













MFA Design for Social Innovation Thesis School of Visual Arts New York City, May 2018

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But we also remember how we lifted each other out of these moments of conflict, how we carried the bag up the mountain when the other couldn't. And we also remember the big wins, leaving workshops with bright smiles on participant's faces, making amazing new friends, building wacky cardboard machines. And our relationship with the JCC... Alison, Alex, and Caitlin continued to support us when we were exhausted and needed their support and confidence.

So we started to see this, really, as a universal story. A story about loving ourselves fiercely, nourishing our independence, caring for ourselves, and reframing our limiting beliefs. A story about developing deep trust in our partners: building effective feedback channels, lifting each other up to be the best version of themselves, handling controversy with civility.

...But most importantly, doing it together, the only way we can, as a team.

Partners in crime,

Nick and Malé



In some ways, it was curious that we, as emerging partners, were working on a thesis about teamwork. While the external work was about building collaborative and equitable making spaces for adults on the autism spectrum, we started to see that the internal challenge was learning how to replicate that for ourselves. We ourselves, felt the emotional arc that we were so dedicated in producing for others. We both remember our own pits of despair, the long nights before our pilots, feeling immense pressure and exhaustion. We toiled with our personal limiting belief systems.... we witnessed just how powerful internal narratives could be...

# FOREWORD

This journey started in Vancouver, BC. While working upon lacking thereof. It's about our bias towards being to embed R&D practices into social service agencies, 'above average.' But more so, it's about how we frame we felt ourselves becoming distanced from individuals disability from the onset. From the world's perspective, at the end of the service delivery. We asked ourselves: those who live far 'below the average' are inherently where are the people in this process? What do they 'less than', 'other', and dehumanized. From the moment want? And how are we including their voice in this these communities of people are born, the stigma process? While we learned a lot about social service of society becomes their identity, and they spend delivery models, and embedding ethnographic their entire lives trying to be like everyone else. And practices, we learned that we were both extremely somehow this becomes their problem. Not society's passionate about being on the ground with the problem. community. So when we returned to New York, we made an unspoken oath that in our work we will But I would argue that this is society's problem. always do our best to work directly with people, and Society's stigma placed on people living with an not in an office. impairment is society's problem to solve. No one

One day, in a car, Malé reflects on her experience they can't do. No one should be what others think of communicating with people who are deaf. She tells me them. And no one should be left behind. that it was completely insane that the world wasn't required to learn sign language. I initially argued that Conversely, they should be humanized, identified for it would be a huge ask for society to prioritize sign what they love, the roles they play, the people they language in our education. But on the other hand, care about, the values they want to lead with, and so I thought it was ignorant to design for the average, on.... the mainstream, the norm. In fact, that's where we have often run into problems. Making one-size-fits all And they should speak for themselves. So I'll stop solutions begets normative complexes. It discounts our individuality and the minutiae that makes us unique.

I used to think that diversity was a term reserved for ethnicity, sexual preference, gender, religion, age, and even political ideologies. But never had I given a thought to neurodiversity, a term that speaks to different intelligence quotients, learning styles, cognitive capacities. And while neurodiversity includes more severe cognitive differences (i.e down syndrome, PDD, Autism), this is really about everyone. It's about our desire to uphold intelligence, but look negatively
I'll design for the outliers in the data, with the hopes that maybe it will solve the other's inability to see the importance of humanization.
All of our work is not to help them be someone else, but to let them be themselves, feel proud and happy of who they are. The MakeGuffin project is merely creating the conditions so that they can thrive.

But I would argue that this is society's problem. Society's stigma placed on people living with an impairment is society's problem to solve. No one should have their identity attributed based on what they can't do. No one should be what others think of them. And no one should be left behind.

I And they should speak for themselves. So I'll stop ur talking on their behalf, and continue to my work as a social designer, re-orienting systems to bend toward individuation, uniqueness, and humanity. In this way, I'll design for the outliers in the data, with the hopes that maybe it will solve the other's inability to see the importance of humanization.





