Kind
By Amwaj Alzahrani
amwaj.alzahrani@gmail.com
Advisor: Sahar Ghaheri
April 28th, 2021

Table of Content

Introduction

Acknowledgment

Faraj's Flowers

Doing this work is harder than I thought and more rewarding than I could have ever imagined. None of this would have been possible without my husband, Abdulrahman. He stood by me during every struggle and all my successes. I want to thank my family for the tremendous support they offered me and the love they filled me with. Also, I want to thank DSI classmates and advisors, uniquely my thesis advisor Sahar for helping me progress and face challenges with confidence.

My Bio


Faraj's Flowers

Amwaj is a Designer, Educator, and Strategist with a background in Graphic Design and Multimedia. She worked in several positions in design-related entities doing all print-media and branding work. In 2018, she led the Solutions Design Team in the E-learning department at IAU among a multidisciplinary team where she managed to improve students' learning environments and tools, systems design, engagement initiatives, and more. Besides that, she was a designer and facilitator for innovation and design workshops in Ithra.

In 2019, Amwaj moved to New York to pursue a master's degree in Design for Social Innovation at SVA. Amwaj's work aims to shed light on people with disabilities abilities and create experiences to explore their talents and find their skills. She applies human-centered design principles to achieve mutual success in communities. She leverages art and visual communication to raise awareness and drive advocacy. Currently, She is a lecturer at the College of Design at IAU Saudi Arabia and a Communication Designer and Creative Visualizer for the SIX, Social Innovation Exchange, London.

Context

Problem framing

Individuals with Down syndrome

Down syndrome has been the most commonly occurring genetic condition. Individuals born with DS possess varying degrees of cognitive delays, from very mild to severe. They face difficulties such as the following:

- Cognitive and physical growing delay. [1]
- Heart and lung diseases. [2]
- Visual and hearing problems. [3]
- Difficulties in verbal communication which affects their confidence, learning and engagement with the world. [1]
- Need help with self-care, such as dressing and grooming
- DS-ASD (people with co-occurring Down syndrome and autism spectrum disorder). [4]
- Some research suggests up to 39% of individuals with Down syndrome also have autism spectrum disorder.

However, because it is the nearest condition to a typically developing child, they are under served.

---

[1] What is Down Syndrome?: National Down Syndrome Society. (n.d.). From https://www.ndss.org/about-down-syndrome/down-syndrome/
[2] Colvin, K. L., & Yeager, M. E. (2017). What people with Down Syndrome can teach us about cardiopulmonary disease. European Respiratory Review, 26(143), 160098. doi:10.1183/16000617.0098-2016
[3] Nunes, M. D., & Dupas, G. (2011). Independence of children with Down syndrome: The experiences of families. Revista Latino-Americana De Enfermagem, 19(4), 985-993. doi:10.1590/s0104-11692011000400018
[4] When Down Syndrome and Autism Intersect, A Guide to DS-ASD for Parents and Professionals, P.1, Woodbine House, 2013, http://woodbinehouse.com

Meet Firas

My lucky charm and inspiring sibling Firas born with Down Syndrome, which made him look and grow differently. He shows significant cognitive delays. Firas is 14, and he has difficulties in overall comprehension. He can't form full sentences and struggles with pronunciation, affecting his engagement with the world. He depends on his mom in almost everything.

In my journey working with the community, I wasn't practicing empathy because I have lived it myself and still can see the marks of all the struggle and uncertainty in my mom's, dad's, and siblings' faces.

Problem framing

The family

What I have understood from the interviews with practitioners and families, in the very initial phase of my research, is that:

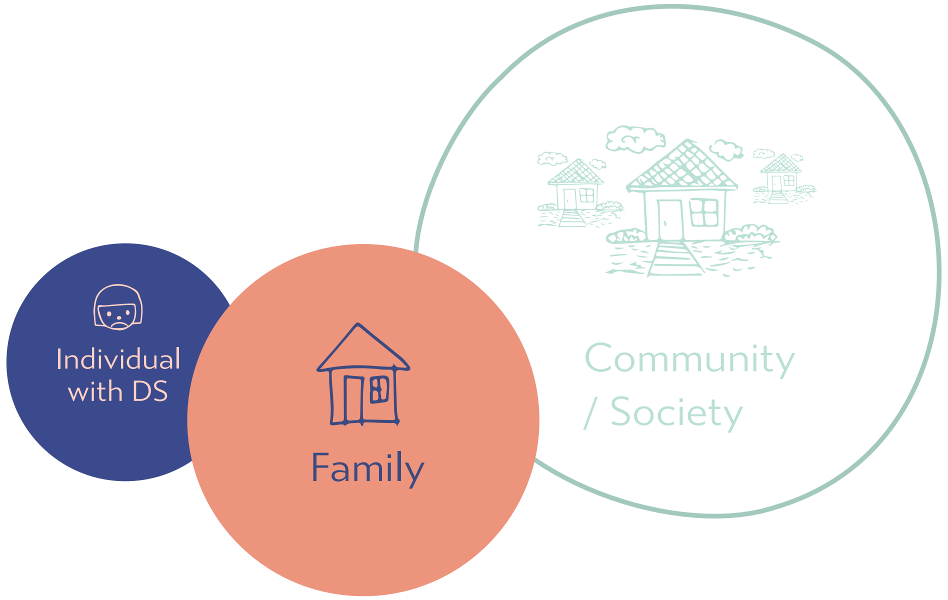
- Families with a child with DS are facing challenges at different levels.
- Psychologically they are dealing with grief, and some are in denial. The family faces tremendous uncertainties regarding the child's health and development. They are navigating the need for mental support and a safety net.
- Socially they are stigmatized and dealing with the social perspective of the individual with DS. People call their child names like Mongolian or retarded, which makes them feel ashamed and want to stay in the shadow.
- Financially, access to adequate health care services and education is expensive. The condition demands immediate and constant care from a parent, caregiver, or a nanny, which cost the family most of the time.
- Physically, family mobility is limited due to the condition's nature combined with other social, financial, and psychological challenges.

"People with Down syndrome have been subject to exclusion from society and from discrimination across the board — in educational settings, employment, and in their communities,"
David Tolleson
Executive Director of the National Down Syndrome Congress.

One of the pain points of individuals with Down Syndrome and their families is being isolated or excluded. Changing this social narrative needs support and preparation starting from home.

"This condition affects all family members, it alters the relationships and creates new roles for each member to play in order to give the most help to the individual with DS."
Mona Alsahali
Psychologist and family specialist

Resource: Global Down Syndrome Foundation



In the beginning, the reasons for the exclusion seemed to be as the following:

- The social discrimination against people with disability in different social settings,
- Lack of confidence in kids with DS,
- Communication barriers
- Moreover, the overprotective families feel responsible for speaking on their child›s behalf and expressing them all the time.

However, after conducting more interviews with stakeholders, practitioners, and families through a community partner to understand some of this social narrative's root causes, I got more profound insights than the initial findings. Primarily, the family is one main reason for individuals with DS's low engagement with the community. The family stands in the middle between their child with DS and the outer society. Families are stigmatized and ashamed. Some parents are living in denial since the child›s birth. Parents and siblings are not equipped to face critical situations when they feel offended or othered. Furthermore, the most crucial insight is that families want and need support, but this community does not exist or is fragmented. Families lack the ways to create this supportive community.

Problem framing

The family in Saudi Arabia
In Saudi Arabia, the occurrence percentage has exceeded the global rate. Down syndrome's estimated incidence is approximately 1 out of five hundred fifty births. Many families are sharing the same experience.

Here is Safia's story which I heard from her father, Alla. The family went through difficult times, Precisely, from that very moment when the obstetrician doctor went to her office crying directly after the child's delivery. Mom and dad panicked and knew there was something wrong. Unfortunately, in Saudi Arabia, the healthcare system is not necessarily trained to deliver such news.
The family was stigmatized, traumatized, and left alone to navigate the uncertainty. Safia's family dealt with patience and faith, but they faced many meltdowns along their journey. Besides telling siblings and the larger family about the child's condition, they struggled in looking for adequate services in the eastern province in Saudi Arabia back then.

Resource: Disability Survey 2017- General Authority for Statistics, Saudi Arabia

My community Partner

جمعية همم
لأسر ذوي الإعاقة
Hemam Association for Families with Disabilities

Hemam Association for Families with Disabilities is working in supporting families since 2010.
Their mission is to support and empower families of people with disabilities through advanced methodologies and an attractive environment.

The problem

People with Down syndrome's community feels frustrated, unsupported and demands more opportunities and inclusion.

Process

Research question

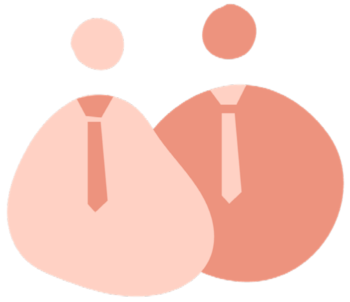
How might we create channels for the community of families of children with Down Syndrome to feel supported in Saudi Arabia?

