we discover that light in each other, in love, and are transformed.

For L’Arche, that is “the secret sauce,” to allow oneself to be a vulnerable human, to learn from those with disabilities and to celebrate life, to suffer and be human together, to proclaim to each other that “It’s good that you exist, it’s good that you are in this world” (Vanier, *Living Gently* 20). It is another possibility, a different way of being that affirms love is possible, even in the messiness of day-to-day existence, even when it is the most hard thing to do. For “Community means the respect and love of difference,” where we learn to recognize “[difference] as a treasure and not as a threat” (Vanier, *From Brokenness*). For, as Nancy writes, it is not that I “rediscover myself” or “recognize myself in the other,” but that “I experience the other's alterity, or I experience alterity in the other together with the alteration that ‘in me’ sets my singularity outside me and infinitely delimits it. Community is that singular ontological order in which the other and the same are alike... that is to say, in the sharing or identity” (Nancy 34). The sharing of vulnerability, while encountering and celebrating alterity, is the “joy” of community: “Joy is possible, it has meaning and existence, only through community and as its communication” (Nancy 34).

Community is an event, a moveable feast where all are welcomed. “Friends come in all different shapes and sizes,” Jack Medved says. “Friendship means we have to care for one another and understand our feelings. That’s showing empathy. We always have to rely on each other. Friends are always there when you need them, like for company and help.”

These friends in all shapes and sizes are the treasures that make community the place of communion. The community’s identity remains open and fluid, always pushing toward a world



of justice and peace. ‘Resistance’ to the immanence of a lonely and isolated world is a call to instead “make our world a place of love and not just a place of conflict and competition” (Vanier *Living Gently* 63). Ideologies mean nothing if we do not treat each other with love and do not respect each other’s dignity. To do that, we must know each other and be physically present to each other. “The only answer in this life, to the loneliness we are all bound to feel, is community,” writes Dorothy Day, which includes “the living together, the working together, sharing together, loving God and loving our [sibling]” (Day, *The Long Loneliness* 243).

### **Community as a Gift of Possibility**

Community is a gift—it is saturated in time and specificities. It is “given to us—or we are given and abandoned to the community: a gift to be renewed and communicated, it is not a work to be done or produced. But it is a task... an infinite task at the heart of finitude” (Nancy 35). This infinite task at the heart of finitude beckons us to remain in love, to act in justice and stand in solidarity, for this where community is found: “Love unveils finitude. Finitude is the being of that which is infinitely inappropriable...” (Nancy 98). The touch of the inappropriable other whom I encounter is the site of community, which is always set in the present. It is the infinite task that is constantly revealed in a touch, in a heart beat.

Community, as a gift, reminds us to be constantly working toward a world in which communities of justice and peace flourish, for this is not guaranteed. The future remains open to possibility. ‘L’Arche’ means ‘the ark,’ and this ark is an infinitely open arc, a non-enclosing arc that continues to welcome the unexpected guest, a covenantal ark of justice, love and peace.

### **Community as a Eucharistic Celebration**

It is a mystic vision to recognize hope and fullness in the broken body, in the broken bread of the Eucharist, the broken body of Jesus. In the act of the Eucharist, the body is broken open, not broken and disposable, but broken and made beautiful—not beautiful by modernism’s standards of wholeness, but beautiful because of its vulnerability and *Imago Dei*. The act of the Eucharist is a constant reminder of what it means to live in solidarity and celebrate life in its precarity: “Hope and the possibility of liberation welling up from a broken body is the miracle of the Eucharist. At the table, we remember the physical reality of that body broken for a people broken. At the table, we understand that Christ is present with us” (Eisland 114). In sharing a meal together we remember Christ in the beautiful, broken bodies gathered around that table, “laughing together with belly laughs... Around the table we see the relationship between prayer, food and celebration. It’s the place of our covenant. We are bonded together” (*Living Gently* 38).

Celebrating the Eucharist “means affirming the unexpected participant” as “a body practice of justice and inclusion [that] welcomes” those with disabilities and “recognizes the church’s impairment when we are not included,” disability theologian Nancy Eiesland writes, for “The church is impoverished without our presence” (Eisland 115). For Dorothy Day, the Eucharist was a political act of eating the flesh and drinking the blood of Christ as a direct remembrance of the body and blood of everyone she served at the Catholic Worker, for they were Christ in her midst, revealed to her through the act of the Eucharist. Communion, especially in the context of L’Arche and intentional Christian communities, is an act of remembrance and celebration of the existence of those with disabilities, for even Jesus, after he was resurrected, still had wounds, was still vulnerable, was disabled, and is physically broken again in the form of bread at every Eucharistic celebration.