Autism, or autism spectrum disorder (ASD), refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication.

A global condition

Increasing diagnoses as 15%.<sup>2</sup>

A threat to health The average lifespan of someone with autism to be half that of the general population - an average of 36 versus 72 years. Related issues, such as isolation, depression, anxiety, and obesity threaten the quality of life and life span of those living on the Autism Spectrum.<sup>3</sup>

"It's a detour, some down the road... I have to go on the

> Leiah Adult on the spectrum range from 25-45 years old.

> > 3. Ibid

people can go straight road, get off the road and then get back on it"



In NYC alone, there are 400,000 people along the autism spectrum. 3.5 million in the USA and 76.3 million world wide.<sup>1</sup>

According to the Centers for Disease Control and Prevention (CDC), autism's prevalence in the U.S. increased from 1 in 150 in 2002 to 1 in 68 in 2010 and 2012. There is an upward trend in diagnosis every year, reaching as high

# Service Gap for Emerging Adults

Community Centers are main hubs for services for individuals living on the ASD, providing social therapy, employment services, fitness/health, arts + culture, and social programming.

"Most Autism organizations are focused on the early development of an individual on the spectrum, from childhood through the teenage years, often leaving young adults stranded and unsupported when tackling adulthood social situations..."4

Though the age group of Emerging adults is qualitatively defined, it tends to

<sup>1. &</sup>quot;facts\_and\_figures\_report\_final\_v3." Autism Speaks, 24 July 2012, www.autismspeaks.org/. 2. Joseph Guan, Guohua Li, "Injury Mortality in Individuals With Autism", American Journal of Public Health 107, no. 5 (May 1, 2017): pp. 791-793.

<sup>4.</sup> Etmanski, A. (2016). Impact: Six patterns to spread your social innovation. Surrey, BC: Orwell Cove.





PROBLEM

# **Emerging Adults on Low Support**

Low support autism, commonly known as high functioning autism, is at one end of the spectrum and the challenges are less severe than other forms of autism. Adults on low support are verbal and have average to above average level of intelligence.<sup>5</sup>

Emerging Adults on Low support are challenged by:

-Initiating interactions, -Responding to the initiations, -Sharing enjoyment, -Reading non-verbal cues, and -Taking another person's perspective

The above conditions make it challenging for Emerging Adults on the ASD to have conversations, socialize with peers, and build informal support systems necessary to sustain independence.

"They are lonely, isolated and don't feel good about themselves. **Their human needs** and desires aren't being met. They see that everyone has friendships and relationships and they are not included."

Allison Kleinman Director of Adaptations at JCC

5. "facts\_and\_figures\_report\_final\_v3." Autism Speaks, 24 July 2012, www.autismspeaks.org/.

# Journey toward Independence

While conducting interviews, we discovered that adults on the spectrum are on a journey towards independence. About the framework Independence for them is defined by 3 things: (1) as access to an stable income, (2) independent housing, and (3) a informal support system (friends) to make the above sustainable. We learned that housing and income can be provided. But, informal support systems only can be built by the individual.

Lifetime Advocacy Network (PLAN), describes the genesis of the organization:

"...we knew we had to rethink the whole approach to disability. We realized that one of the biggest handicaps facing people with disabilities was their social isolation. PLAN believed that if this challenge could be addressed, parents would have an answer to their worries about the future. That's why we specialized in developing personal networks of support for people with disabilities..."6

With this, we understood that friendship and unpaid relationship was a more reliable way to support individuals.

Loosely based on Maslow's hierarchy of needs<sup>7</sup>, we developed this pyramid framework to highlight insights discovered in our research. We learned that housing and job supports are provided by family and community centers to support these individuals. But the efficacy of those initiatives are Al Etmanski, a pioneer in social service, and co-founder of Planned undermined if the individual can't develop informal support systems, friends and unpaid relationships.

