

Pandemic Learning Project

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Galen is a photographer and Artist in Residence at *posAbilities* (2020-1).

Introduction

The following represents some of the actionable insights that have come from the pandemic learning project conducted by UNITI, Burnaby Association for Community Inclusion, Kinsight and posAbilities, and funded by the J.W. McConnell Family Foundation. It uses Participatory Narrative Inquiry (PNI) methodology to codify first-hand stories and story fragments in order to identify patterns that, combined with the stories themselves, can be further analyzed in order to come up with action items, both for the present as well as for future emergency planning. The analysis occurs in sense-making sessions with folks we are supporting, family, home-share providers, staff and management. The action items come chiefly from within these sessions, although additions have been made based on a review of patterns coming from all the sense-making sessions.

The following recommendations, or actionable insights, are based on story data, story trends, and sense-making sessions held between May and November 2020. You are welcome to apply them to your own context, though we would urge you to involve your constituencies to test, refine and adapt them.

Recommendation 1: **Mental health is just as important as people's physical wellbeing.**

What is needed now

- Workshops and training around dealing with anxiety, depression, helplessness, trauma, loss, managing change

What to start building for the future:

- Begin building repository of virtual training/workshops
- Is there a way of building relationships/MoUs with counselors and counseling schools so that they can be more readily engaged during future disasters?
- Do we have employees with counseling backgrounds that can be redeployed as counselors?

For the next crisis/emergency planning:

- Incorporate considerations/plans for mental health supports
- Make workshops/training readily available from the outset of the next crisis
- Provide access to counseling supports for those who critically need it

Rationale:

The focus in emergencies tends to be on people's physical needs, but their emotional and mental needs are just as critical. Not only are there pre-existing mental health issues that can be exacerbated by crises, but it can produce overwhelm, exhaustion, depression, anxiety and helplessness--all of which can be paralyzing and destructive.

Recommendation 2: Don't simply support people with disabilities and families: mobilize them.

What is needed now

- Engage families in advocacy/grassroots change--there is a readiness to negotiate the social contract so that people with disabilities/families don't fare so poorly in the next disaster

What to start building for the future:

- Convene families and people with disabilities to explore how best to mobilize during disasters. For example:
 - Phone trees/regular check-ins/buddy systems
 - Sourcing and delivering supplies
 - Fun/excitement (see below)
- Engage in a grassroots movement to negotiate the social contract so that it is based on an acceptance of our vulnerabilities, empathy, care, personal responsibility, etc., versus government accountability.

For the next crisis/emergency planning:

- Incorporate contingency strategies to mobilize people with disabilities/families for disasters

Rationale:

The question is not only "who needs help" but "can you help?" This not only greatly expands our capacity to respond to disasters and advance resiliency, and grows our collective sense of caring, solidarity, and empathy, but it addresses a series of other key learnings, such as:

- Purpose: this is highly correlated to stability and positive outcomes.
- Connection: mobilizing to assist others provides more opportunities for people to connect with others
- Skills: people with disabilities began losing skills during periods of closure--this will not only enhance existing skills but build new ones

Recommendation 3: Make information available in plain language

What is needed now

- Supplying plain language information, compiled in one place, that answers questions like: "what is COVID," "what are vaccines and should I get one?," "when will things get back to normal?," "how do I stay safe?"
- Ensure there is (virtual or otherwise) training available for persons with disabilities re: how and when to wear PPEs, how to wash hands, etc.
- Coordinate messaging in newsletters/websites among the organizations: e.g. plain language Q&A

What to start building for the future:

- Begin conversations with CLBC, health authorities and emergency response teams to ensure there is better coordination of information and that it is available in plain language
- Coordinate the development of a provincial website for disaster information in plain language

For the next crisis/emergency planning:

- Incorporate a communications function into future plans that ensure information is being translated into plain language and is easily and widely accessible

Rationale:

During the pandemic there was a confusing array of changing information related to what COVID actually was, what the threat levels were, what to do or not do, and how health authorities, CLBC, organizations and other institutions were responding. For persons with disabilities, especially, but also families and staff, it was a very confusing time which not only worsened the threat, but also anxiety levels.

