We've Got Each Other's Backs!
A Found Poem on the Meaning of Family from the Perspectives of a "Client", Parent and Caregiver

On se serre les coudes ! Un poème ancré sur la signification de la famille du point de vue d'un « client », d'un parent et d'un aidant

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Abstract

This arts-based submission reflects the perspectives of David, who identifies himself as a person living with an "understanding disability and mental health challenges", his mom Shari, and Stephen, David's formal caregiver in a "family type resource". Our poem explores the idea of family as a concept and an experience. We created our poem through a combination of discussion and reflection on how our understanding of family has been shaped by our journey together. We pulled meaningful statements from recorded conversations, discussed our choices, and created our poem. Over the course of 5 years our connection has resulted in what we call a "found family"; bound by shared values and experiences in which hope has become possible. In creating this poem, we explore our experiences of "recovery to discovery". Our poem reveals the possibilities for, and challenges in, creating a sense of belonging akin to family within a group home setting. We share, in our own words (using different fonts to identify our unique voices), our thoughts about key factors such as trust, comfort and belonging that reveal pathways to emotional and spiritual growth as individuals and together. We've got each other's backs is a celebration of "found family".

Résumé

Cette publication fondée sur l'art reflète les perspectives de David, s'identifiant lui-même comme une personne en situation de handicap « qui fait face à des défis de compréhension et de santé mentale », sa mère Shari, et Stephen, l'aidant formel de David au sein d'une « ressource de type familial ». Notre poème explore l'idée de la famille en tant que concept et en tant qu'expérience. Nous avons créé un poème à travers une combinaison de discussion et de réflexions sur comment notre compréhension de la famille a été façonnée par notre parcours commun. Nous avons extrait des passages significatifs à partir de conversations enregistrées, avons discuté de nos choix, et avons créé notre poème. Au cours des cinq dernières années, notre alliance a évolué en ce que nous appelons une « famille trouvée » ; liée par des valeurs et des expériences partagées à travers laquelle l'espoir est devenu possible. En créant ce poème, nous réfléchissons à notre expérience, en passant de la « réadaptation » à « l'exploration ». Notre poème révèle les possibilités et les défis de créer, au sein d'un foyer de groupe, un sentiment d'appartenance semblable à celui d'une famille. Nous partageons, dans nos propres mots (en utilisant différents styles de polices pour identifier nos voix uniques), nos réflexions à propos des facteurs fondamentaux tels que la confiance, le confort et l'appartenance, qui révèlent des trajectoires de croissance émotionnelle et spirituelle à la fois personnelles et collectives. « On se serre les coudes » est une célébration de la « famille trouvée ».

Mots-clés : handicap, services residentiels et hebergement, famille, aidance, méthodologie basée sur l'art, poésie trouvée

Introduction

This poem addresses our collective story, all the while honouring our unique experiences and perspectives. Our work follows in the tradition of others who have used artistic form as a means to explicate lived experiences of disability, family and care (Chandler, 2018; Rice et al 2015; Richards et al., 2019). Using a methodological approach integrating collaborative ethnography (Rinehart & Earl, 2016) and found poetry (Butler-Kisber, 2002; Butler-Kisber & Stewart, 2009)[i], we explore the issue of family, both conceptually and emotionally. We ground our work in our subjective lived experience.

This is our first act of co-creation. We chose a medium that we believed would be accessible for each of us as individuals and as a collective. We are: David, who identifies himself as a person living with an "understanding disability and mental health challenges"; his mom Shari; and Stephen, the formal caregiver providing care in a "family type resource" home in Montreal. Shari and David first met Stephen in June of 2014 when David moved into Stephen's home following David's decision to change the direction of his life after several years of personal and relationship struggles as an adolescent. David put in motion a process of finding a congregate housing setting that would enable him to get the support he needed to build his independence. Prior to this, finding inclusive formal support services for David and Shari had been like a "puzzle with too many missing pieces", with long wait lists, navigation barriers, many "pass the buck" transfers between workers and sectors as a result of complex "presenting problems", and the requirement to pay for private services to fill in the gaps. All of these factors created moments of isolation, crisis and resilience across the life course for both mom and son. Luckily,