Interviews

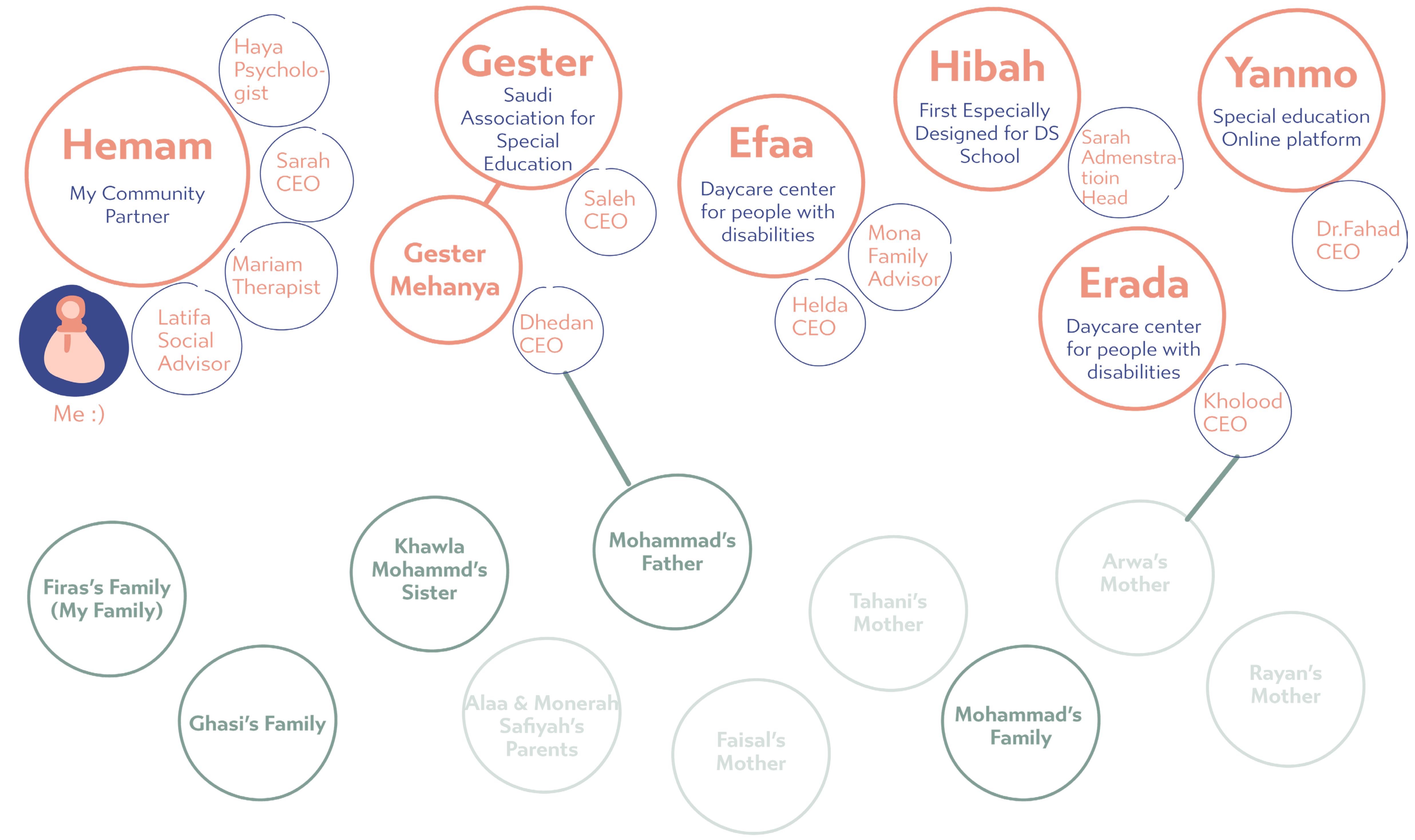
Faraj’s Flowers

With the help of Hemam, my community partner. I have reached more than ten families (over 25 family members, mothers, fathers and siblings) and Working closely with five families to develop the intervention.
Beside, working with practitioners to be better prepared for the work and validate assumptions regarding the cognitive disabilities realm. I had 8 deep conversations with practitioners working on the space.

Research Activities | 2 Co-creation sessions | 5 Meetings | 2 Interviews | 3 Interviews | Interview | Interview | Interview



Professionals



Hemam
My Community Partner

Haya Psycholo-gist

Sarah CEO

Mariam Therapist

Latifa Social Advisor

Me :)

Gester
Saudi Association for Special Education

Saleh CEO

Gester Mehanya

Dhedan CEO

Efaa
Daycare center for people with disabilities

Mona Family Advisor

Helda CEO

Hibah
First Especially Designed for DS School

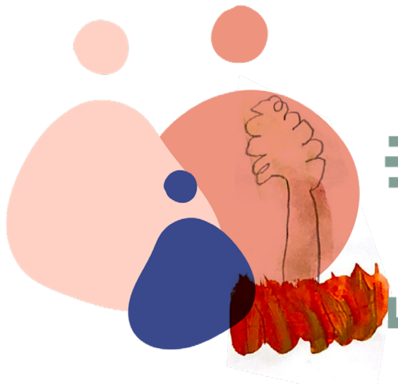
Sarah Admenstra-tioin Head

Erada
Daycare center for people with disabilities

Kholood CEO

Yanmo
Special education Online platform

Dr.Fahad CEO



Families

Firas's Family (My Family)

Ghasi's Family

Khawla Mohammd's Sister

Alaa & Monerah Safiyah's Parents

Mohammad's Father

Faisal's Mother

Tahani's Mother

Mohammad's Family

Arwa's Mother

Rayan's Mother

Research Activities | 5 Co-creation sessions | 10+ interviews | 1 Cultural probe | 2 prototypes

The in-depth family interview guide

Goals and questions

To understand the family feelings having a child with down syndrome

- Do you remember when you knew that you would have a child with down syndrome, how was it like?
- What was in your mind?
- What were your biggest fears?
- How did you imagine the future back then?

To understand the family's ways of navigating uncertainty and shame. To Discover the phases family went through since having a child with DS

- How did you tell your family?
- What was their reaction, and how did they deal with the news?
- How did you respond to other's questions?
- What was your plan to feel better or make your family feel better? How did you educate yourselves and others?
- Did you prepare how you are going to reveal this news?
- How was the first-year experience of having a child with DS?

To spot the family challenges dealing with the idea of having a child with DS

- How is your experience years after having a child with DS?
- What is the knowledge source you rely on to learn how to deal with the condition?

To know the change in roles that happened in the family.

- What was your role, and how does your role evolve?
- The mother?
- The siblings? Relatives? Caregiver or the nanny?

To understand the family dynamic.

- Who has the responsibility of taking care of the child?
- How supportive are the family members?
- How do you ask each other for help?
- How do family open critical conversations?

To list the services family pursued their child.

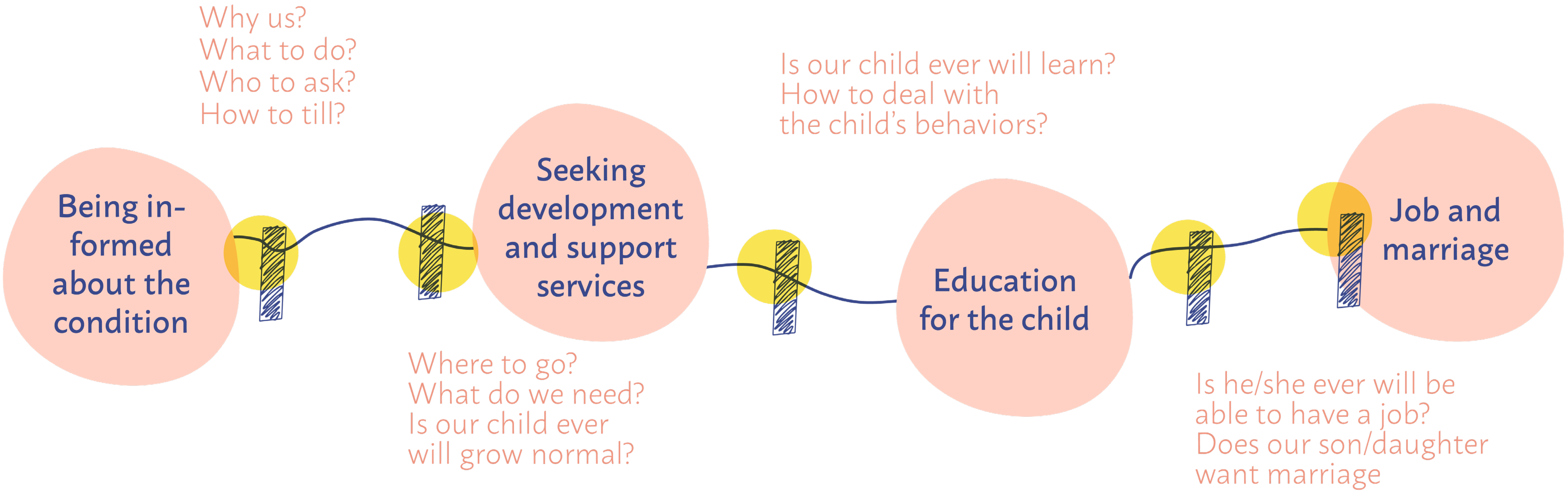
- How do families get the help they need?
- From where do families get support and help?
- What was the most helpful person, place, source?
- What was the support you most benefited from?
- How do families navigate the services?

Outcome

Understanding the family's journey and what does it entail.

Learning:

- The family's journey starts with tremendous uncertainty; hence parents hold different reactions.
- Navigating all the negative emotions, denial, ambiguity, sorrow, and sometimes even guilt is the main challenge of this stage. Family members look for education channels to learn and people with the same experience to get hope from.
- The second crucial event is seeking a development plan and searching for services. This happens when the family decides to facilitate the child's growth and development. But The limited access to sufficient people with disabilities services in Saudi Arabia makes it difficult and a source of frustration for families.
- In the early intervention stage, which starts from newborn to 6 years old, families wrestle with social stigma and the idea of being a family of a member with a disability.
- In education, families share a constant dilemma of choosing their child's educational path between traditional inclusive schools or daycare centers. This confusion grows with them each year.
- Lastly, having a job and getting married are big subjects that are impacted by social stigma. And most of the time are neglected in Saudi Arabia.



Why us?
What to do?
Who to ask?
How to till?

Being informed about the condition

Seeking development and support services

Where to go?
What do we need?
Is our child ever
will grow normal?

Is our child ever will learn?
How to deal with
the child's behaviors?