To break bread together is an act of resistance—resistance to isolation and loneliness. To break bread together is to celebrate all human beings, especially the most vulnerable. And to live as a vulnerable human being made in the Image of God, “we must know each other,” Dorothy Day writes. “We know [God] in the breaking of bread, and we know each other in the breaking of bread, and we are not alone any more. Heaven is a banquet and life is a banquet, too, even with a crust, when there is companionship” (Day, *The Long Loneliness* 285).

Community is life’s banquet. Drawing on the Biblical story of the parable of the wedding feast, Jean Vanier writes of those who are excluded from society, and those who are well-integrated in society, but who “have no time for the banquet of love. So the king, or the head of the house, tells the servants to go out into the highways and byways and bring in all the excluded—the poor, the people with disabilities, the blind. Bring them all in. And they come running to the banquet of love” (*Living Gently* 30).

Community is the “banquet of love” that we all run to, a feast we all can share, of which L’Arche is a sign. Community is where the presence of God in each human being, in the broken and disabled body, is celebrated, making “these days of communion a feast of hope” (*Living Gently* 40). And we are not alone anymore.

### **Society’s Desire for ‘Wholeness’**

In a society that rewards abstract notions of progress, beauty, wholeness and order, the disabled body can often be perceived as that which needs healing or treatment, as that which is not beautiful or is lacking in some way. To understand disability as sin or lack allows for ‘God’ to become an abstract notion of modern beauty or perfection, ignoring the fact that Jesus became a vulnerable body that remained broken even after he was resurrected. No body is perfect, and

the constant striving to reach some body 'ideal' has manifested itself in a certain societal sickness and ignorance of pain and suffering: "By creating the set-aside named 'disabilities,' society shields its eyes from the vulnerability of birth and the risk of becoming; it always already buffers the existential conditions of precariousness by marginalizing certain bodies and excluding them from the pool of aesthetic value" (Betcher, *Spirit* 15). Disability theologian Sharon Betcher names theology's role in perpetuating this narrative of modernism's desire for wholeness, perceiving the disabled body in pain and assuming pain to be "an argument against existence, perhaps because of theology's historied tendency to yoke pain with fault" (*Crip/tography*).

Churches and places of worship captive to modern notions of 'wholeness' often perpetuate these harmful narratives yoking disability with sin. "Disability, we are inculturated to assume, must be overcome, if nothing more than by 'tolerant' inclusion under conditions of the normal," Betcher says (*Crip/tography*). This "tolerant inclusion" is dangerous, as Eiesland writes, "Many religious bodies have continued to think of and act as if access for people with disabilities is a matter of benevolence and goodwill, rather than a prerequisite for equality and the foundation on which the church as a model of justice must rest" (Eisland 67). Rather than truly incorporating and listening to what those with disabilities have to communicate, they are "included" under conditions of the normal, creating a certain kind of alienation and pain.

### **The Disabled God**

Eisland, in her book *The Disabled God*, talks about how the Disabled God shows up as Jesus, who, even after he is resurrected, is not cured and made whole, he is himself disabled, and his disability is not seen as divine punishment or opportunity for miraculous healing, but is part

of his humanity *and* his divinity. “The resurrected Jesus Christ in presenting impaired hands and feet and side to be touched by frightened friends alters the taboo of physical avoidance of disability and calls for followers to recognize their connection and equality at the point of Christ’s physical impairment” (Eisland 101). Jesus’ body is a physical reality and reminder for us that God not only became human, but God became a broken human on the margins who, by his very being, rejects any notion of wholeness or beauty. This is a cause for celebration and liberation for disabled bodies: “In a society where denial of our particular bodies and questing for a better body is ‘normal,’ respect for our own bodies is an act of resistance and liberation” (Eisland 96). Disabled bodies “participate in the imago Dei, not in spite of our impairments and contingencies, but through them” (Eisland 101). To be human is to be wounded and vulnerable, and Jesus, as the Disabled God, “disorders the social-symbolic order,” appearing “in the most unexpected bodies” (Eisland 100). When we begin to open ourselves to the presence of Christ in unexpected bodies—in all bodies—we are transformed. The liberatory good news is that God is the Disabled God who became human to bring hope, justice and peace to a radically unjust and violent world, challenging our imaginations and giving us a different kind of possibility for life founded on love. L’Arche, and the emerging Friend Ship community, give us a sign of this.