challenges were offset by the fact that we have a devoted extended kin network nearby including David's dad and maternal grandparents, Shari has secure employment, and our strong sense of devotion to each other, no matter the circumstances, took us through some difficult times. The coordinating agency located Stephen's Family Type Resource home, and David went for an interview. Stephen accepted him into his home, and we all have never looked back, in spite of (or because of) the ups and downs that we have experienced. We have identified our relationship as an authentic reflection of inclusive family life, which fundamentally led to our decision to engage in this writing process.

We created our poem through a combination of discussion and reflection. Our first conversation took place via Zoom in which all three of us openly discussed (a) our understanding of the meaning of home and family, (b) our five-year journey beginning when David first moved into Stephen's home at the age of 20 years, and (c) the words we use to describe the essential elements in the creation of family. Subsequently, we chose meaningful statements from the conversation transcript, balancing all three of our voices, discussed our choices in another recorded session, and created our work of found poetry (see endnote for a fuller discussion of our process and what we mean by "meaningful statements"). Our unique voices are identified through the use of different font styles. The use of regular font identifies components of the text which were written by Shari in order to introduce, fill gaps and link ideas. These regular font segments serve as a "symbolic collective voice" and although written by Shari, were discussed and validated collectively. Individual voices are identified as follows: "underlined segments" are in Shari's voice, "bolded" segments are in David's voice, and "italicized" segments are in Stephen's voice. All of these voice segments are taken directly from the transcript itself. Together our unique perspectives are woven together to create one collective voice.

Over the course of five years our connection has resulted in what we call a "found family", bound as we are by shared values and experiences of struggle and accomplishment in which hope has become possible. And so, in creating this poem, we explore our journey of, as Stephen describes, "recovery to discovery". This is a concept Stephen developed long before we sat down to create our poem, to challenge the limiting discourse currently operating in the health and social services sector which assumes that people living with disabilities, including those with neurodiversity and mental health challenges, need to simply "recover" from their "embodied deficits", as though this was a possible, or even desirable, outcome of intervention. Instead, a shift from recovery to discovery embraces disability as a strength, foregrounds goal-setting and achieving as an individual and shared practice of imagining, and operationalizes change as an ongoing journey of personal and relational growth and self-discovery.

This work of poetry not only speaks to our experience of found family using our own words as individuals, but also reveals the possibilities for, and challenges in, creating a sense of belonging and safety akin to family within a group home setting, that includes the 'client', parent and caregiver. Our conceptual contribution centers on questioning taken-for-granted ideas of what constitutes 'family' and 'care' using artistic form in order to facilitate a personal, affective and emotional connection to the work. Our poem seeks not only to tell our story but also to challenge dominant assumptions about who counts as family, and what and how families care, to open up space to be more "inclusive" of different forms of family. It disrupts definitions of family and care that are reified, unidirectional, patriarchal and static, to make room for a definition of family which is fluid, flexible and unbounded by gender, biology or role (for a critique of patriarchal, non-reciprocal discourses of family and care see Livitsky, 2014 and Neysmith et al., 2012). Our

story asserts that each of us, with our own identities and roles, and in our own ways, care for and about each other in ways that move beyond the normative labels of client, informal and formal caregiver. Finally, our poem calls for a shift from dominant ableist social discourses of dependence to a recognition of the importance of interaction, power-sharing and relational autonomy (Butler, 2020) by situating each of us as experts of our own lives. In our own voices and words, we present our thoughts about key factors such as belonging, trust, struggle, and comfort (and, most definitely a sense of humour) that facilitate shared meaning and open up pathways to move beyond recovery to a place of emotional, psychological and spiritual growth. *We've Got Each Other's Backs* is a celebration of "found family".

We've Got Each Other's Backs!

