

SeanOBrien

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What does your father do for a living? A question that comes up as you're growing up, right?

So this was a bit of a puzzle for me. My mother, Mary, Lou, kind of made it a little easier, not much, because she was a teacher, teacher. And so once you realize that your teachers don't like sleep under their desks in school, you know you see them at the store or something, and you realize they actually like live a life, you can kind of figure out that maybe they went to school and maybe they had a teacher, and maybe somebody taught them to teach other people how to speak English.

But for my Dad, boy, I'm going to tell you the story of a 20 year quest to answer this question.

We start, picture if you will, the TV show, Stranger Things. There's a creepy building, the Department of Energy. It's also formerly known as GMHI, where a three year old would play on the floor of his Dad's office and push back cars while experiments were apparently going on in the basement. And very nice people would come, you know, hang out with me and help me draw pictures while he was in meetings and things like that. So there was a, you know, like a more normal thing there.

But then what happens next? Well, I would ask him from time to time, and he would say something like, "Well, I help people think about problems." How many of us can say that that's our job. Super helpful. It's accurate. He was always honest in that, curious.

So I would look for clues, right? I look for clues kind of anywhere I could find them.

One is, there was this brilliant, wonderful collection of oddballs from all over the world that would come to Lithonia, and we would get to see and have dinner with and have the most delightful times.

One was he seemed to like books a little bit.

One was that he that he loved playing with legos. He really would get down on the floor, and really do that for as long as possible.

And then, of course, that he would travel about 300 days.

And so this led to one of the things he would do. H would send us postcards, and what he would say in the postcards, often, he'd say, 'Here I am in Spain.' 'Here I am in Ireland.' 'Here I am in Australia.'

'I'm in New Zealand, tilting at windmills.' And I don't know what that job is, you know, Don Quixote had it, and it didn't go super well for him if you remember the book, and story was not in that postcard.

But again, that didn't work on the recess field, right? What does your Dad do?

I'd ask him, you know, from time to time. "Help people think about their problems...", was the one that came up most often. But other ones were, look for solutions to challenges alongside people.

Another one I remember, which is a beautiful one, listen to people's stories and share them to learn lessons.

Now I just had this amazing memory, we could have the greatest dress, like John O'Brien party. It would really be an amazing event, and we

would have a hard time telling each other apart. But otherwise, we could have a great Dad costume part.

But how do you have a costume for somebody who listens to people's stories and tries to find lessons for them to deal with challenges? I don't know how to use I don't know how to address it.

And then when I got to be in seventh grade, I had to fill out a form, and I was excited about it, because I had to put his job on, and he said, consultant. Worse! What does that mean?

So Kevin and I have kind of the vinegar of adolescence, so we would tease him and say that he was an enforcer of the Irish mafia. But I gotta be honest, I knew that wasn't true.

So you know, I sat until I in my teens, when he would invite us to the summer institutes he would run. And 20s, when I would continue to go to conferences, that Connie would organize, and watch him speak and watch him participate. Then we got to kind of get an understanding of, an understanding better of watching him work and watching this kind of quiet person who was really happy, cooking, really happy, reading, really happy reflecting, just become this magnetic personality, electrifying a room of people, providing them with energy as they did some of the most challenging jobs our society offers.

And by watching him, I decided to, you know, pay attention and to see what I could observe and see what I could learn. Around the time that I came up with my answer for what he did for a living, he was disguised. I don't know how many will know this story. I'm happy to tell you the whole story, but he disguised himself as an Irish monk to go to Bosnia, at tail end of the four year war. To try to bring positive energy through an Irish NGO.

He had to wear a helmet and a flak jacket. He flew on a Ukrainian military flight where there were no seats. You just have to hold on to a scrap wearing your wearing your flak jacket that were, you know, there were bullet holes behind his bed. And I was like, this is an interesting job!

And so I settled on, now he would still go with, I help people tell their stories right, or listening to people's stories. But I said, Disability Rights Activist. And I kind of tried to think about what that was, what that meant in the world, right?

And so, you know, the thing I want to say, as I talk about him as a disability rights advocate, is that would be the first, second, third, and last person to tell you that he didn't do anything that we're going to talk about is that he did anything by himself. He had collaborators, co authors, mentors, mentees all over the world, some of whom are joining us virtually across 20 or more time zones right now. I'll give a shout out to Australia, where it's like 4:20 in the morning, very impressive that you're here.

And of course, his partner for this half century of work time, without whom none of these good things would have been possible.

As the overwhelming outpouring of thought and writing that people have shared during this tough time have rolled in, one of the darkly comic thoughts I've had is that if a fraction of this tidal wave of praise had come Dad's way during his Life, he would have positively unschooled.

He was always outwardly polite, of course, but like when we would praise him for his gourmet cooking, you could see him inwardly squirm like a toddler in a hue and Easter Vigil mass.

Let alone if you think about all these beautiful affirmations, they would make him evaporate into a cloud of embarrassment. So, none of this, he didn't do any of this alone, and he would never say he did.

But what did he teach us? Well, he starts with a radical idea that's troubling and embarrassing. The radical idea is people are people. It's troubling because we should all kind of know that, right? And it's embarrassing, because he was part of a group of people about 50 years ago that started talking about this, and started trying to make changes in how people were cared for, educated, looked after, lived based on the idea of their personhood, not thinking about a problem first or a challenge first, or a label first, but just building community around a person. And how do you do that? How did he do that?

Well, my observation is with openness, kindness, always looking for dignity, sharing it, giving it, accepting it, being endlessly, endlessly curious about everything under the sun, being kind, generous, listening and listening and listening and listening some more. And learning as much about as many different things as possible. Using that seven decades of knowledge to help people. To help people be people first, before anything else. And yet, the cruelty, and injustice, and indifference, that's in our beautiful, flawed world full of beautiful, flawed people with hope and imagination, he inspired other people to do the same.

So by listening and learning, and telling stories, and reading, reading, reading, reading, Dad was able to be a significant part of a group of people who helped make the lives, and families, and jobs, and schools, and hospitals, and centers, better places, better people, better communities for countless people all over the world.

Kevin O'Brien

Thanks everybody for being here.

Sometime in 2003 as our country was descending into a terrible war in the Middle East. Dad taped a quote from Elvis Costello to the side of his computer screen. It said, "Well, I used to be disgusted. Now I try to be amused." 22 years later, five days ago, Dad died. I thought of that quote. Maybe it's some guidance from Him. Now, maybe we should try to be amused.

Dad was funny. He loved to laugh. I remember being eight years old. My brother Sean was 10, and Dad sat us down in his living room, and he said, "Gentlemen, I'm concerned. I've been neglecting your education." So I prepared for a big lecture or a six pack of books, and instead he put a VHS of Monty Python's Holy Grail. "Pay attention. This is a sacred text."

A couple of years later, I was assigned to record someone in my family talking about what they learned from an elder. Dad got out his tape recorder and he told me a story. A few days later, in class, everyone else played an interview that lasted about a minute or two, and was about how their grandfather taught them the value of hard work. My tape was 18 minutes long, and it was about how Dad's great aunt had taught him that jell o salad can be scary, he said. And I remember these voice heaven. It was green, but not the kind of green found in nature. It was a green that gives a boy nightmares. He described the guava mayonnaise. He talked about peas bordering a blistering red sun as a maraschino cherry. My classmates laughed out loud at that one. I was very proud. They asked to borrow the tape so they could listen to it again.