Education for the child

Job and marriage

Is he/she ever will be
able to have a job?
Does our son/daughter
want marriage

Insights:

I- Stigma is a continuous struggle that fades in and out along the journey. Families in a lifelong battle with this social stigma.

2- Parents and siblings have different expectations and uncommunicated goals for the child. All along the journey, family members face ups and downs, affecting their involvement and the amount of support they can give to each other. Sometimes Mothers feel alone in the journey and don't know how to keep the family united.

This leads us to the third insight; family members need each other's support and compassion to have that feeling of "okay, we have a collective responsibility, and we are in this together."

3- families have more than one small WhatsApp groups to share knowledge and experience. But these groups are usually gender-segregated, which is a cultural norm that adds more complexity.

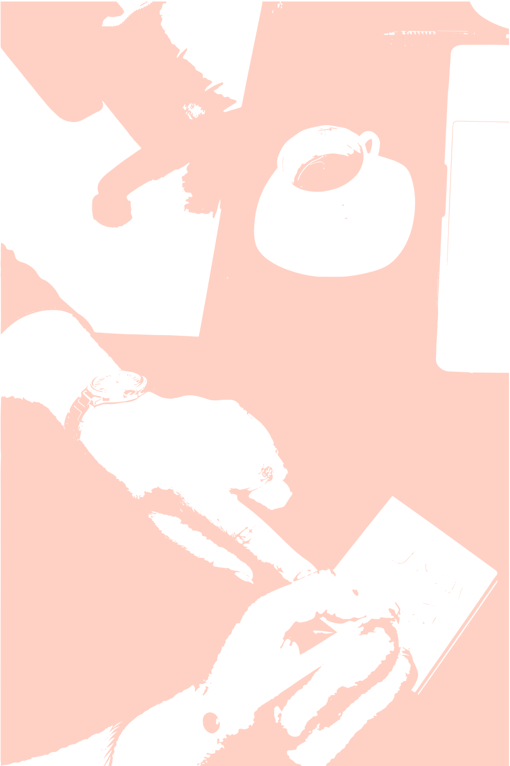
Crucial tool

In working with the community, I had to build trust over time, showing my devotion and commitment every time I show up.

Co-ideation Session

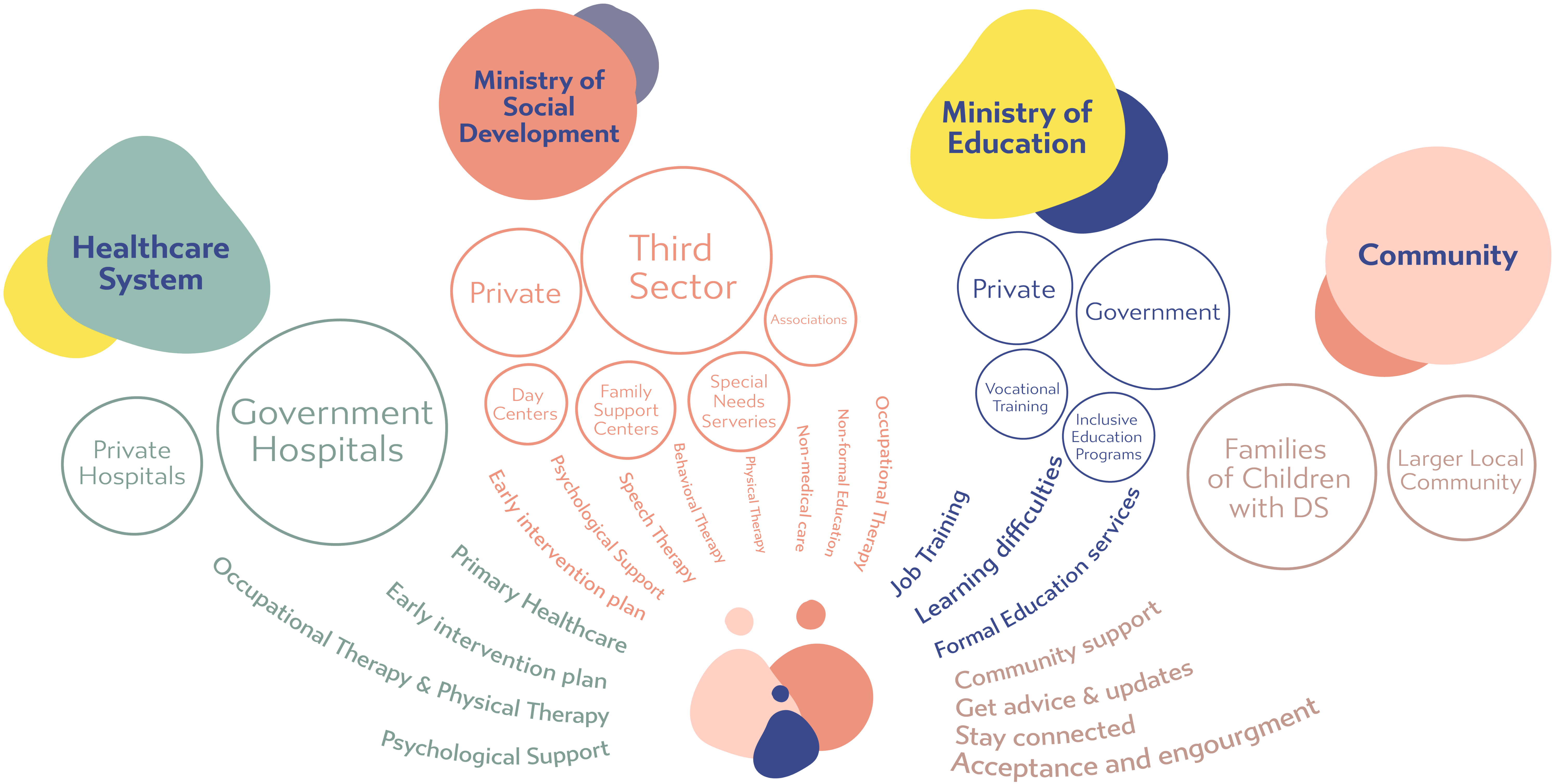
Faraj's Flowers

I worked with four practitioners to understand the landscape of services and the shape of the support provided for families with down syndrome in Saudi Arabia. The outcome was a deep understanding of the support ecosystem and defining potential gaps that my intervention could make some effort to fill.



Learnings:
How does the current family support ecosystem look like?
It is a very complicated and tangled situation that I have been investigating and learning about during my thesis journey.
The broad spectrum of the family needs is provided from four main support system resources, as the following:

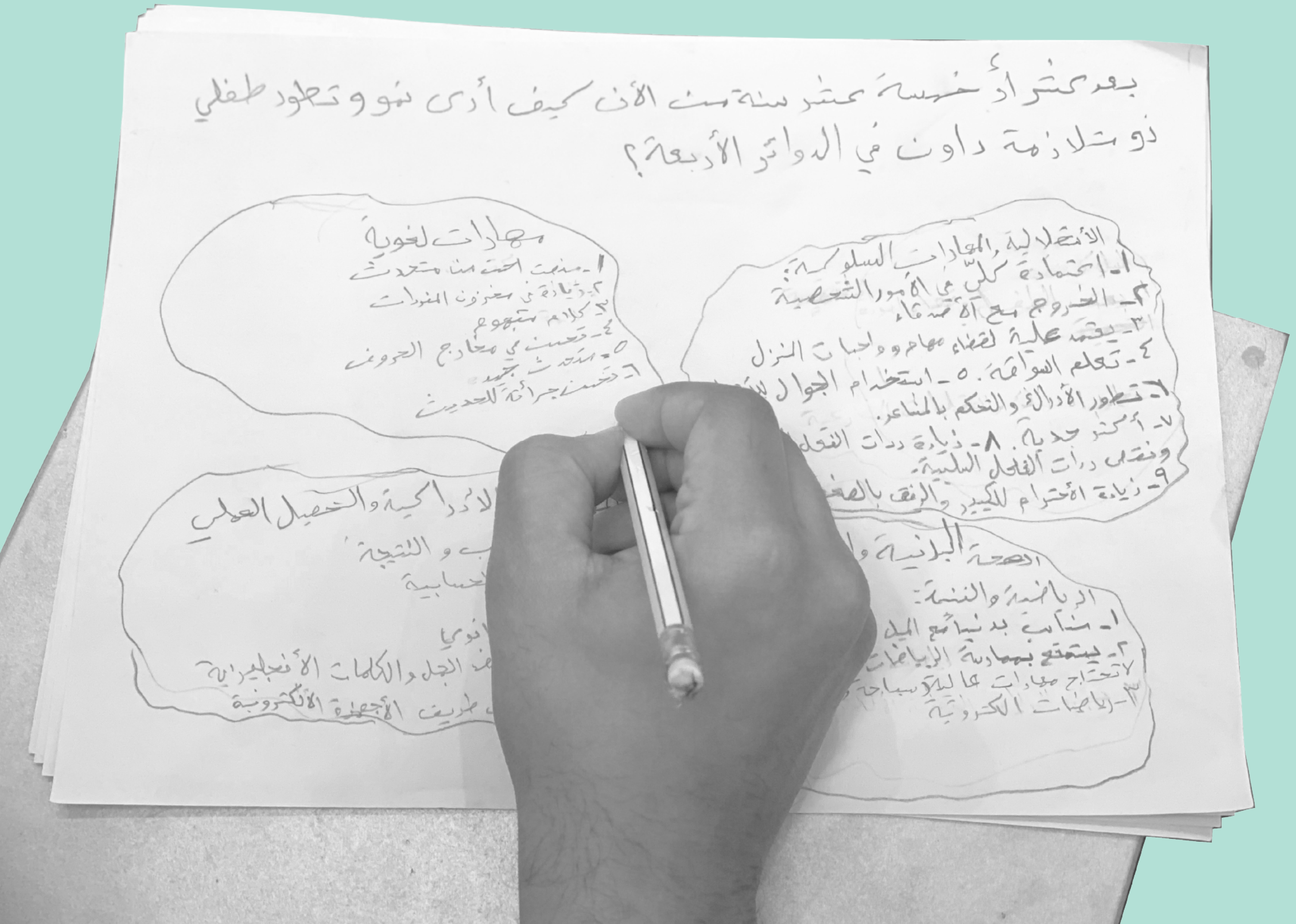
- The first interaction, and also the lifelong one is with the healthcare system. Individuals with DS need more frequent medical checkups to maintain mental and physical health.
- On the other hand, most non-medical services are provided under the Ministry of Social Development regulation, including non-formal education services.
- Because the formal education for people with cognitive disabilities is provided from the Ministry of Education such as inclusive education programs and vocational training.
- Finally, the community support, and it appears in two levels; the internal level; the families of children with DS's community where they get advice, have conversations, and keep updated and connected. The second part of the community piece is the larger local community, where awareness and acceptance contribute to the family's well-being and their beloved ones with DS.