Not all families are born of blood and bone
Some are found through love and hope
Through struggle and solidarity
Through loss and fear
Through anger and forgiveness.

It takes a decision
To look forward
To embrace difference and disability
To let someone in
To choose help.

And, as if like a miracle, a door opens
And there it is – the possibility of finding family;
      Well positioned to care
      <u>A co-parent</u>
      My Big Brother.

> **Who is speaking?**
> Shari: <u>underline</u>
> David: **bold**
> Stephen: *italic*

Belonging.

When I began this work of being a caregiver
My mom always told me to treat everyone as family
Healthier, happier
It really speaks a lot to how healing works.

I was kind of lost
Too old to always listen to my bossy mom
Not ready to be on my own
Tired of following other people just to try to fit in somewhere
Tired of fighting
No more bad things
Mom helps, but I wanted support to find my own way
I made the decision myself.

Each of us wanting to belong somewhere and to be understood
With each other but apart
Parent and adult child
To speak our own truths
To care about each other but to be independent

I was tired and burdened by stress and responsibility
I was ready for the next big commitment.

To make a choice
To move…
From recovery to discovery.

From day one with Stephen
We were at home
Safe and secure.

Belonging.

He got me a welcome cake!
The little everyday things matter.

It was an opportunity
How aware he was of change
His natural qualities
How charming he could be
You fall in love with David from the get-go
With David it was an opportunity to have more dynamic life experiences.

A home is about safety and security but more so about comfort
When you're comfortable, you'll be yourself
Not on guard
Not defensive.

And that provides the space and the opportunity to grow
        to receive new information
        new suggestions
Trust develops
Being circular
Being from both ways.

I learned how to reach him, speak clearly and repeat
Keep the wording simple to reach for complexity.

I just enjoy talking to Stephen sometimes you know
Having those conversations and actually getting to success!
That's what we do, right, we talk it out.
And then we solve the issue.

Hug it out!

<u>We all get there!</u>

It's growth
When you see me growing for you... then maybe,
When I ask you to grow it is like
"He's making changes, so I'm gonna make changes too".

We evolve together
Not just going for the easy thing

I teach him to be more open
And I teach him to draw the line
She helps me to better understand him
<u>And you both teach me to slow down and trust</u>
<u>   Letting go but still being there.</u>

Learning together and supporting each other
Working through it
Not taking the easy road.

A home is:
mingling with your roommates
socializing
getting to know other people
all that kind of stuff.

A family is:
Communication
Organization
Understanding.

A family is:
<u>Acceptance and compassion</u>
<u>Negotiation</u>
<u>Containment.</u>

Found family.

Mother and son and caregiver.

Belonging.

<u>Proud of each other</u>
<u>Excited to see what happens next</u>

Back a few steps and forward a few steps
<u>Taking the journey one day at a time</u>

And that's something that we've had to work at
     and work at
<u>Working together like a team</u>
Not simple or easy but possible.

Hey! We've got each other's backs, right?!
Right!

Key Messages from this Article

People with disabilities: Families are diverse and include both people you are related to and those who you choose to be with. Families can include people that you work with and live with. Family is about belonging, trust, comfort and having a voice. Care is about relationships in which you both give and receive care.

Professionals: Group homes can be places that have deep meaning, not only for residents, but also for formal care providers. Treating clients/residents (and their relatives) like family, creates spaces of comfort and trust, and can lead to opportunities for discovery and growth for all involved, including clients/residents, their relatives, and formal care providers.

Policymakers: Policy must move beyond recovery models based upon disability as deficit-based to a model of discovery centred on honouring the relational capacity, strengths and resilience of people with disabilities.

Messages clés de l'article

Personnes ayant un handicap : La composition des familles sont diverses et elles incluent autant les personnes avec qui vous êtes liées que les personnes avec qui vous choisissez d'être. Les familles peuvent inclure des personnes avec qui vous travaillez ou avec qui vous habitez. Être une famille, c'est l'appartenance, le confort et avoir une voix. Les soins, c'est une relation à travers laquelle chacun donne et reçoit des soins.