I don't have a way yet to make Dad's death funny, but I think Dad would want me to tell you that 'amuse' is an old French word from the 15th century, and it's based on the Greek word Musa that dates back 1000s of years, and that word refers to the daughters of Zeus who inspired and guided human artists.

To amuse isn't just to make someone laugh, but to produce any kind of art, to make people pay attention, to feel something, maybe to make sense of something.

Dad would probably give you at least another half hour about the Muses and his take on a variety of ancient temporary interpretations, but he's not here, and I don't know as much about Ancient Greeks or those things. But I do know that I'm trying to pay attention to his death. I'm trying to get in touch with my feelings about it, and I'm trying to make any sense, trying to work toward understanding it. And I think I need art.

Dad's primary art form was storytelling. He would often answer a simple question, say, what's for dinner with a lengthy story about his childhood and how he came to have a particular skillet that used to belong to his mother, and what he liked to cook in it, and what didn't work in it.

Anyone who's ever been at Dad and Connie's house knows they have surrounded themselves with the stories in books. You could pick up any random book, and he would tell you the story inside that book, and also the story of when he read that book and what he learned from it, and what he did with it, and what he told people about it.

Dad came from family storytellers. His father didn't talk much, but when he did, he would tell long, fascinating stories. Dad's brother Tim, is one of the world's great story tellers. Dad taught my brother and I to appreciate stories.

He taught Sean that our Irish heritage gives us access the ancient terror.

Stories can help us find our place in the world. He taught me that religion, even when it is broken, when it is abusive, when it is simplistic, keeps a record of our species, most enduring narratives.

And Dad understood his own work as storytelling. He gathered and shared stories of people in communities who tried to include everyone. He found and

told stories of how people can do a better job of treating each other human beings. He knew that these were rare stories that so many communities keep failing, that institutions keep excluding people, but he found a way to keep telling stories about how it could be better. He was still working to share those stories on the very last day of his life.

I want to read you something dad said recently was he was interviewed. This is a quote from Dad. I won't keep doing my impression of him. "I probably thought more ways to fail at influencing people than anybody else, and I'm obsessed about this pretty consistent failure. People are sometimes complimentary about what I've got to say, but if you look at the average impact of lots of it, it doesn't add up to very much. That doesn't bother me probably as much as it should, so much as it keeps me curious. Lives, and so I keep looking around to see who else is doing something that might help, that might reduce my next failure or make my next failure more interesting.

My father did a lot of good in the world and touched a lot of lives, but he knew he had limits in his work, in his personal life. He thought a lot about the institutions he had failed to change the people he had failed to help in these last few years. He talked a lot with me about how much of this country seemed to be moving exactly away from the sorts of communities he spent a lifetime trying to build.

But he tried not to be disgusted, he tried to be amused. He tried to tell stories about his failures that he and we could learn from. He tried to make sense and process his frustrations, and he always stayed radically, obsessively, overwhelmingly curious.

I do not know yet how to tell the story of my Dad's life. I probably never will, but I know one part of it is that he was someone who could tell a story that made people laugh, but also made them feel seen and heard, and cared for, inspiring them to treat each other just a little bit better at his best.

I also know that another way to tell Dad's story is a love story, because nothing was more important to him than his wife, my stepmother, Connie, and the life and work they built together is a testament to how powerful it is when two people find each other, commit to each other and use the strength of their love to choose

Those of us who love John O'Brien now have to figure out what the story of the rest of our lives is going to be without him. And I have no clue here. I'm sure it will be hard. I think some of us will be tempted to give up and disgusted but to honor my Dad, to honor John O'Brien, I hope that we can instead try things.

CANADA

Rebecca Pauls (PLAN)

From Planned Lifetime Advocacy Network (PLAN)

John O'Brien profoundly shaped the foundation, philosophy, and evolution of PLAN.

His influence runs through every part of our work—from the way we plan with people and families, to how we think about belonging, contribution, and community. More than three decades ago, John's ideas helped us articulate what we already believed to be true: that relationships are essential, that everyone has gifts to offer, and that a good life must be defined by the person living it.

Through his visionary thinking, generous mentorship, and deeply principled work, John offered ways of seeing, understanding, and supporting people that continue to guide and inspire us today.

He helped us define what a good life looks like—one rooted in belonging, purpose, and contribution—and how to support that life with respect and intention.

His approaches to person-directed planning encouraged people to dream together, to listen deeply, and to take meaningful action rooted in relationships. His work invited us to replace standardization with imagination, and to trust that people—when supported to lead their own lives—create better futures.

John's reflections on citizenship, social role valorization, and inclusion challenged us to confront injustice, center lived

experience, and think beyond programs. He pushed us to ask harder questions and stay deeply rooted in the values that brought us to this work in the first place.

The ideas John and Connie Lyle O'Brien introduced to the world—such as the Five Valued Experiences, PATH and MAPS, and the enduring importance of ordinary places and roles—have become part of PLAN's everyday language and practice.

But more than any one concept or tool, it was John's unwavering belief in people—their uniqueness, their beauty, their worth—that shaped our community most. He reminded us that people are not problems to be solved, but mysteries to be honored. That inclusion isn't just a strategy—it's a commitment. That love and justice are not separate things.

John passed away peacefully this week, leaving behind an extraordinary legacy that will continue to guide and inspire us. At PLAN, we will carry that legacy forward—in every relationship we nurture, every plan we facilitate, and every time we act on the belief that no one should be alone.

Thank you, John.

Rebecca Pauls: PLAN rpauls@plan.ca

Joyce Balaz and Bill Hilz

Such sad news....a great loss is an understatement.

Thank you the work you are undertaking to ensure John's teachings are gathered together.

Joyce and Bill joyci@rogers.com

Al Etmanski al@aletmanski.com

A giant indeed. Thanks for letting me know. In the quantum world of grieving that I inhabit, John has 'merely' passed through, still entangled with us in space and in time. You have a lot to look forward to.

blessings to both of you and all who are dear to him.

Melanie Panitch mpanitch@torontomu.ca

Dear Jack, I'm so shocked, and of course deeply saddened by this news. There is so much flooding to my mind, memories of interactions and engagements with John over decades. Such a sad loss personally as well as to the movements and struggles for disability recognition and rights. I appreciate that I had these recent contacts with John and could once again bask in his sharp analytic mind always tempered by kindness and the way he could listen and respect those with whom he was conversing.

My heart goes out to you

Susannah Joyce susannahjoyce@rogers.com

Stories...first....last...and aways... are how I think of John. His stories were such a powerful invitation to thinking more creatively about how we connect with and respond to people who have a disability.

In the early 80's I was asked to organize a weekend of training by him on "quality assurance" and "quality of life". My committee requested that I ask him to include topics such as its history and benefits, but fortunately John had other ideas.

I had never met him and I still remember the first words I heard from him at the Friday evening session. It was a story about a woman whose dream was to visit her mother's grave in a neighbouring town. The problem was that she would have to be gone for two nights to do this, but the "regs" stated that anyone away from the group home that long would lose their place.

So, he concluded, a good quality of life for that woman was something as seemingly simple as getting to say goodbye to her mother. But not so simple, given how her support services were organized. I've remembered her story for more than forty years, along with many others he shared.