Betcher argues that theology itself needs a new imagination and language to speak about suffering and pain in a way that does not negate or try to “fix” disabled or broken bodies. We must begin to understand suffering as a teacher, not as that which must be remediated. Henri Nouwen, a well-known spiritual writer, priest and theologian, recalls a time when a visitor came to the L’Arche Daybreak community where he was living with Adam, a man with severe disabilities. The visitor saw Adam and began fervently praying for his healing, praying that he

would be rid of his disability. Nouwen said one of the L'Arche volunteers “gently tapped her shoulder and said, ‘Adam doesn’t need any healing; he is fine. He is just happy that you came for dinner. Please join us at the table’” (Nouwen 68). Nouwen did not know “whether this visitor was ever ready to be touched by Adam, to see his wholeness and holiness in his brokenness, but she did come to realize that everyone in the house was very happy with Adam the way he was.” To begin to recognize “wholeness and holiness” in the disabled body and to celebrate that, to live with and lean into the suffering and pain we all share—that is where we begin to encounter God and form new imaginations about beauty that move away from modernism’s standards, even to the point of rejecting ‘beauty’ as a necessary attribute to existence in the first place. One does not need to be ‘beautiful’ to exist, to be created in the Image of God, to be human, to love and be loved.

Understanding disability as sin, or as that which needs to be healed, is an ableist narrative within theology that has ignored and continues to ignore the voices and lived experiences of those with disabilities. In the book *Living Gently in a Violent World*, John Swinton tells the story of Angela, a deaf woman who had a dream about visiting heaven. She said “‘Jesus was everything I had hoped he would be... And his signing was amazing!’” Swinton writes that “For Angela, heaven’s perfection did not involve being ‘healed’ of her deafness. Rather, it was a place where the social, relational and communication barriers that restricted her life in the present no longer existed... that which had led to exclusion, anxiety, separation and loss of opportunity now became the precise mode in which Jesus addressed her” (*Living Gently* 13). The real “healing” Angela experienced was not to be rid of her deafness, but that she was no longer excluded. The ‘society’ itself was radically different and founded on justice, and Jesus met her at the site of her

disability. It is Jesus' body and presence on earth that reminds us that "the world of disability is the place God chooses to inhabit" (*Living Gently* 15).

### **The Word Became Flesh**

Whispering Winds Catholic Camp in the desert mountains of Julian, California holds a Special Needs Family Camp each summer. It was during this hot, dry and joyous weekend in July last year that I was paired to be buddies with Jack, and we became quick friends. He rattled off facts about every animal we saw, and we had fun conquering fears on the zipline, drawing pictures and swimming in the pool. The most transformative part of the weekend was celebrating mass together on Saturday evening. Jack and I, in our sweaty shirts and sunscreen-oiled skin, sat with his parents in the large gathering hall full of families, buddies and special friends. The mass was noisy and chaotic, and it was because of this that the profundity of communion and the Eucharist—of bread being broken for broken bodies gathered together—revealed itself to me all at once as happy grunts and squeaky wheelchairs and drooling smiles moved toward the makeshift altar to receive Jesus into our bodies. What a gift and celebration of love it was. The sharing of life and the physical act of consuming bread, consuming Jesus, together and realizing then that we all had Jesus's blood pumping in our blood, in all of our various bodies and abilities—what a sign of hope! For a split second I barely began to understand what 'the Word became flesh' means, how it is a force of love in the world that is embodied in each and every human being.

God became vulnerable and human to remind us of the fundamental truth that we belong to each other and are made in the Image of God, that we all bear Christ's body in our body, fully, in our brokenness. "The Word became flesh to bring people together, to break down the walls of

fear and hatred that separate people. That's the vision of the incarnation—to bring people together" (*Living Gently* 70). And together we were at that mass, dancing and singing and happy crying and crying laughing. Whatever holiness is must look like Jack, telling me a story about Humphrey the Whale, as we walk to the dining hall holding hands, allowed to simply be ourselves under a purple sky freckled with desert stars.

*The Word became flesh and dwelt among us.* Flesh is this communal response to vulnerability, to a messy, broken people gathering together to break bread. The term 'flesh,' as opposed to the term 'body,' is a eucharistic way of being that pushes against the economic use of bodies. Flesh is vulnerable and reminds us that a body doesn't have to be useful or productive or beautiful at all. A body just has to *be*, and to practice justice and love is to be present to flesh and to respond to the call of the other. Flesh is the "dynamic and fluid physics of embodiment" that God became. Betcher writes of the "fleshy becoming named disability" that rejects the "trancendentalist metaphysics" that the term 'body' is often co-opted into: "Whereas the term body thus can invite the hallucinatory delusion of wholeness and thus the temptation to believe in agential mastery and control, flesh, I would propose, admits our exposure, our vulnerability one to one another" (Betcher, *Spirit* 155). God's glory is shared in flesh, in the raw physicality and messiness of existence. Flesh speaks to the pain that modernism is so afraid to recognize.