Recommendation 4: Build technological infrastructure and supports

What is needed now

- Provide training to the people we support on the use of key apps/software (Zoom, WhatsApp, internet browsing, email, etc.)
- Begin and/or expand training in online safety for people with disabilities
- Provide training to employees on the tech so that they can help coach/assist people we support/families

What to start building for the future:

- Building pipelines that provide people with disabilities access to affordable cell phones, laptops, ipads, etc.
- Advocacy to ensure that people with disabilities have access to WIFI with adequate bandwidth during disasters
- Ongoing training in key software

For the next crisis/emergency planning:

- Incorporate strategies that identify how technology will be immediately used to address people's physical and emotional wellbeing

Rationale:

The pandemic separated many people from their friends and families which made contact and support that much more difficult. Many had no technology, or computers that were too old to run conventional software, or their bandwidth was too low for the software to run (e.g. Zoom), or the apps/software we were running was too new and confusing for people to use. This increased isolation and amplified threats to their physical and mental wellbeing. Although there has been a lot of work to source new technology, it has also created new perils around online safety.

Recommendation 5: Human connection is hugely important

What is needed now

- Provide more online opportunities for people in similar situations to meet online (Zoom, other) so that they can become supports to one another
- Create pen pal opportunities
- Link families/individuals and see whether family bubbles might be expanded to incorporate other families

What to start building for the future:

- Build relationships with faith groups and volunteer organizations (with some intentionality around human connection during disasters) so that there are pre-existing networks and strategies available for future disasters

For the next crisis/emergency planning:

- Make human connection a central tenet of future disaster planning. This can include: (1) developing strategies that advance human connection, (2) augmenting strategies to incorporate broader involvement from others and as many human interactions as possible, and (3) assessing the impact of protocols and strategies on human connection (e.g. social/physical distancing, PPEs, self-isolation, quarantining, etc.) and amending or mitigating them as much as possible.

Rationale:

Human connection shows up in more than half the stories, and it figured prominently in stories ending well and things becoming more stable for people. It is essential to our physical and mental wellbeing.

Recommendation 6: Keep the learning going—but do something with it!

What is needed now

- Continue with sense-making sessions around the stories
- Learn more about why some people with disabilities and/or their families are coping/doing reasonably well during the pandemic
- Learn about how other people, organizations and jurisdictions are coping with COVID

What to start building for the future:

- Engage with people we support and their families to envision future models of support based on the new reality and all our collective learning

For the next crisis/emergency planning:

- Incorporate learning into future emergency plans
- Incorporate a reliable mechanism for immediate learning as soon as the next disaster occurs.

Rationale:

The pandemic has been rich in learning—from the gaps and faultlines in systems, to adaptations and pivots by organizations and families, to increased recognition of the role of neighbourhoods and communities in caring for each other. There is an opportunity to harvest this learning and use it to build back better—before the window closes and things return to status quo.

Recommendation 7: Bring on the Fun!

What is needed now

- Bring more humour, delight and fun into the everyday. This can include everything from inviting staff to bring more levity into their meetings and interactions, to organizations using their channels and messaging to include humour, to designing activities, experiences or events that will bring delight to people.

What to start building for the future:

- Research the role of fun/humour in coping with prolonged disasters

For the next crisis/emergency planning:

- Develop a mechanism for promoting fun/humour (e.g. fun committee, activations, etc.)
- Develop a strategy for incorporating fun and humour into communications, routines and activities, including urging stakeholders to find a way to bring them into their everyday.

Rationale:

A third of the stories highlighted fun--more than almost all other categories, including "resources" or "safety." As humans, we need lightness and delight to counterbalance our fears and anxieties. It makes our difficulties easier to face.

Recommendation 8: Neighbourhoods can make all the difference

What is needed now

- (n/a)

What to start building for the future:

- Engage in placemaking in the neighbourhoods where people are living
- Develop new service models, roles, and approaches that build neighbourhood connectivity and resilience
- Convene conversations with persons with disabilities, families, home share providers, staff and others to explore approaches to local placemaking/neighbourhood connection, and how organizations can play a supportive role.
- Where neighbours are interested, extend emergency planning beyond programs and services to a neighbourhood level.