Another part of the weekend focused on two contradictory stories about the same person...one a description of them from a deficit perspective of traditional services and the other a community exploration of their gifts and positive qualities. Still such a powerful way to help people understand those deeper truths about others from a much more helpful perspective.

John also introduced us to a different approach to thinking about supports ...and evaluating them ... that he and Connie were creating, that turned out to be Framework for Accomplishment. I was fortunate to attend their first one, in Kingston, Ontario and later to organize some and host John and Connie to lead this week long learning in various communities in our province. The truth of those values remains a foundational piece of our work.

Over the years, in so many settings and circumstances... in Canada, the US, and the UK ... *I saw how John, the storyteller, offered opportunities to reflect on and develop our own stories as a*

way to learn from them and help others to do so. Process and content were woven together with integrity and elegance to invite and inspire change.

Because of John's example many of us continue to use stories in our work in various ways... just one of the many sources of gratitude I hold in my heart for him.

Zana Luf Zana Lutfiyya - Zana.Lutfiyya@umanitoba.ca

These are sad times indeed

I had heard about Cathy and Scott.

Also great contributors to all of us

Thanks for the offer. Who knows.

And I think of you several times a week as we witness genocide in action. And the spirit of survival also thriving

USA

Pat Beeman - communitasest@cox.net

Hi Beth,

Got to listen to part of John's service with words from Sean and others. Still hard to believe it. I was remembering deeply the gift John gave me when

I was in a dark place at The Community Place being sabotaged by an employee. I never asked but the next thing I knew he was on a plane from Georgia to Ct. Bringing me light to find my way out of the deep forest. I will never forget it. He saw where this was going for me and he literally saved me from despair.

At the same time this was going on my brother was dying too and I truly could not see clearly at all.

What a gift he was to humanity.

With you in spirit as you heal from such a deep loss, 🙌 Pat

Emma Sullivan elsconsulting7@msn.com

To the Inclusion Press Family,

Words fail me. I am so sorry to hear that John has passed. His words still ring true in my heart and mind. He definitely influenced me. Thank you for sharing this news with all of us.

I wish you peace and togetherness in this transition.

Emma

Mike Green mikebgreen@mac.com

Thank you for letting me know about John. I was yesterday morning thinking of dear friends now gone with tears and grateful, like Henry, Judith, John McK... and now John O'Brien. I feel such sadness and gratitude and tenderness about these dear old friends.

Jack, Working on our ABCD book with near weekly conversations with John for almost two years was such a precious experience for me. I am grateful for you Jack for encouraging and really holding this intention from an idea of a book to a reality. A great blessing in my life was our work and friendship all together.

This morning I also remember Marsha with you in Colorado telling me I needed to come to the Montreal Institute saying, "Mike, You're a mess. Annie's fine but you, you're a mess." You Jack encouraged me as you have many times. I came to Montreal in 1992 and 1993. In Montreal I met the two Johns, started my unexpected wonderful journey working with John McK and the dear friendship with Judith started.

Years later I remember when you Jack and Lynda and I were in New Zealand, Lynda challenged me about my work starting in Georgia with the DD Council, "Why aren't John and Connie involved? No one knows more. You need them." I went home and immediately said to the funder, we can't do this without John and Connie which started such a delightful chapter in my life so often me staying at

John and Connie's home as we worked together in Georgia and other places.

Today I remember how much friendships mean, as we get old and so many of us are leaving. I am grateful for you Jack all these years and Marsha too and Lynda too and John and Connie.

If there is some way I can contribute to your work developing, I want to do it. Please just tell me how.

Love to you Jack and Lynda. I am grateful you are in my life, and will love to see you again sometime ,Mike

Lynn Breedlove, former E.D. of Disability Rights Wisconsin

I first met John and Connie in Syracuse when I was working for Dr. Wolfensberger in the late 70s. They were always gracious and supportive, and patient with my dumb questions as a newbie in the field. Listening to John walk through the famous decision tree in the Universal Issues module of the old Training Institute Planning Workshop helped me make the decision to leave the stereo business and join forces with so many good people working in the disability field. I never looked back.

After I moved to Wisconsin to work at Disability Rights Wisconsin, John and Connie had already done a lot of work here. It would be an understatement to say that they were revered by many people in Wisconsin. They continued to visit often for PASS training, consultations, program evaluations, speaking and teaching, and acting as guides and mentors for agencies, organizations, state and county officials, and others who were trying to achieve the vision that John and Connie kept inspiring us to pursue.

It's impossible to quantify the impact of John O'Brien in our state - - he energized and inspired us, he helped us stay hopeful and he encouraged us to keep searching for new ideas that deserve to be tried out and refined. There is a discernible thread of John and Connie O'Brien through so many of the good things that have happened in our state.

Darcy Elks darcyelks@aol.com

John was such an extraordinary person. He was so kind, helpful, unassuming, curious, trustworthy, and brilliant. He could have chosen any path in life, yet he chose to use his amazing gifts to walk with some of the most marginalized people in world and their families. John's body of work has been such a blessing to our family and has assisted our grown children who live with disabilities to have a better life than they might have had. As a mother and a colleague, I am so thankful for having known John. Although he most likely did not know it, he had quite an impact on me, my work, and most of all on my family.

Chris Heimerl intandem2@mac.com

I apologizing for missing the font preference in the first post

John's brilliance was often revealed through a few words holding profound meaning and enduring impact. His insatiable curiosity, capacity to listen thoughtfully, reflect and then reshape attitudes, values and action informed my career for over 40 years. I was blessed with many, varied opportunities to learn with and from John. Each time I was somewhere between nudged and provoked

into considering my life's work differently. His wisdom and humility were palpable.

Many years ago, I looked up from the podium about to deliver an emotionally challenging keynote to see John, third row just took my right; stoic, impassive. I was trying to gather myself afterward when I felt a hand on my left shoulder. John said, "Thank you for that gift. " Off and on, I have felt his hand and heard his words in moments of need for 38 years. That is John's quiet power in full cry.

The unfolding heartache and heartbreak will be a measure of the love and respect he deserved. For those most intimate with John, I do not envy the blackness of your grief.

Leslie Lederer lslederer@gmail.com

Hi, Sending you a picture of John and Danny having one of their deep conversations. Danny and John had met at a workshop in KY and people who were there commented on how they seemed to have a special connection. Danny was very perceptive on who he chose to have a connection with and reacted the same way whenever their paths crossed.. He knew John was one of those people who really saw him. I can only imagine their joyous reunion in heaven.

Farewell good and faithful servant. You will be missed.

UK

Linda Keys - elsconsulting7@msn.com

Ah John, I am so sad to hear of his passing. I remember meeting him at your house, Jack and Lynda, and that whole evening I was being introduced to these people who had influenced my work for many years. Like many I met that evening, John was humble and human, and had no sense of self-importance about him. He was noticeably kind, and a little bit quietly amused by something somebody said, and was a deeply authentic, a gentle presence. Remarkable really, given the power of his words and the impact of his words work. What you wrote about his listening eyes was spot-on. The world is neither place for having had him in it. I'm sad he's gone.