The support ecosystem for families of people with DS in Saudi Arabia.

Prototypes


Faraj's Flowers


بعد عشر أو خمسة عشر سنة من الآن كيف أرى نمو وتطور طفلي ذو متلازمة داون في الدوائر الأربعة؟

مهارات لغوية
١- [illegible]
٢- زيادة في مخزون المفردات
٣- كلام مفهوم
٤- تحسن في مخارج الحروف
٥- التحدث بجمل
٦- تحسن جرأته للحديث

الاستقلالية والمهارات السلوكية:
١- اعتمادة كلي في الأمور الشخصية
٢- الخروج مع الأصدقاء
٣- يعتمد عليه لقضاء مهام وواجبات المنزل
٤- تعلم السواقة. ٥- استخدام الجوال [illegible]
٦- تطور الإدراك والتحكم بالمشاعر.
٧- أكثر هدوء. ٨- زيادة ردات الفعل [illegible] ونقص ردات الفعل السلبية.
٩- زيادة الاحترام للكبير والرفق بالصغ[illegible]

[illegible] الإدراكية والتحصيل العلمي
[illegible] والنتيجة
[illegible] الحسابية
[illegible]
[illegible] الجمل والكلمات الانجليزية
[illegible] طريق الأجهزة الالكترونية

الصحة البدنية و[illegible]
الرياضية والفنية:
١- [illegible]
٢- يستمتع بممارسة الرياضات [illegible]
٣- الرياضات الالكترونية

1- Online Family bonding activity

It is an on-paper activity with a digital guide to facilitate it. The family›s task was to create a shared future vision for the child in four main development areas. The aim is to invite family members to talk together and connect. The guide also includes physical and mental preparation, breathing exercises, intention setting, and an educational component.
In three days we got 11 responses:
2 Fathers, 3 mothers and 6 siblings did this activity.


أهلًا!

شكرًا لدخولكم هذا الرابط!

من خلال هذا النشاط الأسري الجماعي أنتم تساعدون المصمم والباحث والممارس بأن يقدموا خدمات أفضل لأبنائنا من ذوي متلازمة داون.
هذا النشاط يُعد أداة بحثية لجمع البيانات وكل ما يرد فيه سيكون محفوظ الخصوصية للأغراض البحثية فقط وليس للنشر في وسائل التواصل وغيرها. أرجو اتباع التعليمات في هذا الملف حتى النهاية، وشكرًا مجددًا.

بحث رسالة ماجستير في التصميم للابتكار الاجتماعي بالتعاون مع جمعية همم


المحتويات

في هذا الملف ستجد:

- التحضير للنشاط
- خطوات عمل النشاط
- إرسال النشاط
- استبيان قصير

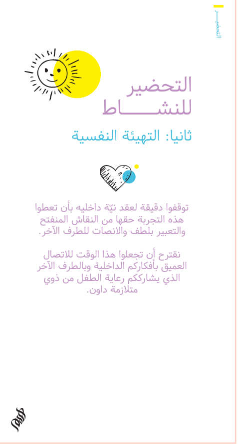

التحضير

التحضير للنشـــــاط

أولا: الأشخاص والأدوات

شخصان أو أكثر من مقدمي الرعاية والتطوير للطفل من ذوي متلازمة داون من أفراد العائلة داخل المنزل.

ورقة كبيره يفضّل غير مخططة وأقلام


التحضير

التحضير للنشـــــاط

ثانيا: التهيئة النفسية

توقفوا دقيقة لعقد نيّة داخليه بأن تعطوا هذه التجربة حقها من النقاش المنفتح والتعبير بلطف والانصات للطرف الآخر.

نقترح أن تجعلوا هذا الوقت للاتصال العميق بأفكاركم الداخلية وبالطرف الآخر الذي يشاركم رعاية الطفل من ذوي متلازمة داون.


خطوات عمل النشاط

خطـــوات عمل النشاط

أولا: نرسم أربع دوائر كبيرة في الصفحة تاركين مساحة علوية للسؤال

كل دائرة يتم تسميتها في الأعلى كالتالي:
الاستقلالية
المواهب والمهارات الرياضية والفنية
المهارات العلمية الإدراكية
التواصل والتخاطب


خطوات عمل النشاط

خطـــوات عمل النشاط

ثانيًا: نضع العنوان وهو السؤال المحرك لهذا النشاط كالتالي:

بعد عشر أو خمسة عشر سنة من الآن كيف أرى نمو وتطوّر طفلي ذو متلازمة داون في الأمور الأربعة؟

تذكر أن تكون واقعيًا وتتواصل بعمق مع الطرف الآخر حول كل نقطه


خطوات عمل النشاط

خطـــوات عمل النشاط

ثالثًا: نسرد كل ما نتوقعه لنمو وتطور الطفل داخل كل دائرة.

تذكر أن تكون واقعيًا وتتواصل بعمق مع الطرف الآخر حول كل نقطه.
الحوار يكون بالتبادل حيث يأخذ كل طرف دوره في ذكر أحد الخصائص التي سيكون عليها الطفل في المستقبل في كل دائرة.


خطوات عمل النشاط

متوقع لهذا النشاط
أن يأخذ بين
40 - 60 دقيقة

شكرا لتخصيصك الوقت لعمل هذا النشاط
نحن ممتنون لكم جدًا!


إرسال النشاط

إرسال النشـــــاط

أرجو أخذ عِدة صور واضحة للورقة وإرسالها لأي من القنوات التالية

Email
aalzahrani@sva.edu

WhatsApp
0543673123


استبيان قصير

استبيان قصيـــــر

نرجو منكم تعبئة الاستبيان على الرابط التالي

https://forms.gle/FHe51Yjngmy4yiJy8


الختام

شكـــرًا جزيـــلًا

Responses from family members

It became clear to us that some points will not be achieved in the future without family effort

Sibling

It was an excellent experience that made all family members discuss our beloved child's future, and it drew attention to some things that we must all focus on and work on together.

Mother

A new experience that showed me new things about my child

Father

It was a unique experience that exercises our dialogue skills with family members. We got more profound in our perceptions and imaginations of our brother's future

Sibling

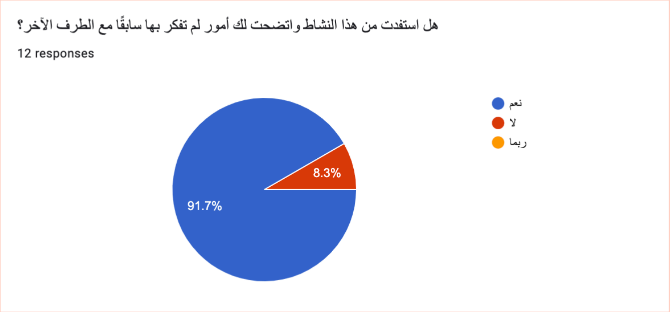
An important experience, even if it was confusing in moments

Sibling

Outcomes and learnings:

- Families found it helpful, but the number tried this activity is significantly low.
- The majority found this type of activities novel, and they have never done it before.
- After more investigation, I found that families do not prefer Online engagement and benefit more from personal interaction.
- Families overlooked the activity because it was in an unfamiliar format (virtual PDF).
- Families digital literacy is not reliable.

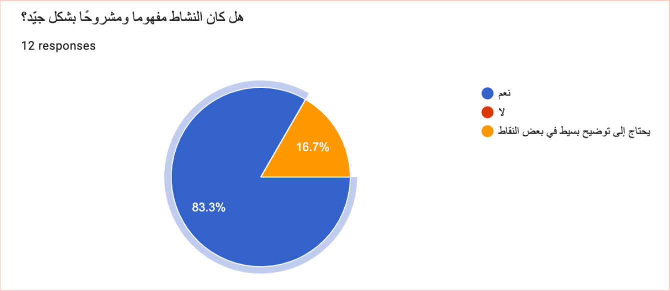
From the after activity survey



هل استفدت من هذا النشاط واتضحت لك أمور لم تفكر بها سابقًا مع الطرف الآخر؟

12 responses

91% benefited from the activity and did something they have never done it before



هل كان النشاط مفهوما ومشروحًا بشكل جيّد؟

12 responses

83% thought the language and steps were well explained

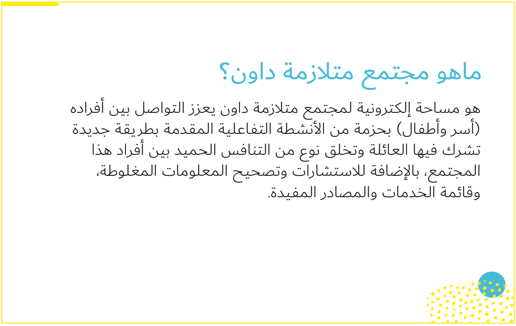
2- Website building

At this stage, the intervention aim was to create a virtual platform that generates activities and gather the community around how to make our relationships stronger with our beloved one with DS. Also, each other as a community. I made a slide deck where I showed the website's wire-frame for the community to comment and discuss via several channels, mainly WhatsApp.