For the next crisis/emergency planning:

- Assess whether there are existing neighbourhood networks where people with disabilities/their families can both give and receive help
- Mobilize families/persons with disabilities to convene/connect their local neighbourhood

Rationale:

Our capacity in disasters is profoundly stretched. Meanwhile, there is considerable good will, trust and capacity in our neighbourhoods and communities. Rather than replicating what neighbours or citizens can naturally do, we need to get better at strengthening and empowering them to support each other. This is what citizen democracy is all about.

Recommendation 9: Time to make mental and physical fitness a priority

What is needed now

- More structured conversations about health and wellness throughout the work week
- Make a list of counseling resources available and easily accessible and make sure people know about them
- Initiate more opportunities for people to participate in (safe) fitness regimes (e.g. Zoom workouts, dance breaks, walking clubs, etc.), and include fitness goals to help people with accountability
- Promote a range of approaches to fitness (including activities and technologies).
- Find ways to give more flexibility and agency to staff in order to offset the loss of control that most are feeling (e.g. scheduling, planning, etc.)

What to start building for the future:

- Identify the patterns of mental and physical health needs during different phases of a prolonged crisis

For the next crisis/emergency planning:

- prepare plans and identify/secure resources to address the mental and physical health needs of staff, caregivers, persons with disabilities and their families as they undergo different phases of a prolonged disaster

Rationale:

As the pandemic trudges on, mental health needs are changing. Employees and caregivers, especially, though not exclusively, are looking for ways to address sadness, fear, grief and loss, setting personal limits, finding balance between productivity and personal needs, relational stress, pandemic fatigue, exhaustion, information overload, lack of physical connection, compassion fatigue, and zoom burnout. This is compounded by a drop in physical fitness levels resulting from less activity and extended periods of (more sedentary) isolation.

Recommendation 10: Creativity will get us through this

What is needed now

- Provide opportunities and resources for people to engage in art, such as song-writing, story-writing, poetry, drawing, crocheting, vlogging/blogging, etc. Incorporate reflective prompts into the art as a way of understanding the purpose, value and context behind it.
- Don't overstructure or overschedule time: leave space for impromptu and creative activities
- Provide space and time to look at ways to do things differently, for example, on new approaches, activities and possibilities to connect with others
- Engage the creative gifts of staff, and invite them to share ideas on new approaches/things to do, and engage

What to start building for the future:

- Capture the creative gifts of employees, caregivers, families and persons supported by the agency in a central way

For the next crisis/emergency planning:

- Have a plan for activating the creative gifts of those within and without the agency

Rationale:

Creativity is an essential and empowering response to the pandemic. Not only can it supply inspiration, release, joy, fun and beauty, but it can also provide us with innovative ways to adapt to changing and difficult circumstances.

Recommendation 11: “Support” can mean a lot of things in a pandemic

What is needed now

- *Emotional support*: people supported by agencies, and their staff/caregivers need some personal attention. Ask them how they're doing and what they want and need. Listen to them; be attentive and supportive.
- *Mutuality and cooperation*: find and enable ways for people to support each other, including staff, caregivers and people with disabilities. This is an excellent opportunity for people with disabilities to help others.
- *Respite*: many caregivers are needing a break: see what you can do to provide them with one.
- *Financial*: advocacy is still needed to increase financial support for people with disabilities
- *Ideas*: Since we're all in this together, is it possible to create a central but more democratic resource for everyone re: information, ideas, inspiration, etc.? A way for everyone to connect and share purposes, activities, creativity and connection? Also, would a collaborative committee designed to collect and share ideas make sense?
- *Who are we missing?*: Find people who are alone and/or who are not well supported, reach out to them and bring them into the larger circle: what do they want/need and how can we help?

What to start building for the future:

- More centralized platforms for information-sharing, connection, inventiveness, collaboration and cooperation amongst all stakeholders

For the next crisis/emergency planning:

- Begin planning with other organizations to build and activate centralized, democratic platforms and collaborative networks that cut across all demographics (circles, people with disabilities, staff, friends, neighbours, etc.)

Rationale:

Supporting each other is how we are going to get through this, and there are many different kinds of support needed: natural, professional, emotional, logistical and so on. This is an opportunity to look at what sort of support requests are coming forward.

Recommendation 12: Time to meet the whole family: siblings, cousins, uncles and aunts, etc.

What is needed now

- Liaise/connect more with one's siblings and extended family (rather than just parents or support staff). This is a great opportunity to reconnect, rebuild and re-engage relationships folks have with their cousins, aunts and uncles, nephews and nieces, etc.