Professionnels : Les foyers de groupe peuvent être des milieux ayant une signification profonde, non seulement pour les résidents, mais également pour les aidants formels. Traiter un client/résident (et ses proches) comme une famille et créer des espaces de confort et de confiance peut mener à des opportunités de découverte et de croissance pour tous ceux qui y participent, incluant les clients/résidents, leurs proches, et les aidants formels.

Décideurs : Les politiques doivent aller au-delà des modèles de réadaptation centrés sur les incapacités en tant que déficits, et proposer un modèle de découverte visant à honorer la capacité relationnelle, les forces et la résilience des personnes ayant un handicap.

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[i] Although describing our qualitative methodological approach is not the central focus of this creative submission, we have nonetheless chosen to briefly explain it in this footnote to provide clarity and establish trustworthiness. Our approach connects features of both "evocative collaborative ethnography" (Rinehart & Earl, 2016), and "found poetry" (Butler-Kisber, 2002; Butler-Kisber & Stewart, 2009). Both collaborative ethnography and found poetry approaches centre on the exploration and presentation of

lived experience through the inclusion of perspectives on a shared experience or context (i.e., event, story, culture) and pays attention to power-sharing practices in the process of co-creation. A collaborative ethnography seeks to document "shared experience" from the points of view of the multiple participants who are part of that story, whilst considering both points of consensus and divergence. Collaborative ethnographic inquiries engage in storytelling from "insiders'" perspectives, as is the case of our project. As such, we developed a process of shared power/voice through collective storytelling and reflection. Shari, as principal author and someone who has experience as a qualitative researcher working in a university context, first found out about the special call for submissions through a work colleague. Since Shari, David and Stephen had spoken about writing together in the past, she brought the idea of contributing to the special call to David and Stephen, who were both enthusiastic about the possibility of engaging in a collective process to create a poem on a subject we had spoken about often over the years and that resonated with us as individuals and collectively. Stephen and David both identify as writers themselves, Stephen having previously published works of poetry in written and spoken word forms, and David having worked on his own autobiographical writing for many years. Shari was tasked with developing a set of "guiding questions" which served to focus our discussions, not only on our shared journey but also on how we each defined our critical concepts of 'home' and 'family'. We shared the transcript to select meaningful statements from the text in our multiple voices. "Meaningful statements" to us, meant those statements which pointed to the essence of our story, triggered an emotional response, or which made us sit up and say "yes, that is me!" or "yes, that is us!" (i.e., linked to our identities, our perspectives, our ideas, our way of seeing the world or ourselves or that simply made sense to us). Meaningful statements not only referred to things we each said as individuals, but also statements that "rang true" in what the other person said. Sometimes, this was clear in the recording, as in when we all stopped and thought about what someone had said during the conversation, smiled or nodded in agreement or reacted to a statement during the interview. Other "meaningful statements" emerged after reading the transcript which were highlighted and then shared to seek out additional reflection or comments. Finally, it is important to note that meaningful statements did not have to be equally shared amongst us, but could either be shared or contested, making room for points of convergence and points of individuation. Shari undertook a preliminary poetic reconstruction using a process of fracturing the data in order to conceptually reorder the meaningful statements that were identified, which were then discussed and integrated into the creative work. Finally, Shari wrote a few segments (represented by regular font) in order to introduce, fill in or link certain segments to finalize the poem's construction in a way which honoured our collective voice. Although written by Shari, these segments were validated in a final reading/editing of the poem by all the authors. Found poetry has frequently been used as an educational (Westgate Pesola, 2008) and self-advocacy (Pocock, 2021; Allen, 2019) tool with and among people living with neurodiversity. As a form of qualitative inquiry, found poetry foregrounds the voices of participants in knowledge production and dissemination by re-storying segments of interview text (re-ordering participants' own words in poetic form) in order to enhance the evocative and relational potential of "study findings" in ways which are meaningful to both participant and audience (Butler-Kisber, 2002).