Condolences to you all, and especially to Connie. X

Julie Stanfield julie.stansfield@in-control.org.uk

We certainly were very lucky. Penny is 21 this year and her love of reading continues. The huge impact John has had on so so many lives. Lynne is recalling washing his underwear! And another when we doing a circle meeting for Nicola and the social worker was misinterpreting the 5 accomplishments, Lynne argued back with no joy but then John walked in so she delighted in telling the social worker, well John's here and he wrote them! The social worker was star struck and couldn't speak for the rest of the meeting. So many

memories! Even him introducing me & Penny to 'lo mai gai' rice dish which we both love.

Hope you and Linda are well and I'm sure have many more memories & stories xxx please send my love to Connie & family xxx

I just got off with Julie Stansfield. She's going to tell Lynne Elwell; and Sandra will tell Oliver.

Julie likely has some pictures to share, and she told me a beautiful story....hopefully she'll write it and share it. But, here's the gist of it....

She is a Catholic (I think Catholic...definitely Christian of some sorts) who left the church and when her daughter Penny was born she had no plans to baptize her. She and John got into a conversation about that. He told her that a naming doesn't have to be a church thing. That lead to a naming ceremony at Julie's kitchen sink, facilitated by John, with close friends, family and community members. At the end John said something along the lines of Penny didn't have god parents but she had this community to support her throughout her life. The "naming at the kitchen sink with John" is evidently a pivotal moment in their lives they often refer to.

Earlier this year, one of Penny's best friends died - by suicide I think - and that group of people stepped up and have been supporting her through it just as John said 20 years ago.

One other little note on Penny - she was always trying to find a book John hadn't read. Eventually she did - just one. He

promptly read it. And then she wrote a book so she could find another one he hadn't read.....

She told the story so beautifully, I'm not doing it justice at all. Julie thinks she has pictures of the naming ceremony John facilitated and will send them on.

Owen Cooper owencooper215@gmail.com

Thank you so much for sharing this exceptionally sad news. John was truly a giant in his contribution to understanding how best to provide real support to individuals, and he will be a great loss.

You must be incredibly rocked by this news, in losing such a close friend and colleague . The two of you brought out the best in each other, to the benefit of so, so many people.

He leaves such a legacy , although he, along with yourself, Marsha , Linda and one or two others have developed so many leaders with the right values and vision of might is possible.

It was such a privilege to have known John, to have been supported and inspired to think differently.

I'm sure Connie will receive great support, and can reflect on the joy of a life shared with John.

You too have lost a great collaborator, so I hope you and Linda are managing this huge loss too.

Much love and warm thoughts

Nan Carlyle

Thank you, Beth for reaching out personally to me. I had heard the very sad news from Don Trites and I also know that you wish to keep it private for as long as possible. As you said, I've known John for what feels like most of my life. His teachings have mattered to every cell of my personhood. I continue to use the five accomplishments and all their intricacies in my everyday life as well as each and every presentation that I make. I intuited that he was slowing down and will miss seeing his "likes" on my photographs. He has touched 100's of thousands of us personally and will live on through everyone we touch. He has changed the world and will continue to do so.

As the family works through how to manage their personal grief as well as to honor John's life publicly, please know I would like to attend any memorial event and if I can help make it happen in anyway, I would be more than happy to do so. Besides anything here in the US, I will return to England as usual in November. I Would be happy to help organize something there though I'm sure David Towell and Simon Duffy would want to be part of it too. For now, I'm just thinking out loud.

I've written you an email, but just also want to say here that you too have changed the world for the better. Life is short and it's important to tell each other that we matter. Even though we have not communicated regularly these past many years I hold you in my heart and in my mind on a regular basis. Your mother's paintings also surround me so you and your family are never far.

Take care of yourself as you go through your own grieving process.

With great love, Nan.

Simon Duffy

At the weekend we learned of the death of John O'Brien - one of the most wonderful people in the world - and for me a friend, ally, mentor, inspiration and more. Everything I've ever done in my work and that I feel some sort of pride in (a dangerous feeling as John would note) really has its roots in John's thinking.

I used to drive around with a tape of a talk by John in my car, lent to me by Steven Rose MSc RN (LD) RN (MH) FRSA. In just one talk there were so many gifts and different ways of looking at the world —but again and again what came through was his ability to find new ways to see how we can realise LOVE in a world full of injustice.

I also want to honour Jack Pearpoint, Lynda Kahn and all his allies at Inclusion Press. I would encourage all of John's friends and allies to share their thoughts and images with Inclusion Press. At Citizen Network we will try to find our own way of honouring John in the coming weeks. Our thoughts and prayers are with his family.

Ben Drew

John O'Brien, a giant in the disability rights movement, died peacefully on June 27, 2025. He's gone now. And already, there's a space where his quiet, fierce hope used to be.

For decades, John didn't travel the world to speak, he came to ask questions. Real ones: What does a good life look like? Who do you sit with? Who dreams with you? Then he listened deeply, persistently. He saw every person as a constellation of gifts waiting to be seen and shared.

With his life partner and co-conspirator Connie Lyle O'Brien, John was a pioneer in the person-centered planning movement, and the belief that services should follow the person, not the other way around. His writing didn't shout. It invited. It whispered justice, love, and the radical act of walking beside.

He wasn't flashy. He wasn't loud. He was precise, grounded, and relentless.

In a world that demands compliance, John asked for contribution. In systems that offered protection, he insisted on presence. And he reminded us that real safety comes through relationship, through community, through simply being human together.

The disability community mourns, yes. But remembering John means more than grief. It means action. It means listening harder, dreaming louder, and refusing to settle for inclusion that stops at the doorway.

John O'Brien is gone. But his legacy is not. His vision is not. The work is not over.

William Case - william.case1@outlook.com

Hi Jack Lynda cath please see my thought about John below
please pass my condolences, Connie and her family

I'm deeply saddened to hear the passing of a great leader, John O'Brien John O'Brien. My thoughts and prayers go out to Connie, his children and grandchildren. John helped me to plan my life using a path that he created called PATH, planning alternatives for tomorrow with hope. He helped me when I was in my 20s navigate

my dreams and aspirations that every 20-year-old would want at that time. He helped me navigate the world that was around me and therefore helped me shape the person I am today.

His teachings have been known worldwide, from the UK to beyond, and they showing that every disabled person has the right to an inclusive society, a society where belonging showed the value of a community working together for the greater good. I got the pleasure of meeting Connie and John for the very first time when I invited them along to my circle of support planning for America for my Winston Churchill Fellowship.

John helped me set up meetings in Washington DC, and he also helped me in Toronto where I met up with Connie and John to meet Jack Pierpoint, another great friend of his, and many more people. Throughout the years, I got the pleasure of being second speaker at an event for Partners in Policymaking asking me if he could go first as he was run later for a meeting in London . I wasn't going to say no to a great man who designed lots of tools to help disabled people.

I pass on my deepest heartfelt thanks to him, his family, and my thoughts and prayers are with them at this time. Rest in peace, John. You've done your work. Your work and teachings will continue on in generations to come. Rest in peace.



William Case CF'

Independent Disability consultant also a Churchill fellow 2011
an CEO of the YSM Group- Your Support Matters and Board member
of NDTi (National Development Team For Inclusion)
Email william.case1@outlook.com

Netherlands

Erwin Wieringa

35 years of cooperation, discussion and learning. Very sad to hear of his passing. A great inspiration, critical listener, and radically progressive thinker. Owed a lot of thanks. My sincere condolences to Connie Lyle O'Brien and family. His essential work lives on in us.