مجتمع متلازمة داون

Amwaj Alzahrani

Welcome cover


ماهو مجتمع متلازمة داون؟

هو مساحة إلكترونية لمجتمع متلازمة داون يعزز التواصل بين أفراده (أسر وأطفال) بحزمة من الأنشطة التفاعلية المقدمة بطريقة جديدة تشرك فيها العائلة وتخلق نوع من التنافس الحميد بين أفراد هذا المجتمع، بالإضافة للاستشارات وتصحيح المعلومات المغلوطة، وقائمة الخدمات والمصادر المفيدة.

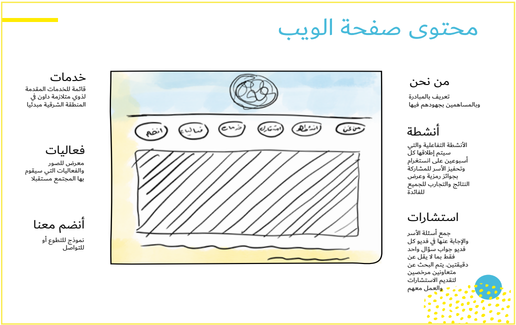
Describe the idea of the intervention


يتكون مبدئيا من حساب انستغرام، وصفحة ويب

صفحة الانستغرام موجهة للوالدين والأخوان و مخصصة للتفاعل ونشر رسالة هذا المجتمع في تمكين أسر متلازمة داون، دعمهم، ومشاركة أفراحهم وهمومهم، كما يتم التوعية من خلالها والتعريف بالخدمات، وتصحيح المغلوطات وغيرها.

صفحة الويب مرجع للمحتوى المصمم للأسر من أنشطة واستشارات ومصادر يمكنهم من خلالها تنزيل المحتوى والاستفادة منه.

What is the aim and the content of the website


محتوى صفحة الويب

من نحن

تعريف بالمبادرة وبالمساهمين بجهودهم فيها

أنشطة

الأنشطة التفاعلية والتي سيتم إطلاقها كل أسبوعين على انستغرام وتحفيز الأسر للمشاركة بجوائز رمزية وعرض النتائج والتجارب للجميع للفائدة

استشارات

جمع أسئلة الأسر والإجابة عنها في فديو كل فديو جواب سؤال واحد فقط بما لا يقل عن دقيقتين. يتم البحث عن متعاونين مرخصين لتقديم الاستشارات والعمل معهم

خدمات

قائمة للخدمات المقدمة لذوي متلازمة داون في المنطقة الشرقية مبدئيا

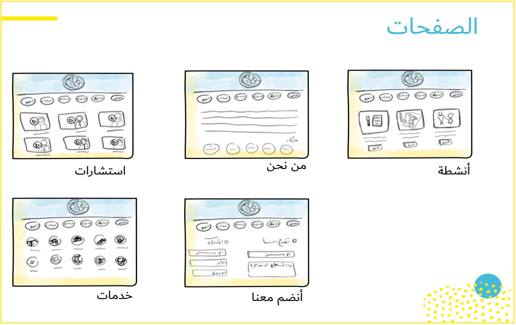
فعاليات

معرض للصور والفعاليات التي سيقوم بها المجتمع مستقبلا

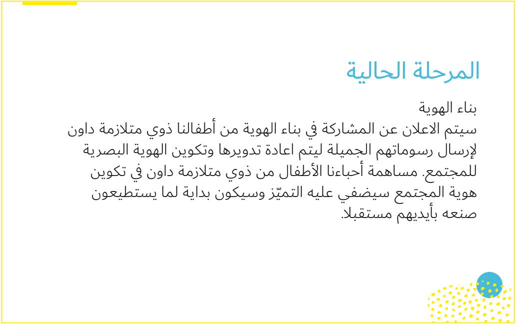
أنضم معنا

نموذج للتطوع أو للتواصل

Show the homepage wire frame


الصفحات

Other pages


المرحلة الحالية

بناء الهوية

سيتم الاعلان عن المشاركة في بناء الهوية من أطفالنا ذوي متلازمة داون لإرسال رسوماتهم الجميلة ليتم اعادة تدويرها وتكوين الهوية البصرية للمجتمع. مساهمة أحباءنا الأطفال من ذوي متلازمة داون في تكوين هوية المجتمع سيضفي عليه التميّز وسيكون بداية لما يستطيعون صنعه بأيديهم مستقبلا.

Next steps

3- Call out for Art


kind . طيّب

@Tayeb_kind

طيّب كطيبة قلوبهم.. مجتمع لذوي #متلازمة_داون قيد الإنشاء ينمو بكم ومعكم 🍄

tayebkind.org · Joined March 2021

7 Following 4 Followers

kind . طيّب @Tayeb_kind · 2d

أصدقائنا الرائعين مددنا استقبال مشاركاتكم بناءًا على طلبكم إلى يوم الأحد.

نستقبل مشاركاتكم عبر موقعنا الإلكتروني
tayebkind.org

أو على النموذج
...forms.gle/9BERr3HEZkVb8X

أو عبر حساب الانستغرام
instagram.com/tayeb.kind/

م المستقبل!


معًا نبدع!

مسابقة فنية لمبدعينا من ذوي متلازمة داون
مقدمة من Kind.طيّب

كيف نشارك؟

أولا: جهزوا لمبدعينا الأدوات الفنية التي يفضلونها ليطلقوا العنان لإبداعهم، دون أي تقييد.

ثانيا: ارسلوا صور رسومات مبدعينا لنا من خلال النموذج المرفق أو زورا موقعنا الإلكتروني.

سيكون من الجميل أن تشاركونا صور مبدعينا وهم يعملون على رسوماتهم لنشاركها مع مجتمع طيّب ونحتفي بهم.

نستقبل مشاركاتكم إلى يوم الجمعة ١٢ مارس

سيتم السحب على هدايا قيّمة لمبدعينا


tayeb.kind

12 Posts 59 Followers 137 Following

Tayeb

طيّب مشروع ينمو بكم ومعكم لنقدم كل ما يدعم صحة وراحة واستقرار الأسرة وطفلها من ذوي متلازمة داون
www.tayebkind.org/

Because families were constantly referring to their kids' talents and how wonderful seeing them interested in any hobby or type of art, I thought of inviting the community to create Kind's visual identity. The intention was to give the community a space to shape and contribute to the intervention. Since I released the call out for art. I have received loads of support and praise.

Families were happy with sharing and celebrating their children's art. Many families asked me to extend the deadline to give them more time to participate.

I got questions about how could Kind celebrate their art?
Where can they see it displayed?
And other out-of-curiosity questions.

These insights had influenced my thesis statement to shift from empowering the community to Creating a local culture that empowers and celebrates people with DS's talents and skills and brings pride and hope to their families.