> One of the individuals, David Morris highlights this: "I went to college to study English literature, and that was another isolating experience. I didn't make friends or any kind of relationships. I wanted to live alone, but my depression was a big obstacle for moving toward independence".



6. Etmanski, A. (2016). Impact: Six patterns to spread your social innovation. Surrey, BC: Orwell Cove. 7.Mcleod, S. (n.d.). Maslow's Hierarchy of Needs. Retrieved from https://www.simplypsychology.org/ maslow.html



"I can't do another repetition of 'this is how you look people in the eye'... I need something else!"

> David Morris Adult on the spectrum



**RESEARCH QUESTION** 

What are the existing barriers for emerging adults to build informal support systems in order to achieve independence and visions of the future?

# **ACTIVITIES**

We conducted 8 subject matter experts and 13 individuals interviews (exploratory and prompted). Expert interviews helped us to develop language and clues in approaching conversation. By using journey maps, we understood their individual's daily routines. Using card sorting and identity mapping, we understood their value systems and social networks. Building profiles uncovered their pain points and visions of their future. Group interviews illuminated peer to peer interaction power dynamics.



# LFARNINGS

(1) Social isolation

learn from others.

(4) Fear of failure

During this process we learned that 4 out of 5 people living on the spectrum are male. Therefore early framing focuses on males. Through these research activities, we uncovered 5 major challenges: (1) social isolation, (2) restrictive clinical approach, (3) broken intuition and social confidence, (4) fear of failure, (5) competition over brotherhood.

Men with high functioning autism feel isolated and left out from society. They are looking for belonging and recognition in a community.

# (2) Restrictive Clinical Approach

Men with high functioning autism feel restricted because of their diagnosis. They want a say in building their own journey/adventure.

# (3) Broken intuition and social confidence

Men with high functioning autism feel unsure of themselves and lack self confidence. They are looking for safe spaces to share their concerns and

Men with high functioning autism feel ashamed of failing. They are looking for trust to try, fail, and learn.

# (5) Competition over Brotherhood

Men with high functioning autism compare themselves with higher/lower functioning individuals. They need to learn from each other and lean on one another. They need to build communities of their own.

# "We don't know how to trust our gut feeling... I've been taught to second guess myself"

Preston Adult on the spectrum





RESEARCH QUESTION

If we facilitate individuals to share their stories and offer support to each other, would they build emotional self-reliance and meaningful informal networks?

Informed by our 5 key learnings, we developed 6 principles to address these challenges: (1) informal communities, (2) belonging and recognition, (3) create your own adventure, (4) safe sharing spaces, (5) trust to fail and learn, and (6) brotherhood.

# ACTIVITIES

To test if our learnings were correct, we developed projective research prototypes, interactions that embodied these notions.

To test if our learnings were correct, we developed research prototypes of (1) informal communities, (2) belonging and recognition, (3) create your own adventure, (4) safe sharing spaces, (5) trust to fail and learn, and (6) brotherhood.

We created interactions that embodied these notions.

We designed a **hero's journey workshop** to hear their journeys towards ndependence or their dreamed life, identify common challenges, and illuminate positive forces in their journey.

We designed a **limiting beliefs workshop** to identify common belief systems, unveil their potential, and develop their emotional intelligence.

# LEARNINGS

It was here when we started to really uncover our biases, our mental models, and large assumptions... disability is not an identity. We learned that we weren't doing anything different from their existing support systems. We learned that even if we connect them, it doesn't mean that they are bonded.We learned that if want to support them, we can't focus on their diagnosis, but instead, focus on their passions and moments of joy.

# **PROBLEM STATEMENT**

This shifted our framing of the problem: Emerging adults living on the autism spectrum lack interdependent relationships necessary to sustain independence.



**VISION OF THE FUTURE** 

Draw how you want your life to look like in 5 years

In S Years, see myself more capable of Being happy with myself to have myself, communicate precisely with dialogues, Working in technical field technical school take countes in college for various engineering, poss, bly mentor someone with similar experiences. not be so over excited with certain situations maybe be involed in a romantic relationship? learn more about it.