Hong Kong

Kari and Lilian cat.kari.rabbit@gmail.com

To John's family members(Connie, Sean & Kevin), friends and colleagues,

It was our privilege to have PCP, MAPS & PATH Workshops in 2001 in Hong Kong. John together with Jack brought us lots of insights, reflections and courage to promote and implement Person Centred Planning in services for people with disabilities and their families.

His words, wisdoms, writings and sharings always remind us never give up and give in. Like a compass to guide us in crossroads with faith and confidence. Make a difference to find a way out.

We'll miss John endlessly as a mentor, buddy and friend in his life journey to engage people's efforts and hearts creating community lives for people with disabilities who deserve dignity and respect.

I remember Jack used to take a photo of John stood in front of a road sign "O'Brien Road " in Hong Kong. What a nice photo!

Besides, met John and his friends again in Summer Institute 2006 was another great learning experience!

Enclosed and share photos of the workshop in 2001.

With deepest and most heartfelt condolences !

Regards,

Austria

Oliver Koenig oliver.koenig@suttneruni.at

Dear Connie, dear Patti, dear Beth

It is with utmost sadness that I write to you and send my deepest condolences and love.

Ever since I was blessed with the immeasurable privilege of collaborating with and learning from John, he has been a constant companion—someone who always responded when I was struggling. But even in his absence, time and again when I've found myself in challenging situations or standing at a crossroads, I would ask myself: What would John say? Or rather: What question would John pose to me now?

The last time I saw him was at the closing conference of the New Paths project in 2015, where in the breaks, he spoke to me about his legacy and questioned the impact he had made in the world. He told me the story of Gunnar Dybwad's passing—how, when he was found dead, his calendar was still full of commitments. John said then that this was how he too would want to go one day: doing the work he did like hardly anyone else.

That day—Beth, you might remember—also gave me the privilege of encountering a different side of John. I remember especially the

words of a man, following a great deal of turmoil after some participants expressed their sense of alienation in a design setting that had invited embodied engagement. He had spent much of his adult life in a psychiatric institution. And as he listened to stories of people whose lives had changed through years of care and commitment, he didn't feel empowered or uplifted—but deeply hopeless and powerless.

The event had reached an inflection point. During the break that followed, it was the first time I saw John truly saddened. He opened up to me about his despair over what he referred to in reference to Peter Leidy as the “cogworld” and its systemic backlash. He questioned the lasting impact of his work.

But what stood out most in that moment, and what made it so profound for me as a witness, was when he spoke about himself—and how, from the outside, people could hardly imagine the steep learning curve, he said, that leading any of these gatherings still demanded of him. A silence followed. Then John began to sob—deeply, honestly, and with a heartfelt vulnerability. In my entire professional life, it remains one of the most intimate and personal moments I've witnessed—and one I will always carry with me.

That day, Beth, you stepped in and moved the group through a process of creative engagement—one that enabled us to dance with our collective demons (and desires) at one of those rare moments at the bottom of the U.

Some of John's thinking from that event is expressed in his reflections on care, deliberation, and the risks and effects of using embodiment in spaces that bring together people from diametrically opposed positions along the power-over/power-with spectrum. I'm

attaching this as well as other documents here—drawn from and encapsulating our network’s learnings and Johns guidance. I feel these documents hold so much of John’s embodied wisdom, and I believe it need to be preserved.

Since the beginning of this year, I’ve found myself thinking of John very often. And I have wished so dearly that he would not have had to leave us in times like these, hearing that he gently slept away does give a small sense of relief.

Even just the many comments on Facebook—only a tiny fraction of the people whose lives, minds, and hearts he touched—show the depth of his and your shared impact. And how it will continue: needed so deeply in todays and tommorrows world.

Holding him—and you—in my heart. If possible I would truly appreciate a link to the memorial service.

with love

Oliver

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Australia

Leanne Pearman leanne.pearman@bigpond.com

Hi Jack and Lynda

I have so many grateful memories of John.. I guess I will write what comes to mind and heart.

In the 90's I had read a lot about John, and person centred planning, and in 2002, I thought I would make contact with him, to see if he could guide me with some of the work I was facilitating in our state disability services. I googled him, came up with a phone number on the internet, which I rang, expecting to get a voicemail, or a work recorded message. I didn't get a voicemail. I got John at the end of the line!! I was in Western Australia, and it was early hours of the morning his time! I couldn't believe it. This 'guru' had his number on the internet, AND he answered! I was so in awe at the fact I was speaking to 'The John O'Brien' I could hardly say anything!

John told me about a conference he was attending in 2003, in NZ called the Nothing Special conference.

Well that was it. I had to go. I managed to get a scholarship through the state, and off I went. As a single parent, I took my kids with me, whose grandparents lived in NZ (right where the conference was). My boys (who were 3 and 6 at the time), met John. My eldest son, asked me if John was Santa. I replied that yes, I guess he is a sort of Santa as he brings many gifts to all people, all over the world. That always stayed with me.

I stayed in contact with John from that point, and he connected me with Inclusion.com. I ordered some books from Inclusion, as I often did, and then one day, in 2006, when I got my books delivered, inside was a leaflet that was reminding me of the TSI. This was 10 days before the TSI In July. I impulsively used every cent of my savings, organised my plane tickets via a number of stops to be able to get there on time, and I rocked up at the start of TSI with luggage in hand after more than 40hrs of traveling. I was then in the company of the 'guru's' (John, Connie, Jack, Lynda, Judith, John Mc, etc) I had only read about, valued, and could only wish to be closer to.

That TSI changed my path. John changed my path. The people there changed my path. John helped my compass to be clearer, and strong and reflective of who I was, my values, and what my work was in the world.

This all started with a middle of the night phone call to John.

It also led to attending most TSI's yearly after that. In 2010, I facilitated a trip for John, Connie, Jack and Lynda to come to Perth to do a mini TSI. My boys, and family know of that session to be something so important to me, and the boys again, knowing 'the other Santa' was coming to bring gifts to people of WA.

Then, In 2015, both my sons (now young adults) came with me, (with my cousins) to the San Diego TSI. Both of my boys knew when I went to TSI, it included time learning with John, and even today, when sharing with them the news of John's passing, they still remember him as the 'other Santa who brings many gifts to people all over the world'.

John gave so much of his time to me over the last number of years, with my work with WAIIS, and with Australian Inclusion Group. He was a mentor. I felt he believed in who I am.

I remember sending a box of Australian treats over to him and Connie for his grandkids. I loved that his family got to share some joy, yes including Vegemite, that I was sending across the water to them all.

He gave his time to me via zooms, regular check ins, and more recent email contact with each other the last few weeks, sharing where we/our families, our work and the world is at. John always cared about Australia and the NDIS, always interested in people I knew and loved like warrior woman Karlene (who I shared some good news about with him recently).

It is hard to believe he is gone. My tears flow hard.

I think I could write a book on what I have learnt from him, and what a gift he was to this world.

My heart breaks for Connie and the family, and extended close friends like you both, and I hope they know they are being held with so much love right now.

I attach a couple of photos from 2014, 2015 and 2019

Judith Stevens judithstevens@yahoo.com

So sad one of our great heroes is gone. He influenced me and so many others in such positive ways. Thank you John and much love to Connie

Love-light's our heartbeat. Feel the rhythm.