Firas, 14 years

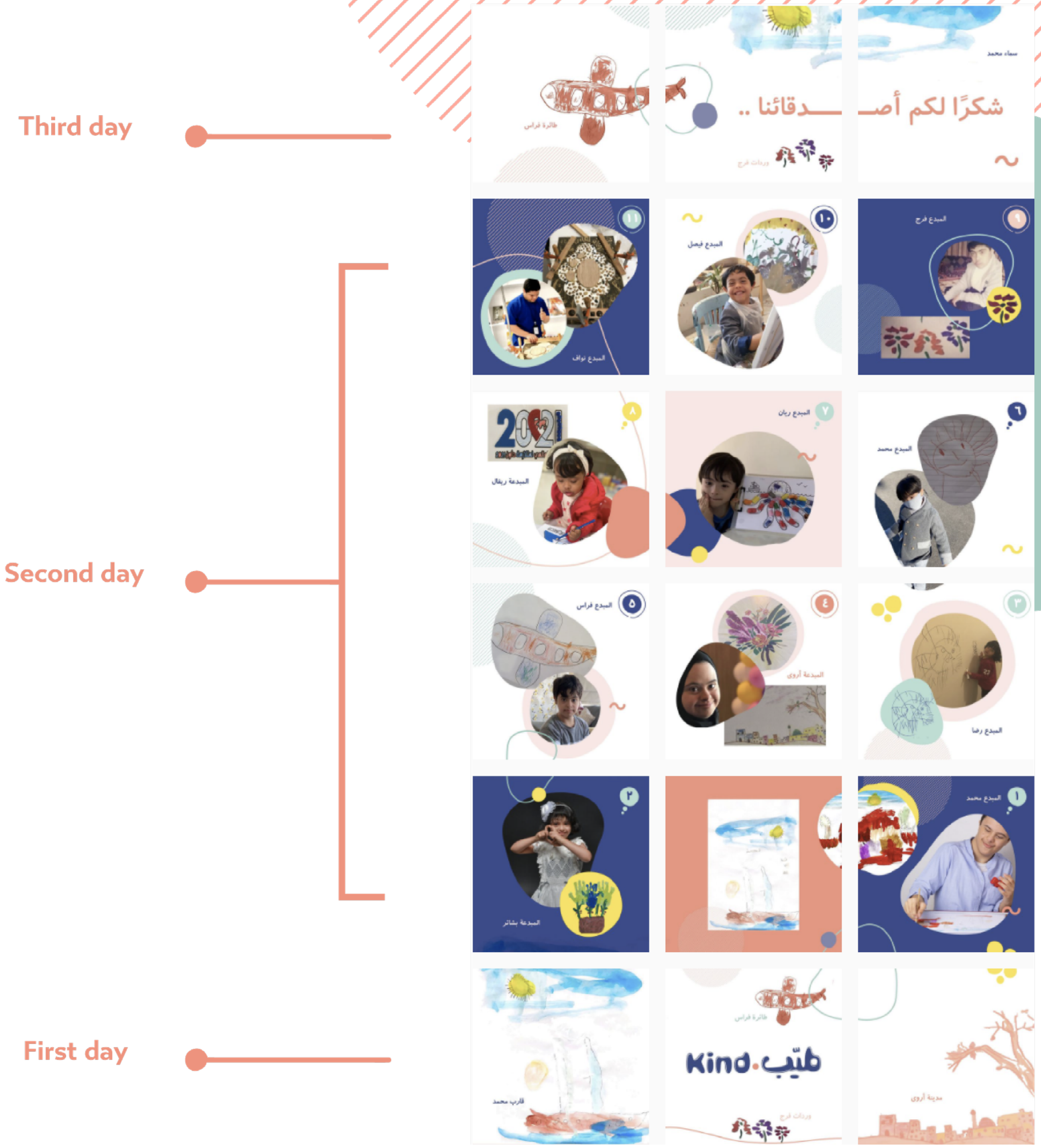
Mohammad, 22 years

Mohammad, 4 years

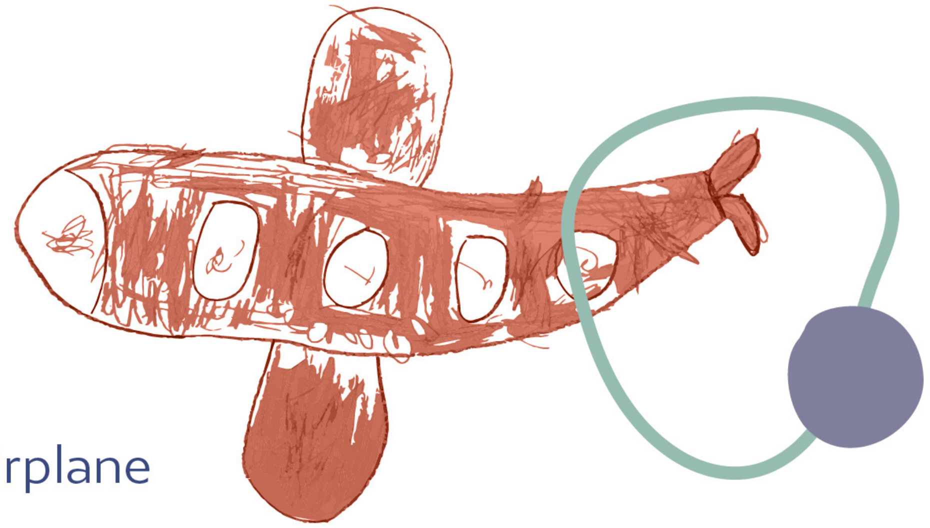
Bashair, 9 years

Ridha, 6 years

Faraj, 16 years



Then I shared back to the community through series of posts on Instagram over three days. Kind has incorporated the drawings in its visual identity presenting it back to kind's community.



Firas's Airplane

Mohammad's tree

Faraj's Flowers

Mohammad's beautiful see

Thesis statement

Creating a local culture that empowers and celebrates people with DS's talents and skills and brings pride and hope to their families.

4- Art workshop

Kind held its first workshop in partnering with a local art studio where the workshop took place. "Welcome Ramadan workshop" is a Ramadan celebratory art session. Ramadan has a great value in the Saudi culture. It is the month of religious rituals. With the help of a team of volunteers, an artist, three organizers, Abdulrahman and I, we created a cozy, joyful experience for the kids and their families.

Kind facilitated a drawing together workshop themed by welcoming the holy month.

We started the session by introducing the painting's shapes and colors to get them excited. Then kids started painting following the artist's instructions. Meanwhile, families were having exciting conversations with much laughter.

After a while, families got excited and asked me to join their kids. I happily welcomed them, and here the fun started. They were having so much fun talking to each other and cheering their kids to finish the drawings nicely. This emergent act had me think of doing family duties art workshop next time. In Kind's social media, we created a virtual after-party posting photos and videos of the two-hour workshop with comments and mentions for our community.

Prototype questions:

- How long does the activity take?
- To what extent children are engaged?
- What worked well in the art facilitation?
- What was the exciting part for kids?
- How does the real facilitation differ from the planned one?
- Is the number of volunteers suitable?
- How do families feel about the photo and video documentation?
- How do families engage with each other and with the prepared materials for them?

During the workshop

Kind volunteers wear tag names to indicate their roles. They had two main roles one is to assist the participant in following the artist's direction. Two is, creating joy and excitement. They were family members of people with Down syndrome. So they worked from a place of familiarity and love.

I started the facilitation by introducing the drawing for the participants, describing shapes and colors. In the photo, Tahani touches the drawing and name colors and shapes with me. This is a way to give guidance and intrigue their senses toward achieving a particular goal using colors.

After painting the blue background, we had a meal together while waiting for the blue base to dry. Participants were talking to each other, so excited to continue painting.

Participants were guided in all stages to bring their drawings to life. Families participated too after feeling so excited to join their kids to paint.

I was prepared with extra canvases if they still want to draw, but their drawings are complete. This is what happened after two hours; they still want to draw.. So while waiting for their paintings to dry, they were experimenting in a free-form drawing session.

Day after the workshop, I got this message from Tahani's mom, "one of the participant," saying, "thank you for last evening. Today After Iftar, Tahani changed her clothes, saying, mom let's go-to colors. She was laughing the whole night and got up excited the day after. Hope you continue this work, and we get to do this again."

I was deeply touched and genuinely cried when I read this message.

Learnings:

- Participants need very close assistance. They were asking many questions and had many demands. So the one volunteer should have no more than two participants to assist in order to maintain ample help for participants.
- Families needed to be encouraged to talk and engage with each other. Next time, maybe I will consider inviting a family specialist who could volunteer to facilitate families' activity.

- Families want these types of workshops in the form of programs to help their kids get familiar with the specific style or technique of art.
- Families were excited to participate with their children, which totally surprised me and was so emergent. When I asked families what made them excited, they mentioned that the setup, environment, and the team's enthusiasm were so compelling for them to make a family race with their kids. This made me think of making more family-kids art competitions where the family have quality engagement time.
- Black outlines in the drawings are hard to draw. Next time, I will consider more color blending and border-less shapes.
- The meal in the middle of the session is working so well in keeping them excited and giving them a healthy break and more reasons to love the workshop.

Challenges:

- There were four mothers, one sister and only one father, which made it very hard for the father to engage with the women majority in the family area. Engaging fathers in Saudi Arabia has always been hard in the community of people with disabilities. Mothers get too close to their kids and take the whole responsibility of taking care of the kid. Kind is mindful of that and trying to create a more inclusive environment for all family members by avoiding making an event for only females. And cross kind's social media, the voice and the invitations have been so inclusive, not specifying one parent over the other.
- I have to equip my self with trauma-informed practices and special care and education training to be in a better position doing this work.
- The volunteers preferred to be trained or from the community to relate with the nature of the condition.
- Maintaining this work needs fund and financial stability, which I will work on after my thesis. Kind gave the community a breath of exciting, engaging, meaningful experience that should live and continue to maintain, providing this feeling to families and their beloved ones with DS.

Kind's group photo

Intervention

Kind.

Kind, translated in Arabic, Tayeb, which also means “I am very well.” It is a platform that creates a culture of celebrating people with DS’s abilities through the arts. It provides diverse Art programs, workshops and engaging Online activities and challenges that show the local Saudi community how awesome and creative people with DS can be.

Kind will facilitate art and skill-based workshops for people with DS and create space for the community to gather. Each workshop will be designed with learning goals for the participants. Then Kind will leverage its website and social media to celebrate the participants’ arts and shed light on their skills. And to the larger Saudi community, Kind will contribute to raise awareness about the community of people with DS and honor their abilities.

Firas’s Airplan

How might Kind create an impact?

Kind hope to creat impact by:

- Help people with DS explore their talents and interests.
- Provide space for families to meet and build relationships.
- Give hope and motivate families of children with DS.
- Spotlight the abilities of people with DS and celebrate them.
- Raise the awareness of Down syndrome in the larger community.
- Indirectly help to inspiring role models.

M&E Plan

Project Overview

> **"People with Down syndrome have been subject to exclusion from society and from discrimination across the board — in educational settings, employment, and in their communities"**

David Tolleson
Executive Director of the National Down Syndrome Congress.

Faraj's Flowers

M&E Overview

Down syndrome has been the most commonly occurring genetic condition. Individuals born with DS possess varying degrees of cognitive delays, from very mild to severe. They face difficulties in verbal communication, which affects their confidence, learning, and engagement with the world. They need help with self-care like dressing and grooming. Some research suggests up to 39% of individuals with Down syndrome also have autism spectrum disorder. However, because it is the nearest condition to a typically developing child, they are under-served.