What do you need to learn? What do you need to do? What do you need? - social interactions practice -insights on real life experiences - communicate more about socializing - How to be none Kishally learn/sec what are my interests connected with wats going on with stay focus emotions/fore me -Support -Guidance



Limitless

ressful Thinking and Limiting Beliefs



**RESEARCH QUESTION** 

How might we facilitate bonding relationships necessary for interdependence?

# ACTIVITIES

As we saw the problem through a new lens, we reviewed our data. We looked out for positive outlying information. We remembered Adapt Labs. Adapt Labs, developed by former DSI alumni, Margarita Korol, is a production company run by a team of individuals on the autism spectrum. In an interview we uncovered the elements of interdependent relationship: (1) the team is creatively making, (2) team bonds when they share an emotional experience, and (3) the group operates best with a common goal.

We built a **Space to Make**, a make-a-thon experience for them to explore and engage with their interests around 'what could be. We asked them 'what kinds of programs do you imagine for the JCC?' 'What are you passionate about?'

# APPROACH We focused the Space to Make around the following:

FROM

Talking Individual journey Programming for Group Diagnosis

- TO Bonding over negative > **Bonding over positive** 
  - Making Shared journey
  - Collective ownership
  - > Team
  - > Personal interests

"Very rarely do the people leading shows up and say: Hey, what do y'all want to talk about?"

# Preston

Adult on the spectrum



Being part of groups with with shared goals, responsibility and struggle makes individuals feel a sense of unity and belonging when the fostered sense of accomplishment facilitates solidarity.

# **Fun and Fearless Exploration**

Playing games (individually or in groups) makes individuals feel empowered, relaxed and confident to act because there is locus of control, encouraged exploration, and there are no consequences of failing.

# Leadership and Ownership

Individuals leading interest-based groups experience ownership, confidence and pride when their capabilities precede their disabilities.

- What kinds of spaces and models are relevant to this context?
- What kinds of challenges will they work on?
- How will they determine the challenges they will work on?
- What kinds of support are needed in the space?





PROTOTYPE QUESTION

What are the key elements of a challenge making space that facilitate interdependent relationships?

# ACTIVITIES

We researched the existing models in the challenge space to understand the service delivery model, balance between challenge and ease, and timing.

We designed and facilitated a Making event. But to make what? Our first prototype was a making event where they could imagine new programs and making challenges. To do this we asked them 'what they wanted to make', 'for who they wanted to make it for', and about which topic. This aggregated into the beginnings of a crowd-sourced challenge database. This content was displayed on our challenge generator cardboard machine for fun.

So the group created prompts like:

'Make a speech for vegans about vegan fish' or 'Make pasta recipes for a butcher about Oscar nominations'.

## EARNINGS

The fun started to happen in two main moments of the event:

(1) generative brainstorming, and (2) cardboard machine interaction. The interaction kept them engaged, and spoke to their age group. They voted on the challenges and this material would eventually become fodder for following pilots. We also learned the importance of space norming. We established rules at the beginning of the event, but believed that this should be co-designed in future events for it to be more effective.



# "I loved mentioning things about myself and the fun machine"

Nicky Adult on the spectrum

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MAKE A <u>Popeet show</u> FOR <u>actors</u> ABOUT <u>Invasic Park</u>	
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# DESIGN DETERMINANTS

We continued to use the following principles to guide the development of the intervention.

## **Passionate Pursuit**

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Individuals need a space to fearlessly explore areas of passion in order to develop their affinities or try new areas of interest.

# Making (space to fail)

Individuals need a space for positive failure. Creative generative thinking and making facilitates the impulse to share, moves conversation from debate to dialogue, and gives them a space to physically manifest an idea.

## Teams to lean on

Individuals need spaces to learn from each other and lean on one another, to build communities of their own.

# Shared Journey

Being part of groups with with shared goals, responsibility and struggle makes individuals feel a sense of unity and belonging when the fostered sense of accomplishment facilitates solidarity.