“What more is possible?”

Thoughts on the encounters with John O’Brien by one of his many followers (and fans), Sandra Fietkau from Germany

I met John O’Brien during the very first German conference on Person-Centered Planning held in Berlin, Germany in 2010. He there helped “giving birth” to the German speaking network on Person-Centered Planning, like he had obviously been a “midwife” for so many other initiatives, groups, networks around the world.

Already there I noticed that John was a man of listening, observing and “well-assorted words”. He would sit back, watch, be present – and then, eventually, bring in his thoughts and wisdom in a precise and articulate way, that left me in awe. His ability to give statements, that would have immediately been ready for being printed in a book often challenged both my capacity of thinking and my knowledge of the English language. With his words, he helped to make progress in many discussions, summarizing words prior spoken by many others or stipulating both thinking and acting. Although his sharp analytic ability could be challenging at times, he always remained positive and won people for his ideas by adding a bit of humor, speaking with a slight grin on his face and a friendly, warm twinkle in the eye – that just could not be missed.

For me, like so many others, it always was a great opportunity to sit and spend time with John. Out of many encounters, I especially remember a Zoom conversation we held in October last year on person-centered work and the interview on Circles of Support for my PhD back in 2010. Both conversations were recorded, lucky me, so I can go back and re-listen to many learnings that John provided (also I can think of and translate some of his more complex sentences).

John’s life and work seem to have been energized by constantly asking the question “what more is possible?”, for himself, for others, for systems, for us all. In his interest and love for the people that don’t have many supporters or allies, he helped them come up with better ideas for their lives and then supported the realization of those dreams. I am amazed by the countless lives, stories and moments both John, his wife Connie and so many other people in his big circle of colleagues, friends and followers managed to change and influence all across the world.

His ability to look at each person, respect and honor that person by fully listening, being present, is a big gift and talent, I hopefully can get better at through John’s exemplary and daily practice: Listening, being present and eventually asking good questions, rather than stating my opinion or talking about my experiences (which are most likely not even relevant in many situations).

Now it is on us – and on me in my circles and relationships – to carry forward the many learnings and ideas John has provided us with. Let’s be present, let’s listen and let’s never stop believing in opportunities and abilities. Let’s be and remain active with words, ideas and deeds to help make this world a little more hospitable and inclusive for all of us.

Thank you, John! With highest regards,
Sandra Fietkau

P.S. Probably, John would not have wanted to have actual “fans”, but I still perceive myself as one of his many fans. In this role, I get to look up to a person and his lifetime achievement and become inspired by the vast number of writings, learnings – a life well lived and a gigantic legacy now to be carried forward.

John O'Brien
Celebrating a life well-lived; inspiring our
efforts to build a better tomorrow

David Towell*

About ten days ago I heard the very sad news that John O'Brien has left us. In doing so, he has also left a very large gap in the global network of people learning together about how to build 'communities that work better for everybody'. Last Wednesday I joined on-line what I am sure was a significant number of people in this network in the memorial service celebrating John's life. I recognised a few people in this video but when they came to personal reflections, I understood everything people shared about their experience with him. John was indeed an impressively virtuous human being with huge talents who devoted a lifetime to using these talents in the service of creating a better tomorrow for us all.

Quite rightly, Inclusion Press has offered many more of us the opportunity to contribute to this process of collective reflection, partly as a tribute to John's life but also, I hope, as one vehicle for strengthening action on this shared mission in the months and years to come.

I first met John (with Connie Lyle O'Brien) I think in 1979. I had recently become a senior staff member in a London-based Foundation with the King's name (simply the *King's Fund*). My role was to lead it's work on what public policy was increasingly calling 'community care'. With colleagues I made a central focus of this work what became the *An Ordinary Life* initiative**: a national movement to bring people with learning disabilities (this term corresponds closely to the North American use of 'developmental disabilities') out from institutions so that increasingly they would show up (to borrow John's words) in valued contributory roles in community places, where other citizens are typically to be found. One of these people was my older sister, Patricia.

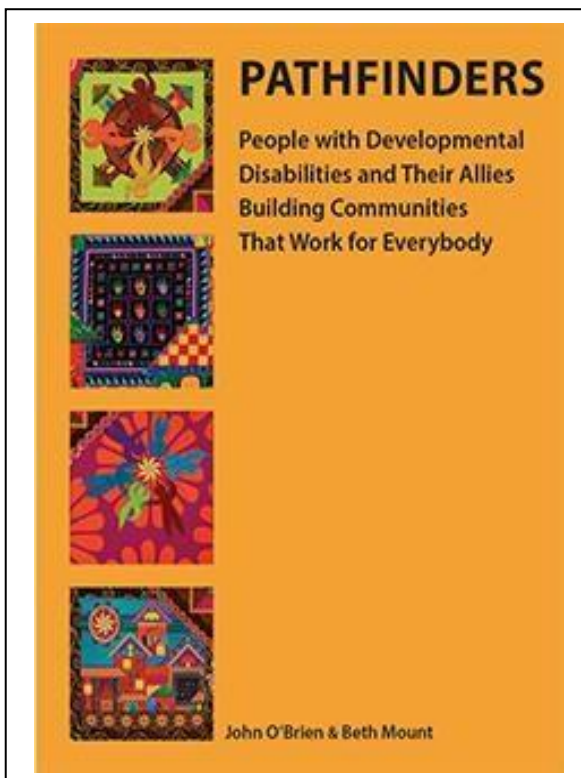
In this initial meeting, John and Connie worked for a couple of days with around 80 participants at our Conference Centre exploring how the principle of *normalisation* might become a valuable guide to this national endeavour. Thereafter John became a regular visitor not just to the King's Fund but increasingly to more local networks in different parts of the U.K. trying to 'figure out' how best to make progress on the *An Ordinary Life* vision in our conditions. Of course, this agenda proved to be work for a life-time! I haven't kept a record but probably John and I have been in the same place at the same time, usually with quite a lot of other people, for well over 100 days since then. John's son Sean amused us in the memorial event by describing how he had always had trouble with the question, 'What does your father do for a living?'. I have learnt quite a lot about this!

There was a typical pattern to these days, all of which took place on my side of the Atlantic. John caught the 'plane and showed up. Meanwhile I would act as convener and get some people together - disabled people, family members, other allies, paid supporters, system managers, etc. - who were interested in some important and commonly occurring questions. We would try to design a process - for example, sometimes using 'world cafe' methods - that

promoted serious conversation on these questions. We would encourage participants to listen carefully to each other and think deeply about the situations they were uncovering. John had an amazing capacity for such listening and would use his analytic skills to help people not only develop a better understanding of local challenges but invent new ways of doing things - taking responsibility for actions, small and large, that make a positive difference.

One aspect of this process would involve reflecting back on what was emerging and capturing some of the learning in graphics or writing. Indeed John was prolific in this kind of grounded writing - grounded in the sense of arising directly from these conversations and so fully resonant with the experience of participants.