What to start building for the future:

- Rethink/explore relationships with circles, together with them, so that a deeper understanding and mutuality may strengthen our collective responses to future disasters, as well as in the everyday.
- Get to know the interests, passions, and work of siblings and start making invitations and connections to engage with their family member and with each other
- Start building structures/processes that grow and engage the community of extended family members

For the next crisis/emergency planning:

- Siblings and extended family can play a role in the community response: figure out how to engage them.

Rationale:

It's important to note that natural and unpaid support has been an essential part of this pandemic and key to ensuring people we support remain safe and well. As a result, we need to pay more attention to this role, especially in terms of what it continues to offer, what it needs, and what sort of new, deeper or more creative relationship may be possible. COVID presents us with an opportunity to build deeper, more mutual, supportive and creative relationships with circles which can extend into the future.

Recommendation 13: Time to take stock of our lives and our society

What is needed now

- More time for reflection as part of meetings and schedules
- Create opportunities for conversation, contemplation and reflection: what matters most? What do we really need to live a good life, in harmony with ourselves and with others?
- Provide resources and workshops that provide different possible philosophical and spiritual frameworks for thinking about life, finding purpose and inspiration.
- Beyond basic needs and employment or contractual obligations, explore ways to respond to everyone's higher order needs: hope, beauty, purpose, humour, connection, etc.

What to start building for the future:

- Begin to build frameworks and resources that respond to the existential and higher order needs of people supported by the agency, their circles, and employees.

For the next crisis/emergency planning:

- Incorporate ways to address people's existential and higher order needs into emergency response plans.

Rationale:

The pandemic has presented us with an imperative to rethink our lives, including our lives together, though the busyness and disruption of the pandemic has made it difficult to find that time. We need some moments to take stock of what matters, what we do everyday and what our purposes should be, and what sort of society we want to live in once we get through this. What might a renewed contract with self and with others look like? Given so many feel stuck right now, there is a growing urgency for deeper soul-searching and for finding motivation and inspiration.

Recommendation 14: Decision-making is stressful

What is needed now

- Ensure the people we support have plenty of opportunities to make choices and decisions, especially as we pivot to new kinds of services where they can play a leadership role.
- Keep installing frameworks and guidelines to help shape decision-making.
- Create opportunities (e.g. decision buddies, team meetings, peer connections) for employees and families to lighten the burden of decision-making by sharing their unique circumstances with others for feedback, advice, support, and, where applicable, shared responsibility.

What to start building for the future:

- Are there pre-existing structures or processes that might be adapted, or new communication channels that could be created, that would help people discuss challenging decisions?

For the next crisis/emergency planning:

- Incorporate a mechanism to capture, learn from and share the sorts of decisions that people are facing.

Rationale:

Decisions during a pandemic are complicated. Not only do people find themselves in novel situations without a road map, but there are escalated concerns around safety. As the pandemic continues, and as people continue to have to regularly problem-solve, often on their own, decision-fatigue starts setting in and the stress starts showing. That said, the opposite may be happening for those we support—they are making fewer decisions and finding their choice and autonomy diminishing, which increases feelings of anger and sadness.

Recommendation 15: Gotta keep growing and learning!

What is needed now

- Provide workshops and learning opportunities (or access to external ones), whether it is around learning new skills, responding to passion areas, or encouraging curiosity and novelty
- Use Zoom (and other COVID adaptations) as a way for people with disabilities to learn and practice skills (e.g. moderating, facilitating, co-designing, etc.).

What to start building for the future:

- Begin to identify the sorts of learning, growth and development that people are interested in, and begin to identify resources and mechanisms to respond to them.

For the next crisis/emergency planning:

- Incorporate ways to address people's ongoing need for growth and development during extended disasters.

Rationale:

As the pandemic persists, people are feeling stuck, which is only compounded by the lack of novelty and stimulation. They're also losing skills as a result of being stuck at home for so long. We all need to experience a sense of growing, learning and developing--this is what informs our purposes, possibilities, inspirations and abilities. We can't stay in these holding patterns indefinitely.

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Burnaby Association
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Mateush, Cindy (2020). *COVID Pinata* [back cover photo].

Cindy is a photographer and Artist in Residence at posAbilities (2020-1).