## Bonding over positive

Individuals need a space to build relationships over common interests besides their diagnosis. Individuals feel proud and capable when they are recognized for their individual and team accomplishment.

## **Collective Ownership**

Individuals leading groups experience ownership, confidence and pride when their capabilities precede their disabilities. Individuals feel belonging when they own and run the programs that they desire. When teams and individuals lead and own a space they feel apart of a larger community.



Participants during second pilot





Alfred Hitchcock, is: a plot device in the form of some goal, desired object, or other motivator that the protagonist pursues, often with little or no narrative explanation.<sup>\*</sup>

experience where individuals can begin to shape a new narrative for themselves.

sprint passion project. It's a story of emotions. Each stage was developed to answer Kurt Vonnegut's classic emotional arc of 'Man in Hole', where the characters get into trouble, but get out of it together and end up better off for the experience... together<sup>2</sup>.

Similarly, a MakeGuffin is an The MakeGuffin has 2 open-sourced parts. One part MakePlaybook, one part Makegenerator content. The MakePlaybook is a simple how-to implement and host guide. The MakeGenerator is a tangible mechanism that facilitates generative, creative conversation. Like this, community centers can easily implement on their own. Before the event takes place, individuals select the challenge theme they want to work on. At the event, they create a manifesto. They decide on a set of principles on how they will treat each other while making. Then they group into teams. Every team uses the MakeGenerator to help scope the project. Then they collaboratively make to solve the challenge. ...teams share their projects with the community... and finally teams and individuals are celebrated with team photos and a community dinner.

It involves:

reference storytelling-kurt-vonnegut



A MacGuffin, a term coined by The Makeguffin project is a relating-by-making iterative program that allows teamed individuals to explore interests and relationships around a

# Individuals Volunteers Facilitators **Community Center Staff**

It's based on the belief that if low support adults on the autism spectrum have access to (1) Passionate pursuits, (2) making (space to fail), (3) teams to lean on, (4) shared journey, (5) bonding over positive, and (6) collective ownership, they will develop interdependent relationships necessary to sustain flourishing independent lives.

8. MacGuffin. (n.d.). Retrieved from https://www.urbandictionary.com/define.php?term=MacGuffin

9. Fusco, J. (2016, November 29). The 6 Emotional Arcs of Storytelling, Why You Should Use Them, and Which One is Best. Retrieved from https://nofilmschool.com/2016/11/emotional-arcs-6-



## Producing the MakeGuffin Journey An overview of what it takes to produce the MakeGuffin journey real. This journey blueprint is a snapshot view of the journey phases (before during, after), the roles required to facilitate the phase (community center, facilitator, volunteer, participants), the key touchpoints (MakePlaybook, MakeGenerator) that guide the roles during that phase, and the key questions that those touch points address. MakePlaybook MakeGenerator Additionally, the corresponding emotional journey of the participants is marked in red. Before During Select Challenge Onboard Facilitator(s) Onboard Participants Event Preparation Create Manifesto Collaborative Making Share Projects Plan event Celebration programming & Volunteer(s) Poll interest. Participants Remind and communicate Prepare material, space, Welcome participants, orient them to event's Facilitate collaborative Teams share their final Teams and individuals are celebrated with medals, logistics and expectations and collateral for the to registered participants. event. making amongst teams. product with the Find suitable facilitator(s) Schedule programming in vote on the desired team photos, and a theme challenge, defining themes and challenges and volunteer(s) to help produce the event. goals (context, agenda), community. community calendar. co-create a manifesto community dinner Introduce the program to the community. with community. Introduce the role and agreement to norm the expectations. space. Community Center ·What do I need to program. Engage community participation. Facilitator(s) program events, facilitate the culture, and engage participants. How do we incorporate the MakeGenerator in the sharing of projects? How will Lengage participa to contribute to the MakeGenerator content? How do I set up the MakeGenerator? How do Linform participant: about the MakeGenerator? Volunteer(s) in producing the $\odot$ Participant Attend and engage $\odot$ with the event activities and are a part of the community as a whole.