Looking around my office now, I have shelves of box files full of material thus generated. (We began this collaboration well before the time of personal computers; now there is a great deal more recent material in my computer and cyber space.) From where I am sitting I can see boxes relating to normalization, PASS/PASSING and *Framework for Accomplishment*. I can see at least three boxes concerned with *person-centred planning*. I can see another whole box on Dane County, Wisconsin.... and so on. The last example reminds me that while I never worked with John outside the UK, he was generous in opening doors for me and other colleagues to learn directly from the best of North America. For example, I went to Syracuse in the days of Steve Taylor, Toronto - where I had the privilege of meeting Judith Snow and Marsha Forest, and three times visited Madison to experience first-hand the great work of *Options in Community Living*. (As an excellent example of grounded writing, John has produced a series of books on how leaders in Dane County have worked to enable people with complex disabilities to be welcomed as full citizens, my favourite being *Celebrating the Ordinary*).



My office also has a lot of books. To the right of my desk-top computer, there is a small set of those I find most useful, most inspiring, or both. Nearest to the computer is the *Oxford English Dictionary*, definitely in the former category. Next and most important in the third category is *Pathfinders****, John's 2015 book co-authored with another of his life-time collaborators, Beth Mount. In this book, John and Beth have lovingly brought together much of the learning from many years of practice into a single text. For me at least, *Pathfinders* remains the best inspiration for continuing our own journeys with others towards what (borrowing from Martin Luther King) they call 'creation of the beloved community'.

These authors are both great story-tellers. Let's start from some of these. *When Harry Met Sally* is a classic Hollywood version of the joys and struggles of building relationships. Famously it includes a restaurant scene with the punch-line 'I'll have what she's having!' Unfortunately society has organised in ways which put multiple barriers in the way of many people, especially with more complex disabilities, getting anywhere close to what many others of us are having.

But the stories of 'When Gail Met Ken', 'When Marcie Met André', 'When Audrey Met Ian' etc. provide powerful accounts of what pathfinders (the people with disabilities) like Ken, André and Ian can achieve in their lives (and in ours) when: 1) they set out to find something better; 2) they are able to become part of lasting relationships with allies; 3) together pathfinders and allies secure the space to co-create new possibilities; and 4) they are always asking 'what more is possible?'.

Pathfinders identifies six elements in a simple and powerful logic that underpins these journeys of personal discovery (and around which the book is organised):

1. We can express our common purpose as citizens as being to play our part in building communities that work better for everyone. The *United Nations Convention On The Rights Of Persons With Disabilities* offers an authoritative and comprehensive set of standards for what this means in the lives of disabled people if they are to achieve equal citizenship.
2. These communities will be places where citizens offer one another opportunities to create and share 'real wealth', not just money but the good relationships, valued networks, development opportunities, etc. which contribute towards a full life.
3. For people with learning disabilities, social inclusion is typically the result of courageous *pathfinding* through a life-long journey.
4. This journey is more likely to be successful when pathfinders recruit personally committed allies (typically, but not only, starting with family) and skilful partners, including personal assistants and public sector managers, able to mobilise different kinds of support.
5. Good allies and partners in the journey to full inclusion learn how to assist people to have valued experiences (respect, self-direction, belonging and contributing) which other citizens enjoy.
6. This calls for fresh thinking and a process of social invention grounded in each person and their relationships.

Simple logic but in practice a deeply creative process in which pathfinders and their allies are fully engaged in a joint endeavour to realise their highest purposes.

However *Pathfinders* is not an easy read for the very best of reasons: many parts of the text, whether individual stories, particular graphics or detailed arguments, require intense reflection and the interrogation of how they relate to our own experiences, if we are to draw insights for better practice. Let me illustrate this with three important examples.

The sense that we are expressing our own will in what we do and how we live is at the core of being human. Article 12 of the UN Convention provides a legal framework for self-determination in its prescription that disabled people enjoy legal capacity on an equal basis with others and should have access to the support they require to exercise this right. This proposition is a radical challenge to much current practice in relation to people with learning disabilities, especially those who do not communicate in typical ways. *Pathfinders* offers a thoughtful commentary on what it means to be an ally in facilitating their self-determination.

For many people with learning disabilities, the key partners in this journey to self-determination and inclusion are direct support staff (sometimes described as 'personal assistants'). Despite the growth in individualised funding, most such staff are still employed by large, service providing organisations. John and Beth offer a detailed analysis of the direct support practices which best enable pathfinders to create their personal journeys to a fuller life and how these practices can be cultivated organisationally.

These journeys require pathfinders and their allies to engage in social invention: together they are seeking to build communities which work better for everyone. In turn this requires that we hold in mind a theory of change. In perhaps the most original contribution of this book, John and Beth offer a detailed exploration of how Otto Scharmer's *Theory U* can guide a process of individual and group reflection that enables us to look with fresh eyes at the challenges we face and take creative action towards a better future.

Pathfinders is a book full of practical wisdom. It is a call to all of us to do whatever we can to greatly multiply the number of pathfinders making their own self-directed journeys to inclusion. In this and many other ways, John has left us continuing inspiration for our efforts to build a better tomorrow. Thank you, John.

London, U.K.

July, 2025

* David Towell is Director of the London -based *Centre for Inclusive Futures*. The Centre defines its mission as 'developing sustainable communities that include everyone as equal citizens'.

** I have recently published a review of the first 20 years of this initiative, recognising John's important contribution: *Towards An Ordinary Life: Insights from a British story of social transformation, 1980 - 2001*. British Journal of Learning Disabilities, 2022, 1 - 9.

*** John O'Brien and Beth Mount *PATHFINDERS People with Developmental Disabilities and Their Allies Building Communities That Work Better for Everybody* Inclusion Press 2015.

Animal-Centered Design and John O'Brien

Anne Mitchell July 6, 2025

Reflecting on John just after his passing and realizing how deep and profound his impact on my life has been and how deep and profound his impact on our entire culture has been is fascinating to contemplate. I met John in October, 1983. I was a brand new group home manager and he was leading a PASS workshop in Lansing, MI. I only participated because my boss got sick and couldn't attend at the last moment and I could. I knew it was about "normalization" and I thought I knew all about that so I was thrilled with the idea of spending a week in a hotel, eating at restaurants and learning something I already knew about. PASS workshops began on Sunday evenings and finished on Friday about noon. John was the workshop lead while participants were assigned teams to work with and each team had its own lead person. Sunday night I started out quite comfortable, only half listening and then I realized that I might not know as much as I thought I did about this idea of normalization. Monday the real work began, some lecture, visiting our assessment site and beginning to talk about what we were going to do throughout the week. I began to think I didn't know nearly as much as I thought I did. The discomfort that comes from realizing your beliefs might not be the whole story can be confusing. By Tuesday I knew I knew nothing and even worse, I had behaved in ways I could not reconcile with my values, ethics and sense of justice. I had so many blindspots. So I decided to leave the workshop, quit my job and find something else to do.

However, I did not want to be rude so I went to John's room that evening, politely knocked on the door and after he invited me in, I told him I was leaving in the morning but not because of him, just because I was not fit to do this work. I poured my heart out to him while he intently listened the way we know he can and does. When I was finished, he paused, and said that it occurred to him I couldn't get a refund so my agency would be out the money even if I left. He said they expected me to stay through the workshop and the expenses had

already been approved and no one expected me back until Friday afternoon anyway. I remember him telling me that I could quit just as easily on Monday morning as on any other day so it would probably be good to stay. For some odd reason, though that response did not address any of my concerns, it made sense to me and I agreed to stay.