Christianity, in particular, has an ancient love of flesh. The third-century father Tertullian writes that "God will love the flesh which is, in so many ways, [God's] neighbor—although infirm... although disordered... although not honorable... although ruined... although condemned" (Betcher, *Spirit* 10). And we are obligated to each other through "a relation of flesh to flesh, a transubstantiation in which the flesh of the Other transforms my body into flesh"



(Betcher, *Spirit* 139). This ‘transubstantiation’ happened to Nouwen, who, while he was living with Adam in L’Arche was reminded that “My many words, spoken or written, always tempted me to go up into lofty ideas and perspectives... Adam didn’t allow this. It was as if he said to me, ‘Not only do you have a body like I do, Henri, but you are your body. Don’t let your words become separated from your flesh. Your words must become and remain flesh’” (Nouwen 49). It was through this recognition of remaining in flesh that Nouwen discovered that “Adam’s way, the way of radical vulnerability, was also the way of Jesus” (Nouwen 79).

It is through a Eucharistic ‘becoming’ and remembrance of flesh that theology can begin to move away from modern notions of wholeness and beauty and begin to practice justice, peace and love. L’Arche gives us a sign of this in the living and working together, of being human together and celebrating each other’s existence. L’Arche is about doing life ‘with,’ not ‘for,’ having “not so much to do with ‘helping the cripple and the needy’ as with recognizing that our liberation is bound up in one another” (Betcher, *Spirit* 20). Vulnerability—flesh—is the gift that makes L’Arche possible. For “to become human, it is not necessary to become whole, but to attend to the call of the other, and thus to become just, to practice love, pardon, tenderness, mercy, welcome, respect, compassion, solidarity and communion” (Betcher, *Crip/tography*).

### **A Sign of Hope**

In these moments, like the moment of a messy Eucharistic celebration at camp or a belly laugh shared at the dinner table, we experience what it means to be human together.

“When we think of being human together, it’s recognizing that light that Jack shared, the love between each person,” Maria said. “And that’s what’s good to be human together.”

To be human together is a sign, a moment of hope in our anxious and uncertain and scary world. L'Arche is a sign of hope. L'Arche is imperfect, "it seeks to offer not a solution, but a sign that a society to be fully human must be founded on welcoming the weak and the downtrodden" (*Living Gently* 45).

Hope is radically bent toward love of neighbor, as 19th-century philosopher Soren Kierkegaard writes: "The one who truly loves says, 'Hope all things: give up on no human being, since to give up on [them] is to give up on your love for [them]'" (Kierkegaard 255). To love, to be human together with people of all abilities and to celebrate life with one another, is an act of resistance—it is an act of hope.

"When all misfortune befell on the human race, hope still remained," Kierkegaard writes, "but the hope that did remain remained only with the one who loved. If there is no love, hope would not exist either..." (Kierkegaard 259). To live in the world is to experience this misfortune, loneliness and betrayal that marks the human condition. Yet, we must re-commit ourselves in spite of this to stand in solidarity, to practice communion, respect, justice, peace and love, even though it is often the hardest thing to do. To hope is to be human together, and in our being human together, we celebrate life, remembering those who are not celebrating, but hoping for them nonetheless.

"We hope that the Friend Ship extends and creates all sorts of ideas in people's minds to include and live life 'with' [those with disabilities]" Laird said. "That there's something really good about being human together. And I think it's that phrase 'let's be human together,' and let's do this with each other... with celebration and with joy, not with obligation, not with any other motive but... that it's a joy to live with one another."

## **VI. Regarding the news about Jean Vanier:**

L'Arche was founded in 1964 by Jean Vanier (1928-2019), a Catholic theologian who wrote many books about Imago Dei and human dignity. He visited various asylums throughout France where people with disabilities were sent, and he wrote in a book that he was overwhelmed by the human degradation he saw. He invited three of the men he met in the asylums to come live with him in a small home north of Paris. Two of the men stayed with him, and the first L'Arche community was born.

It is a beautiful origin story, and one that has defined the identity of L'Arche itself. That's why it was with immense shock and pain that on February 22, 2020, the results of an investigation came out and revealed that Jean Vanier had been involved in decades-long sexual abuse and manipulation of at least six women without disabilities from 1970 to 2005. These were women he was a 'spiritual mentor' to, and the abuse took place in the context of spiritual help or guidance with highly unusual spiritual or mystical justifications for the abuse. The investigation, launched by L'Arche, began as a decision to look into similar abuse allegations against Father Thomas Philippe, who Vanier thought of as a 'spiritual father.'