## After

## Remembering

Play back the event, share Share stories with the photos, and engage event community at large. participants for future events.

## Sharing

# MAKEPLAYBOOK

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The community center use the MakePlaybook, a play-by-play guide that facilitates the production of a MakeGuffin program in its entirety. The MakePlaybook assists in the following activities: Schedule programming in community calendar. Find suitable facilitator(s) and volunteer(s) to help produce the event. Introduce the roles and expectations.Remind and communicate logistics and expectations to registered participants. Prepare material, space, and collateral for the event.

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MakePlaybook

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MAKEGUEEIN

START













card game challenge

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# **CREATE MANIFESTO**

At the event, they create a manifesto. They decide on a set of principles on how they will treat each other while making. This creates collective ownership, reinforcing that this is their community.



# **COLLABORATIVE MAKING**

Then they group into teams. Every team uses the MakeGenerator to help scope the project.Then they collaboratively make to solve the challenge. Teams pass through a shared emotional journey, where individuals compromise and leaders emerge for the team. Which ultimately facilitates bonding.

Make No.

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-327





We will do our best to ....

Not use the word NO to other's idea.

(2) Build on my teammates idean

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# SHARE PROJECTS

When the making is finished, teams share their final product with the community. This moment should be fun, stress-free and nonjudgemental. Facilitators encourage celebration and recognition.



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Finally teams and individuals are celebrated with medals, team photos and a community dinner. The community reflects on the experience, share stories, and discuss what they want their next challenge to be. Groups exchange contact info. and hangout over a meal.

MARTECULTRIX

We will do our best to.

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CONN

# IS IT SUSTAINABLE?

# A system towards sustainability

The program gives life to a more thriving system, where individuals and community centers co-own the space. A sustainable system is dependent on its ability to crowdsource content, illuminate emergent leaders, and develop new narratives.

**Crowd-sourced content** ensures that the materials are fun, engaging, and representative of the people. Challenge content can be updated by the community in the form of new challenges and card decks.

**Emerging leaders** empower the system because they can assume new roles, whether it be volunteering at events or co-facilitating events. They are the potential to produce future MakeGuffin events outside community centers.

**New narratives** develop new pathways. There are 2 narratives that need to shift: (1) Individual narratives, the stories that individuals tell themselves, and (2) Community narratives, the stories that the community holds to be true. The stories produced from the event could shift individual narratives, but together, the community narrative begins to shape new ideas of what's possible, together. Ultimately, this could alter the way that society views the community, moving toward a more inclusive environment.





# "Im going to tell Alex, we should do this once a month..."

Nicky Adult on the spectrum

# WHAT'S THE IMPACT?

The MakeGuffin project creates interest-based challenges, collective making experiences, randomized and diverse team arrangements, shared emotional journeys, diverse roles and levels of engagement, co-created manifesto and content...

# So that...

they increase sharing of passionate pursuits, increase access to a making (space to fail), increase access to team experiences, increase access to shared journeys, increase collective ownership of spaces and interactions, and reinforce and increase positive interactions...

# So that...

they increase relatedness and connectedness between other individuals, increase initiations of social interactions and responses to other's initiations, reduce negative feelings during social interactions, reduce anxiety during social interactions, increase access to spaces that facilitate leadership skills, reduce fear to failure and increase desire for exploration...

# So that...

they have increased access to informal unpaid social networks, increase comfort when sustaining social engagement, increase social confidence when interacting in public spaces, and increased access to systems that facilitate practice of social interactions...

# So that...

they can access stronger informal support systems...

# So that...

they increase their ability to achieve a sustainable independence.