In our country Saudi Arabia, the occurrence percentage has exceeded the global rate. Down syndrome's estimated incidence is approximately I out of five hundred fifty births. Many families are sharing the same experience.
One of the most challenging tasks for all families with Down syndrome is Navigating support. The support provided for families with DS is coming from four primary resources,
The first is the healthcare system, where the family gets the news about their child's condition and the early moments of their journey start. Unfortunately, the healthcare system contributes to making this phase the hardest for families because of the lack of healthcare training on preparing the family for such news.
Second, most non-medical services are provided under the Ministry of Social Development regulation. They are often charities such as day centers and family support centers but neither consistent nor sustainable. This makes the family frustrated and concerned about the quality of their services.
Third, formal education for people with cognitive disabilities, such as inclusive education programs and vocational training, is provided by the Ministry of Education and still taking its shape.
Lastly is community support. It appears in two layers; one is the community of families with DS's where they mainly communicate over WhatsApp to keep connected. The second part of the community piece is the larger Saudi community, where awareness and acceptance contribute to the family's well-being and their beloved ones with DS.
I have reached more than ten families, and they are my guidance in doing the work. I have been working closely and co-creating my intervention with five families.
I found it very important to reach out to entities doing similar

Mohammad participation in call-for-art

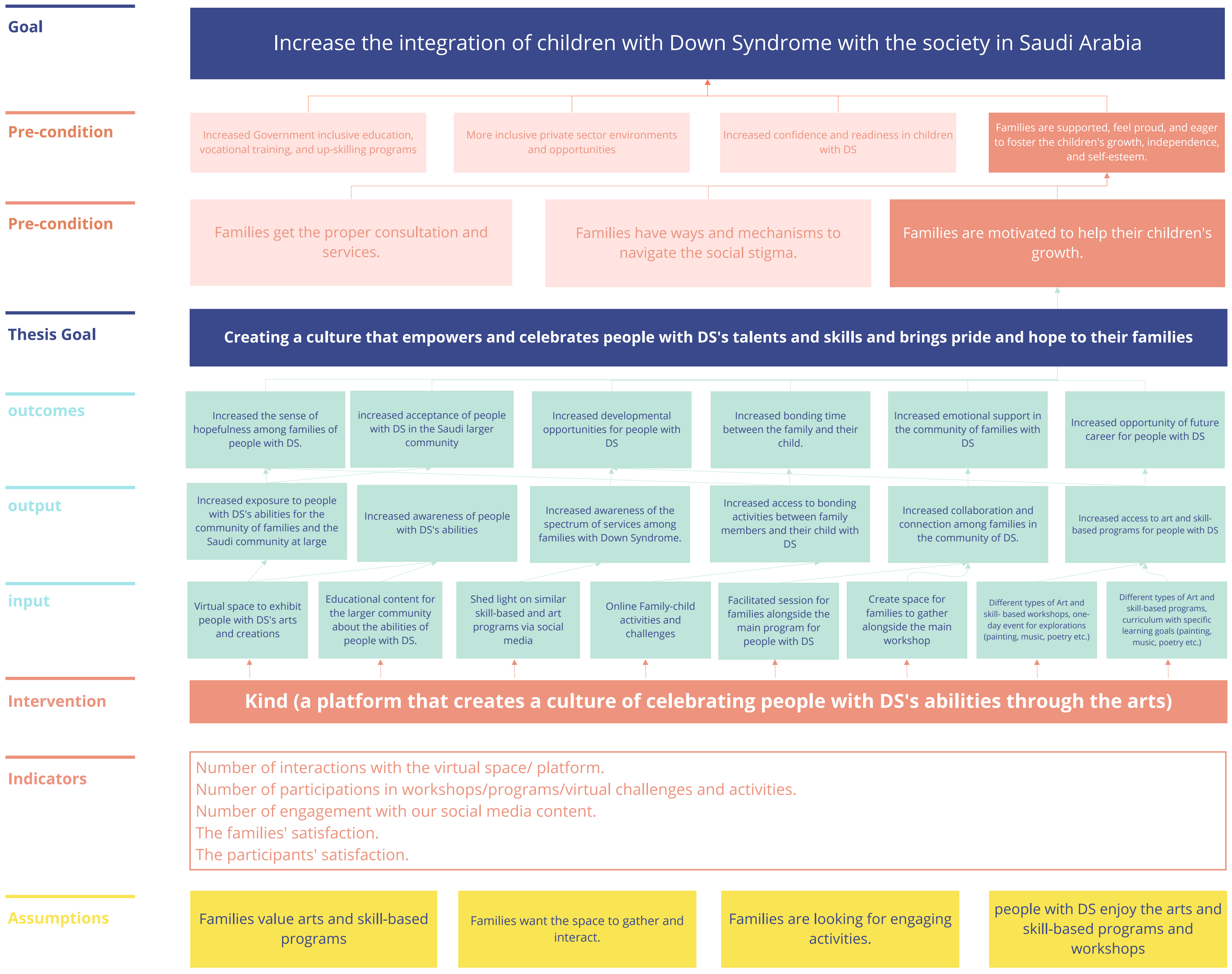
work to get insights from their practice. I have reached out to day-centers, advocacy associations, special education entities and met people working in the space to find the gaps and opportunities in supporting the community of families.

From over ten Online interviews, seven co-creation sessions and an Online cultural probe.
I have found that there are many efforts in helping and supporting people with DS and their families, but the need is still massive. Also, I found that families are frustrated over their children's future with DS and eager to see them growing healthier and practicing life and engaging with their surrounding as typically developed kids. Here I found an opportunity to fill a gap in the current support system.

What about bringing joy to families?
What about spreading hope and motivation among families?
What about concentrating on people with DS's abilities?
What about raising the Saudi community's awareness of DS?
These will lead to families feeling supported, proud, and eager to foster the children's growth. Which will help the manifestation of my ToC greater goal, to increase the integration of children with Down Syndrome with the society in Saudi Arabia?

Why art and skill-based programs?
There is a lack in the after school and extracurricular programs in the spectrum of services provided to people with down syndrome from age 4-22. Art area an area is untaped, very few and unsustainable initiatives have been done in the space.
While researching, I found demand from families to create more experiences for people with DS similar to the experiences available for typically developed people. The lack of these experiences limits the opportunity for exploration and self-discovery among people with disabilities, which affects their future career and future self-actualization.

ToC



Goal

Increase the integration of children with Down Syndrome with the society in Saudi Arabia

Pre-condition

Increased Government inclusive education, vocational training, and up-skilling programs

More inclusive private sector environments and opportunities

Increased confidence and readiness in children with DS

Families are supported, feel proud, and eager to foster the children's growth, independence, and self-esteem.

Pre-condition

Families get the proper consultation and services.

Families have ways and mechanisms to navigate the social stigma.

Families are motivated to help their children's growth.

Thesis Goal

Creating a culture that empowers and celebrates people with DS's talents and skills and brings pride and hope to their families

outcomes

Increased the sense of hopefulness among families of people with DS.

increased acceptance of people with DS in the Saudi larger community

Increased developmental opportunities for people with DS

Increased bonding time between the family and their child.

Increased emotional support in the community of families with DS

Increased opportunity of future career for people with DS

output

Increased exposure to people with DS's abilities for the community of families and the Saudi community at large

Increased awareness of people with DS's abilities

Increased awareness of the spectrum of services among families with Down Syndrome.

Increased access to bonding activities between family members and their child with DS

Increased collaboration and connection among families in the community of DS.

Increased access to art and skill-based programs for people with DS

input

Virtual space to exhibit people with DS's arts and creations

Educational content for the larger community about the abilities of people with DS.

Shed light on similar skill-based and art programs via social media

Online Family-child activities and challenges

Facilitated session for families alongside the main program for people with DS

Create space for families to gather alongside the main workshop

Different types of Art and skill- based workshops, one-day event for explorations (painting, music, poetry etc.)

Different types of Art and skill-based programs, curriculum with specific learning goals (painting, music, poetry etc.)

Intervention

Kind (a platform that creates a culture of celebrating people with DS's abilities through the arts)

Indicators

Number of interactions with the virtual space/ platform.
Number of participations in workshops/programs/virtual challenges and activities.
Number of engagement with our social media content.
The families' satisfaction.
The participants' satisfaction.

Assumptions

Families value arts and skill-based programs

Families want the space to gather and interact.

Families are looking for engaging activities.

people with DS enjoy the arts and skill-based programs and workshops

ToC Narrative

Faraj's Flowers

I am working with the community of families with DS to increase the integration of children with Down Syndrome with Saudi Arabia›s society. This lofty goal has significant preconditions for it to happen. One precondition is that the government gives more attention to cognitive disability populations by creating inclusive government education, vocational training, up-skilling programs, healthcare services, and more inclusion policies to serve their needs. Another precondition is the private sector›s contribution in providing more healthcare services, education programs, inclusive environments, and opportunities. The third precondition is the children with DS›s readiness and confidence to blend with society. One last precondition is that families feel supported, proud, and eager to foster the children›s growth, independence, and self-esteem, which I will focus on in my intervention.

In order for the community of families with children with Down syndrome to feel supported, proud, and eager to foster the children›s growth, independence, and self-esteem, they need the following:

First, families get the proper consultation and services:
One of the ways families feel supported is when they reach the proper consultation services. Navigating the services for people with disabilities here in Saudi Arabia has been a long struggle because of the messy structure of services and these services› shy advertisement. Families need help and support in this regard, and they always ask these questions about what is there for us?

Second, families have ways and mechanisms to navigate the social stigma:
Stigma, especially in eastern cultures, is a considerable obstacle to progress and growth. Families wrestle with shame and fear and all the dark thoughts associated with having a child with a disability. Openness to having sensitive stigma-related conversations could help the family release the stress and negative emotions and help them facilitate their way out of the stigmatized mindset.

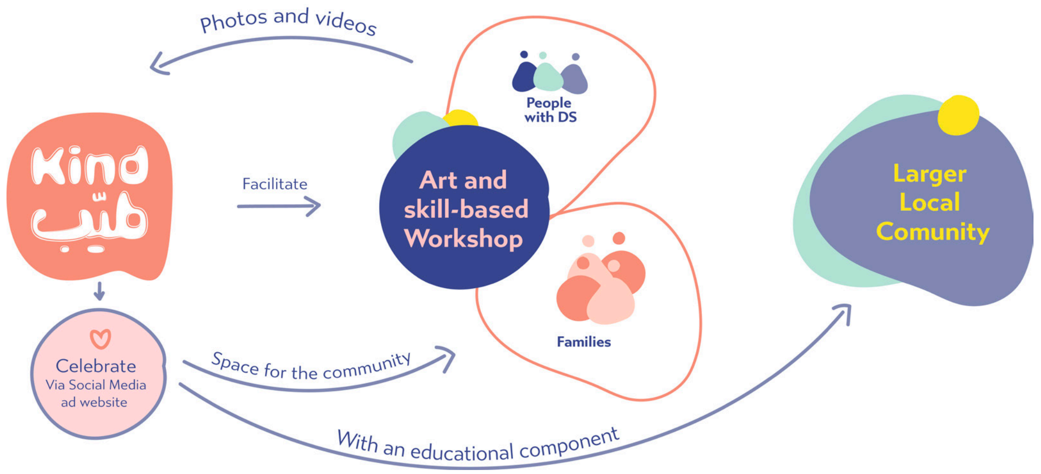
Finally, families are motivated to help their children›s growth:
Because of the problematic experience families go through, they struggle to find motivation. The excitement of their journey car-

ries many ups and downs. So fueling the family motivation i one of the conditions that make the family feel eager to contribute to their child›s growth and help him/her to be influential.