John's ability to listen and then say the thing you need to hear is remarkable and reminds me of the Bodhisattva, Avalokiteshvara in Buddhism. Here is the invocation about his listening superpower:

We invoke your name, Avalokiteshvara. We aspire to learn your way of listening in order to help relieve the suffering in the world. You know how to listen in order to understand. We invoke your name in order to practice listening with all our attention and open-heartedness. We will sit and listen without any prejudice. We will sit and listen without judging or reacting. We will sit and listen in order to understand. We will sit and listen so attentively that we will be able to hear what the other person is saying and also what is being left unsaid. We know that just by listening deeply we already alleviate a great deal of pain and suffering in the other person.

This is how John listened. This is how John alleviated suffering.

What would my life have been like if I had left? What would I have missed? Who would I have become? His power to see, be curious and stay open to the possibilities is remarkable. And that was 42 years ago. I'm still connected to the people and ideas and values and ethics and sense of justice John shared during that workshop. The complexity. The gray of it all. The responsibility to pursue it. I wonder at the thousands, perhaps tens of thousands, of people he has had similar impact on and with.

I have done many things in the past 42 years trying to see and find and clarify those ideas and values and and ethics and sense of justice from

that workshop. I know those things lived in me before PASS but they took on new meaning that week and have never left me since.

My own learning, this past decade especially, has taken me outside, beyond people with disabilities. Over many twists and turns my commitment to other groups of people who have been marginalized and my commitment to non-humans and the earth herself has become much stronger and I have pivoted to working more directly for non-human and earth justice. And yet all the lessons from those early days still apply. Justice is justice wherever we are. Suffering is suffering no matter how it manifests or in whom. I strongly believe our planet is suffering deeply, in profound ways and that there is still time to support her in recovery. All the work needs to be done and I am grateful for the lessons John shared with me - even the many lessons that were painful to learn.

The one lesson I still mightily struggle with is one I read after his passing:

On the curiosity that comes with humility, and never ending work...

"I have probably found more ways to fail at influencing people, than anybody else, or anywhere else. And I'm obsessed about this pretty consistent failure. People are sometimes complimentary about what I've got to say. But if you look at the actual impact of lots of it, it doesn't add up to very much. That doesn't bother me probably as much as it should, so much as it keeps me curious. And so I keep looking around to see who else is doing something that might help, that might reduce my next failure, or make my next failure more interesting."

- John O'Brien

I never had this conversation this specifically with John but this quote resonates deeply and will accompany me the rest of my life. And I am

re-reading some of his work and will find pieces I never read before that will shape how I move forward.

One of the most interesting things that happened very recently is that I am peripherally involved in documentary projects about the human relationship with non-humans and raising all the questions we need to consider about this relationship. I was watching the trailer for a new documentary that will be available this fall at the earliest, <https://www.foreverhome.love/why> and I heard the phrase “animal-centered design”. I was filled with a deep sense of warmth and of belonging and purpose - I know the people who coined the term “person-centered planning” and have learned through and with them over decades and now this phrase has led, through many iterations, to “animal-centered”. John’s (and all of us but significantly held together through John) impact on our entire culture, far beyond the disability world is awesome to contemplate. Here is what AI had to share about the origins of the phrase:

The term "person-centered planning" originated in the 1980s, primarily in the US and Canada, as a response to the limitations of traditional service models for people with disabilities. It emphasizes placing the individual at the center of the planning process, focusing on their goals, preferences, and needs, rather than solely on deficits or service provider convenience.

Here's a more detailed look at the origins:

- **Challenging Traditional Models:**
Person-centered planning emerged as an alternative to the medical model of disability, which often prioritized professional diagnoses and treatment plans over the individual's own desires and aspirations.
- **Key Pioneers:**
Individuals like [John O'Brien](#), [Connie Lyle O'Brien](#), [Beth Mount](#),

Jack Pearpoint, Marsha Forest, were instrumental in developing and promoting these ideas.

I can simply change some of the words and all this applies equally to animal and environmental justice. While I failed at convincing most at TSI that it is time to expand our circle of compassion to include non-humans and the earth herself in our journey toward justice for all, (an idea I presented at TSI in 2016 but which did not gain much traction) - I can now look at this failure as being really interesting and develop my curiosity about what I might learn from that. If one chooses to go to <https://www.foreverhome.love/why>, they will find language very familiar to our work including people with disabilities in the beloved community but with a different subject altogether.

John's work, our work, has been about making the invisible, visible in people with disability and in our communities. Seeing the unseen. Our culture teaches us not to see. To see those who look or behave differently as less than - less than adults, less than people without disability, even less than human. We look past them. We literally don't see them even when they are right in front of us. We make up things to justify the way we treat them — they don't feel pain like we do. They don't think like we do. They don't want or need like we do. They don't participate in relationships the way we do. They don't have dreams or aspirations or higher callings. We commodify them.

John was a master at helping us to see the fallacy in this, to see the myths we have constructed. To actually see the person, the essence of who they are, the role they do or can play in our communities regardless of their differences To offer us a glimpse, a taste, a sense of the promise of the Beloved Community. All means all. Everyone is needed.

I have come to apply all of this to non-humans and to the earth herself. We do not see insects or any other animals or plants or water or air or soil - in the way we see humans. We see humans as having value in and of themselves. Because of who they are. But for every being that

is not human we only see their value in what they can provide to humans. We deny non-humans everything. We make up fallacies and myths to justify the way we treat them. And just like with people with disability - we commodify them. We built institutions and whole economic sectors that rely on people with disability as the commodity. We have built many economic sectors that rely on non-humans for food, clothing, entertainment, research and we use leftover animal parts in many, many ways that the average person has no idea about. In the words of Upton Sinclair:

"It's difficult to get a man to understand something when his salary depends on his not understanding it"

Sinclair too failed to influence people. I don't know if he was curious about that, but one of his messages was about the plight of the animals in our food system and the plight of the immigrant laborers forced to work in appalling conditions to get those animal parts to our tables. (The more things change... see current struggles about immigration and our food system.)

It's all the same thing. Social justice work is social justice work no matter where or how or for whom. How do we expand our vision to see it all? How do we enlarge our circle of compassion to include everyone? To understand how interconnected we ALL (not just humans but non-humans and the earth herself) are and how each and every one of us is necessary to continued life on earth. How the promise of the Beloved Community includes not only humans but all life on earth.

For me it has become one work. One path to the Beloved Community that Martin Luther King Junior and Thich Nhat Hahn envisioned and Waddie Welcome made real for me for a bit of time in his story in Savannah and for which we all continue to look toward. John has had an outsized impact on us understanding what the Beloved Community is and how we might get there. A quiet giant is how I think of John.

May we continue to feel his curiosity and love of learning, embody his humility and get on with our never ending work.

I wonder what John would think of his impact on animal rights work? I'm certain he would be curious and amused. I will have fun reflecting on how that conversation might unfold.

I have a young friend, Richard Bennett, who sees insects similarly to how John helped us see humans with disabilities. Richard is also a keen observer, fascinating storyteller and photographer. He took this photo of a clymene moth this weekend. The moth looks formal and robed to us and we considered that he does do sacred work - supporting his Beloved Community, quietly and with dignity. The moth reminds me of John in a curious way so I wanted to include him here.