This news gutted me, as it did members of L'Arche communities all around the world. Their beloved founder, who many called a "living saint," had lied to them all these years. I felt overwhelmed with feelings of betrayal, anger and disgust. I expected so much more from someone like Vanier who wrote such beautiful words that resonated deeply with me. Can we even trust the words he's written? What will happen to these incredible L'Arche communities that continue to do incredible and good work? Will they suffer? Will the families I have come to know and love through this project suffer?

I don't know. But, Vanier never 'owned' L'Arche. The idea behind L'Arche—being human together and doing things 'with,' not 'for,' those with disabilities, remains life-changing and needed in this world.

I still believe that L'Arche is a sign of hope, a sign that we can love each other and uphold the dignity of all human beings. These are notions deeply rooted in the Bible and in the teachings of Jesus, not Vanier's original ideas.

L'Arche now has to go through the task of reckoning with a brutal and heartbreaking truth about a founder they loved, and what their story will be going forward. The leaders of L'Arche International said in a statement to all communities: “[We will have to] mourn a certain image we may have had of Jean and of the origins of L'Arche.”

If I've learned anything from these awful revelations about Vanier it's that we should be constantly examining the ways in which we hold people on pedestals, and we should *always* be critical of patriarchal structures that allow charismatic men to rise to the level of “saints” without being held accountable. And we should work to break down those patriarchal structures themselves.

L'Arche may have been inspired by the words of Vanier, but what is truly inspiring about L'Arche is their commitment to create a better world for the marginalized people they serve. Here in San Diego, our adults in the disabled community deserve a place where they are loved and treated with respect for their unique gifts, not just “taken care of.”

So, as I mourn the 'saintly' image I held of Vanier, I have a chance to re-focus on what really matters—working toward a more just society for those who experience disability. The

writings of Vanier helped me realize this, and I am still grateful for the words he wrote and how they helped shape my outlook on life, as angry and upset as I am about his inexcusable actions.

This is something I will continue to hold in tension as I commit myself over and over again to standing in solidarity with the marginalized, in all places, in all situations.

Laird said that L'Arche USA has acknowledged the Friend Ship as a project, and the group can join L'Arche if they choose to. Friend Ship's new board committee had only one meeting before the news about Vanier broke.

"The [news] was just totally unexpected, totally out of the values of L'Arche and it kind of stunned everybody," Laird said. Though the news is shocking and sad, the need in San Diego remains and the mission of L'Arche doesn't change. That's what matters to Laird and to those involved in Friend Ship as they discern whether or not to be affiliated with L'Arche.

"[At] Friend Ship, we've reaffirmed that nothing changes, the same group of people are aging out, the same families want a place to belong for their young adults and want to extend that to others, and so nothing's really changed on the local level," Laird said. "Whether it's the right time to join a national organization who's kind of rethinking its history, we don't know yet, we'll figure that out shortly. But nothing's changed about both the values of Friend Ship and the need, and our sense of call locally to be a welcoming group of people."

The energy to keep doing life 'with' remains for the families in Friend Ship, whether they choose to be formally affiliated with L'Arche or not.

To spend time with those with intellectual disabilities is to have your imagination about what is possible widened and challenged. What does it mean to be human? How do we be human

together? What is truly important in life? What is community? How do we love, especially when it's the hardest thing to do?

L'Arche, and Friend Ship San Diego, shows us that hope does indeed exist in specific moments of communion and friendship. That we can, like the L'Arche International slogan says, "imagine the world differently."

## **VII. Conclusion & Video Summary**

Part of my project includes a short video documentary that includes the interviews that Thomas, Adam and I conducted with the families included in this paper. It explores the difficulties and joys that these families face in their journeys with disability, as well as what Friend Ship hopes to do for the San Diego community.

Watch the film here: <https://vimeo.com/403892110/6f9284df1b>

I also created an Instagram account for Friend Ship San Diego as part of this project, @friendship\_sandiego, and wrote a piece about Friend Ship in The Point, PLNU's student newspaper: <http://bit.ly/2IJ1vj2>.

My hope is that what I have learned in this project—to become vulnerable and human, to celebrate the Imago Dei in each person, celebrate life and find hope in encounter—that others may learn this too. We are not meant to go through life alone, and we are all welcome to the banquet of love.

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