MakeGuffin was piloted twice with 28 total individuals at the JCC's Center for Special Needs Adaptation program over the course of 1 month. It was implemented by two designers in collaboration with 3 staff, including 2 program coordinators, the director, and help from various social worker interns. The pilots had two main objectives: (1) prove early signs of bonding relationships by gathering evidence of decreased anxiety, shift to positive emotion, and new roles assumed (2) prove a demand for the program by gathering evidence of participation, willingness to return, and willingness to recommend (3) gauge readiness and willingness of the community center to adopt and implement the program.

# Measuring Impact (M&E)

To address the monitoring and evaluation (M&E) of the intervention, we asked ourselves key questions, set key quantitative and qualitative indicators, and established an approach for each component.

# Monitoring

Key Question: How might we prove a demand and satisfaction for the program?

Quantitative Indicators: -Overall satisfaction with the experience -Willingness to return -Willingness to recommend -Participant volume -Newcomer volume -Repeat attendance

Qualitative Indicators -Intervention goal alignment

# Approach

To measure this, we will use a mix of quantitative and qualitative questions. After every event we will solicit quick feedback surveys to measure demand and satisfaction. We will use registration cards as a way to understand attendance over time.

# **Evaluation:**

Key Questions: How might we prove early signs of bonding relationships? How might we gauge readiness and willingness of the community center to adopt and implement the program?

> Quantitative Indicators -Decreased anxiety -Shift to positive emotion -Increased social network -New roles assumed

Qualitative Indicators -Shift in behavior (Individual) -Shift in Attitude (Individual) -Shift in emotion (Individual) -Perceived value of program (Staff)

## Approach

To measure this intervention, a baseline measurement will be taken at the beginning of the program, then as the participants leave the program, they will be asked to answer the same questions. The aim is to determine whether there is a decrease in anxiety, positive shift in emotion, new roles assumed.

Additionally, interviews were conducted with staff to establish a baseline of individual's narratives. The staff were asked same questions about the individuals after they participated in a MakeGuffin. The aim is to track the progress of individuals through impact stories to get qualitative understanding in the shifts in behavior, attitude, and emotion.

To understand community center's willingness to adopt the program, we will interview staff to gauge the perceived value of the intervention.

# Limitations

-Differences in outcomes between people in the program are unaccounted for.

-Extended exposure to intervention is likely to be connected to the outcomes.

-Outcomes can be highly dependent on the community's exposure to 'neurotypical' population (us)

-Outcomes can be highly dependent on relationship to facilitators (i.e. their level of trust in facilitators developed through consistent engagement).



# **PILOT LEARNINGS**

# The MakeGuffin project creates a new community and interest in making.

100% of participants liked the experience 90% of participants would do it again 60% of participants expressed interest to volunteer producing the event.

In both pilots, we observed other teams listen to other teams' presentations, recognize their efforts, and applaud their concepts. We noticed individuals exchanging phone numbers and invite others to connect after the program.

# The MakeGuffin project develops confidence, reduces anxiety, and positively shifts emotions. 75% of participants reported positive shift in emotion

50% of participants reported reduction in anxiety 100% of participants left feeling happy 82% of participants left feeling zero anxiety

# The MakeGuffin project encourages coownership of program spaces.

In both pilots, we observed participants holding each other accountable to the manifesto. In the second pilot, the group helped to author the agreement. In both pilots, we observed participants actively seeking to help set up, run, and clean up the space.

# The MakeGuffin project develops collaborative practices and social skills that can be carried in other areas of individual's lives (i.e. compromise, controversy with civility).

In both pilots, we observed individuals compromising their ideas, apologizing for speaking out of turn, and sharing the 'microphone' while presenting the project. In the second pilot, we noticed individuals taking ownership over

their parts of the project (i.e. Maddie owns the storyboard aspect of the project, Arturo sketches out the ideas of others)

# The MakeGuffin project develops leaders and leadership skills necessary for interdependent relationships.

In both pilots, we observed in every team a leader who emerges to guide the group through challenge, toward the required deliverables of the challenge. For example, leaders stand up to draw on the white board, encourage dialogue from the entire group, present ideas to share with the group, or quietly guide the group with action.