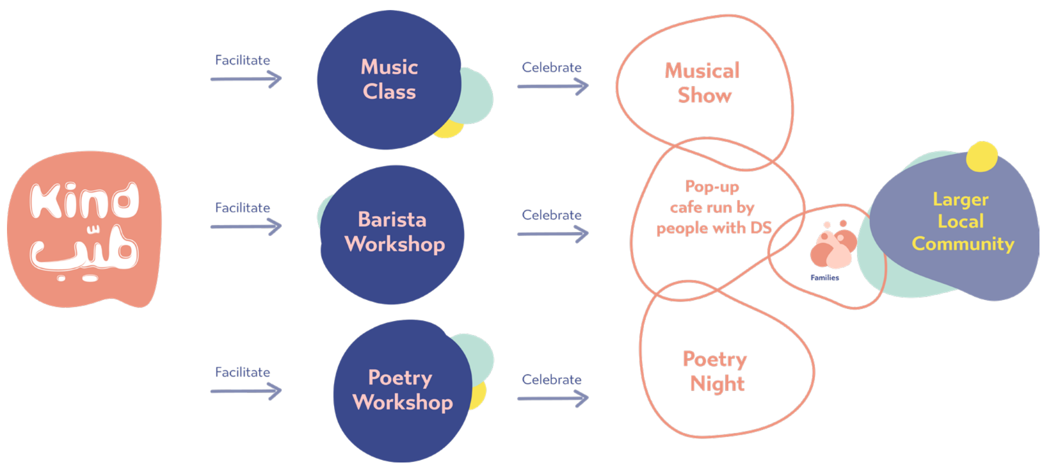
Eventually, here where my intervention is trying to make a change — my thesis›s focus on motivating the community of families with DS. The thesis goal is, creating a local culture that empowers and celebrates people with DS›s talents and skills and brings pride and hopes to their families.

The intervention

Kind, translated in Arabic, Tayeb, which also means “I’m very well.” It is a platform that creates a culture of celebrating people with DS’s abilities through the arts. It provides diverse Art programs, workshops and engaging Online activities and challenges that show the local Saudi community how awesome and creative people with DS can be. Kind will facilitate art and skill-based workshops for people with DS and create space for the community to gather. Each workshop will be designed with learning goals for the participants. Then Kind will leverage its website and social media to celebrate the participants’ arts and shed light on their skills. And to the larger Saudi community, Kind will contribute to raise awareness about the community of people with DS and honor their abilities.



Mohammad participation in call-for-art



Kind growth

Kind will grow and continue celebrating its community. Soon it will include more arts. It could be a tow months music class that produces a musical show people can attend. Kind could offer a Barista class then fund a pop-up cafe run by incredible people with DS. Kind could prepare a poetry workshop and arrange a poetry night through collaborations, fundraising, exhibitions, shows etc. It will grow to be the leader in enabling individuals with Down syndrome to be active members of their communities.

The intervention inputs

Regarding increasing families motivation

The intervention aims to create a culture of celebrating people with DS’s abilities, art, and creations by providing access to art and skill-based programs to explore their talents and potentials. In addition to the workshops and the programs, one input is about creating space and facilitated sessions for families to leverage their presence while waiting for their kids. The social media and the website will exhibit people’s with DS’s art and creations to the larger Saudi community and gather resources for places that provide unique experiences for people with disabilities to encourage these efforts and help the community get more exposure. The

intervention will create Online activities and challenges open for the wider community all around the kingdom of Saudi Arabia. All the outcomes of these challenges will be shared and celebrated with our community and introduced to the Saudi larger community to draw attention to our beloved community of people with DS. When the families see other families connect and engage, this might motivate them to pick up some activities and benefit from the power of the community. In the long term, spending quality time with the child with DS will entertain the family and help them stay motivated and connected.

Assumptions

- Families value arts and skill-based programs
- Families want the space to gather and interact.
- Families are looking for engaging activities.
- People with DS enjoy the arts and skill-based programs and workshops.

Log Frame

Faraj's Flowers

Inputs	Activities	Outputs	Outcomes	Goals
Team: ▪ Designers ▪ Amwaj ▪ Partner organization **Facilitators:** ▪ Amwaj ▪ An artist, Reem **Volunteers:**	**Co-creation:** ▪ Calls with the community of families to ideate about the content of Kind and the platforms. ▪ A deck proposal includes the wire frames and other details sent to the community via WhatsApp to comment on. ▪ Zoom meeting with family members to test the usability and functionality of the component of Kind. **Call-out for art:** ▪ Competition for the community to join the creation process of the visual language. People with DS's drawings created the visual identity of Kind. ▪ Share back to the community the application of their art. ▪ Give incentives to participants and build Kind's social network. **Art workshop:** ▪ Create an in-person draw together experience for people with DS and their families. ▪ Create space for	**Co-creation:** ▪ Instagram ▪ Twitter ▪ Webpage **Call-out for Art:** ▪ 16 drawings ▪ Kind's visual identity ▪ Branding assets ▪ Social media content **Art workshop:** ▪ 2 hours workshop	**For people with DS:** ▪ New experience with colors. ▪ Facilitated art workshop with outcomes. ▪ Joyful time ▪ Discover their relationship with a specific type of art (painting) ▪ Training on drawing certain shapes using certain techniques **For families of people with DS:** ▪ A place to gather and connect with the families. ▪ Share quality time with their kids. ▪ Sens of hope for equal opportunity. ▪ Source of pride from the social media streaming and celebration.	- Increased opportunity of future career for people with DS - Increased emotional support in the community of families with DS - Increased bonding time between the family and their child. - Increased developmental opportunities for people with DS - Increased acceptance of people with DS in the Saudi larger community - Increased the sense of hopefulness among families of people with DS.

Monitoring

Prototyping questions

- How do families interact with Online materials?
- How do families respond to instructions about new ideas or concepts?
- What do families think about art programs for their kids with DS?
- How do families deal with Online registrations?
- How do families interact with each other in a space that gathers them?
- What conversations emerged from the community gathering?
- What do people with DS think about art?
- How do people with DS follow the artist›s instructions?
- What do people with DS need to cultivate their exploration with different arts?
- What makes families interact with a call for art?
- How do families feel about celebrating their kids' art through social media?
- What do people think about creating new experiences and opportunities for their kids?
- What do families think about the impact of such programs and workshops on their children›s development?

Faraj's Flowers

Inputs	Monitoring Questions
Painting together Workshops	▪ How many people registered? ▪ How many people interact with the announcement? ▪ How many participants stayed to the end? ▪ How many participants achieved the workshop goal? ▪ How many families engaged with the community building side activity? ▪ How do families use their time being around? ▪ What is the ratio of volunteers to participants? ▪ How many complete the evaluation? ▪ How do families respond to social media streaming? ▪ How many kids/participants expressed their excitement? ▪ To what extent the kids/participants were engaged with the content of the workshop? ▪ To what extant families think this type of workshops are helpful for engaging their children with the community?
Online activity	▪ How many people registered? ▪ How many people interact with the announcement? ▪ How many families did the activity? ▪ How many family shared their activity outcomes? ▪ How many family filled the evaluation?

Evaluation

Faraj's Flowers

Indicators

Quantitative

- Number of participants in workshops/programs/virtual challenges and activities.
- Number of interactions with the website.
- Number of engagement with our social media content.
- Number of survey compilation.
- Number of smiles created.
- How long those smiles kept up.
- Conversations among families.
- Staying beyond the time.
- The families' satisfaction. (on a scale)
- The participants' satisfaction. (On a scale)
- Number of attention from other organizations.
- Number of collaborations.
- Number of opportunities created for people with DS.
- Number of talents or hobbies discovered.

Qualitative

- Feeling of hope - the shift from they can't paint to they enjoyed it and they can learn and find their passion.
- Feeling a sense of community, enjoying the gathering, wanting more of these activities, sharing anecdotes and stories.
- The families' satisfaction. How do families describe the experience?

Outcomes	Evaluation Questions	Method
- Increased the sense of hopefulness among families of people with DS. - Increased emotional support in the community of families with DS	▪ How do you see this workshop/program benefiting your child with DS? ▪ How do you feel seeing your child with DS has a space to express a specific type of art? ▪ How does interacting with other families impact your perspective of your own journey with your child? ▪ To what extent are you in a relationship with another family you met in the program?	Post activity Interview with families
- Increased bonding time between the family and their child.	▪ How many hours did this activity take? ▪ How many family members participated? ▪ How do you see your child use his/her talent? ▪ How do feel about doing similar activities? ▪ What was you child reaction to the activity?	Online survey for families
- Increased opportunity of future career for people with DS	▪ To what extent this intervention helped people with down syndrome to build a career? ▪ To what extent this intervention helped shifting the thinking about people with DS's abilities?	▪ Keeping a track and good

Evaluation questions

- How does celebrating people with DS's art is motivating families?
- How does gathering in the place of the workshop help families feel a sense of community?
- How does art programs for people with DS are helping them explore their passion and develop their skills?
- How do art and skill-based workshops participate in creating a career for people with DS?
- How does celebrating people with DS's abilities affect the acceptance of the Saudi community and raise awareness of people with DS?

~

Kind

By Amwaj Alzahrani
amwaj.alzahrani@gmail.com
April 28th, 2021