# The MakeGuffin project empowers individuals to self-start ideas, take risks, and step outside comfort zones.

After the first pilot, we heard individuals' interest to continue working on their projects with their groups. Jessie wanted to save the cards to continue working on the card game concept. Harrison and Ben wanted to continue building the card game. In the second pilot, we heard Phillip's desire to continue working with his group to continue developing the Netflix series. Ben exclaimed, "I want to do this every day as my career!"

# The MakeGuffin project created new conversations around the way in which JCC creates programming.

After sharing progress of MakeGuffin with JCC staff, we heard evidence in shifts of thinking. We observed staff using whiteboards to ask the individuals what kind of programs they desire. The director exclaimed, "I'm taking notes on your use of language. This is great." She exclaimed on another occasion, "This is innovative stuff. What you guys are doing here is on a new frontier. This is changing the way we program."



# "What you're doing here is on a new frontier... this is changing the way we program"

**Allison Kleinsman** Adaptations director



# Next steps for the MakeGuffin project include:

- -Implement pilot programming at JCC
- -Test others in facilitator role
- -Evaluate impact of pilot programming
- -Develop business plan for scaling
- -Promote plan for scaling
- -Acquire funding
- -Produce detailed version of MakePlaybook
- -Produce online version of MakeGenerator materials
- -Develop microsite to access open-sourced content

# Beyond the JCC

The reach of this project is beyond the JCC. The MakeGuffin project can easily be implemented in community centers across New York, U.S., and internationally. By crowdsourcing and open-sourcing content, the model can be evergreen. The scalability of the program depends on the following steps: (1) Business and Marketing plan development, (2) seed funding, (3) MakePlaybook and MakeGenerator production, (4) Microsite development.

# Beyond autism and adults

The implications of the MakeGuffin project extend beyond adults and autism. The impact of this programming can be scaled across other behavioral challenges (i.e. social anxiety, PPD, learning disorders, down syndrome, etc.) and age groups (children, youth, teens, and young adults).

# **Opening Doors to inclusion**

But, really, it's about inclusion. The program has capacity to include a more neurodiverse audience, encouraging different levels of engagement: from volunteer, facilitator, or guest speaker. Skills and relationships learned in the program can be translated into other areas of their lives, encouraging their confidence to engage where they may have feared venturing prior. Independence and interdependence are just one part of the story. The MakeGuffin project is bringing people like Arturo out of isolation. It's allowing themselves to shape new narratives about themselves, to pursue their dreams, toward the flourishing life they deserve.



# OUR REFLECTIONS

## To make social change, grow leaders to take it on.

While we considered leadership in the design process, we didn't foresee how instrumental the role that leaders would eventually play in the sustainability of a new system.

## Document and reflect.

The success of our project was due to our extreme rigor in documentation and reflection. While every big insight is derived from working in the field, it wasn't surfaced until we were in debriefing, reflecting on the conversations with the end users. Some key methods we will always take with us are:

- -Make a running process log
- -Revisit old material and research notes
- -Challenge your assumptions
- -Work to uncover the insights

# Integrate social science

While design is powerful as a method, it demands the substance that social science research and practice provides. For example: social science frameworks drive decision-making, save time and energy, and legitimize the work that you do.

## When you enjoy it, others do too

While not obvious at first, we started to see that our best interventions created when we were having fun with the process. This is evidenced by the MakeGenerator. We got excited by the idea of a cardboard machine, put our soul into the creation process, and it stuck with the community. They loved the fun interactivity, the tangibility, and the nostalgia that it elicited.

## An Intervention is only as good as the relationships fostered

The success of the design uptake was dependent on the relationships with staff and individuals. We developed trust, loyalty, and commitment through the following behaviors:

- -Co-design from the beginning
- -Consistent communication
- -Continuous engagement
- -Openness of process
- -Sharing of knowledge
- -Unwavering commitment



The MakeGuffin Project was built by the support, encouragement, and knowledge of many people:

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Love,

Nick and Malé



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