



TCOP September Creating Home Meeting

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SPEAKERS

Eric Goll



Eric Goll 00:00

So really excited to have everyone here with us. And so just a little intro for myself and then we'll jump right into things. My name is Eric Goll. I'm a sibling. So I have an older sister, Sarah with a developmental disability. And for the last two years, I've had the privilege of really kind of walking alongside and working with the eight families of the Oak Park family group and you're going to hear from five of those families tonight. Three are going to go a little bit more depth into their story and their journey over the last two years of creating home with their son or daughter with a developmental disability so it's really been an honor for me to work with those families and I also support other families as well so I do that online and really helping people developmental disabilities in their families to create a really positive forward thinking vision, and to help their son or daughter really gain their independence and live their best life. So that's a little bit about me and if everyone can stay on mute. That would be awesome. Okay, so before we get started, I just want to do a land acknowledgement. And this land acknowledgement is for the Oakville area so if you're not in the local area just appreciate that you could maybe acknowledge the land that you are on. So, Hamilton as we know it today is rich in history and modern traditions of the First Nations and maytee from the lands of the anishnaabe Bay, the Adirondacks, and the Keaton have shown a and the Met, sir. The maytee and the land surrounding the great lakes are steeped in indigenous history. As we gather today on these treaty lands, we're in solidarity with our indigenous brothers and sisters and honor and respect the four directions land waters plants and animals and ancestors that walk before us, and all of the wonderful elements of creation that exist. So, thank you. So, just a

really quick agenda for our time together today. We're going to kick it off by learning and sharing with you a little bit more about the Oak Park family group. And folks if you can stay on mute. That would be awesome. So, just to prevent background noise. It's really helpful so we're gonna learn more about the park family group methodology and how that really came together and the story behind it so you're gonna hear from Karen and Vicki on that. You're going to hear three families journeys on creating home with their son or daughter. You are going to be able to connect with some other families. We're going to jump into some breakout rooms. So you can share your experiences and connect with others, they're going to do some q&a, so we're going to try and answer as many questions as possible. So there's some really good stuff, it's going to be an action packed 90 minutes here so really excited for that so I just want to quickly turn it over to Vicki McCallum, the founder of the Oak Park. Family Group and the community, Oak Park so Vicki, I'll hand it over to you to do a bit of housekeeping here.



15:36

Great, thanks very much Eric. This is the first meeting for the community park in quite a number of months. Because of the pandemic so I'm really happy to be able to do this now and it's great to have those of you who have been to previous community park meetings here, and it's also awesome to have some new people joining along to. We're a family network for individuals for families that have individuals with a developmental disability for adults and teens. So, we have been busy in the past few months with the Oak Park family group. But our programs that we are always running we had to hit the pause button on that, but they will be coming back as soon as it's safe to do so things like sign language and fitness. And I want to take this time to thank the Oakville Community Foundation because they have funded. Our next program programs. And I think it's, it's going to be a great bunch of bunch of programs and some will be new. So if you are not on our email list and you would like to be to get news about programs and meetings just google the community Oak Park, and you will see how to contact us there. Meet meetings we usually have five a year and we will again this year, our next one will be towards the end of November, and it will be online as well. It's a really important meeting we're going to be talking about the future of the community Oak Park, and how we can make this group sustainable and we need your help for that. So if you if there's if you need any information from us on how you can help out. We will be discussing that in November, you can wait until then, but if you would like some more information please. Again, just send us a message, and we'll get in touch with you and you can partner up with other people and to make it like very small in regard to time commitments. So, thanks. Once again, I'll pass it to you, Eric.



Eric Goll 17:36

Awesome. Thank you, Vicki, two quick things that I forgot to mention was, if it's helpful for you to have close cap closed captioning so for the words to be coming up on your screen as we're speaking them. You'll see this live otter.ai live, live otter.ai live notes on your screen. If you click on the drop down, and then click on View stream on otter.ai live notes, it'll give you a live closed captioning so our live transcription. It'll open a second window in a web browser for you so you'll kind of have to toggle the screens side by side with zoom in a web browser, but many people have found that helpful so if that's helpful to you then, then you can then you can get that we're also recording. Just to let everybody know. Okay, so really to help kind of set the stage for everyone. I want to show just a short video that the Oak Park family group pulled together, right before lockdown. So filming I think completed like maybe a week here a couple weeks right before, like the week before lockdown so I'm going to share that with you and. And then we're going to hear from the really the leaders of the Oak Park family group and they're going to share kind of some more details around the methodology and how the Oak Park family group is set up. So, just let me pull this video up for us here. Okay, so everyone should hopefully be aware. Let me know in the chat, if this



19:16

volume is good.



19:21

I'm thinking McCallum.



19:23

I'm Karen Alexander, and we're founders of the Oak Park family group, the Oak



19:27

Park family group consists of eight families, and we all have a son or daughter with a developmental disability. And we've been spending the last couple of years looking for sense of home and belonging and community for them. And



19:41

we're working very hard together to create inclusive lives and sustainable future for our loved ones.



19:53

The Oak Park family group was started as a result of many sleepless nights I knew that I needed some support from other families I knew that I needed resources. And all I knew at that point really was what I didn't want I didn't want to group home I wanted my son to be able to make his own decisions. So I started a family network with just a few people and it's grown a lot. And we've all been supporting each other since.



20:25

Nick was somewhat cocooned into that protective family environment, and we reached a point where we were aging we were getting to be in our 60s. And with that being said, if something should happen to us, what happens, moving forward and that's what basically led us to where we are today again. It's been a remarkable journey for the two years, incredible journey.



20:51

What makes this model work and one of the key components is making a lot of community connections so we're building lots of relationships and partnerships with community organizations. Another component that makes it work is having our community facilitator Eric. He's very instrumental he's worked with each family in building the vision and plan for their family member on how they want to live in their community. And it's just so instrumental because it makes them more capable and reduces the amount of support they need in the future. What surprised me is that I thought Jacqueline wasn't ready but in fact, she just hadn't been given the opportunity or experience, and it was her parents that needed to get out of the way.



21:46

Yeah. Can you tell me where the goldfish are.



21:49

It's



21:51

right here.



21:55

Great. Thank you.



22:03

Anything is your own decision, he is he can decide when you are comfortable when it's time to find your own. I guess maybe your own place.



Eric Goll 22:18

So there's been some really incredible progress in terms of growth that individuals have had that are involved with it with the family group, including, you know, for all of them being a tenant. And then, many individuals have improved their employment situation so whether it's getting their very first job or getting more hours at their current job and expanding their, their role in their current job so in the community, there's been some really cool roles that people have built as well so volunteering to help run a food bank for example where we have one woman that's starting to build a role at a local ski club, there's so much that everyone has to offer. Everyone has their gifts, and their strengths, and we can all learn a lot from each other, even if we have differences so it's a win win for for everyone, when everyone's included.



23:20

I think without the support if you do part group, we probably wouldn't be where we are today, right now with Noah, living independently, no kept on saying that he wanted to live on his own. He wanted to get his own place and have more independence, and we had this opportunity, and he wanted to choose where he wanted to live and who he wanted to live with you want to be part of a whole community and and meet people in the community and just be very inclusive in the community so we're very pleased with, with

the growth that he's made



23:53

my daily routine is very hard to try new stuff. I can invite you, I want to I can vote my parents.



24:07

Too often, too many of us parents are sitting back you're thinking of so many reasons as to why it can't work. Don't hold back. If you don't overcome it. and you're gonna be 70 and 80 years old, and they're going to be 40 years old. And where are we at now. Don't wait too long. Again, it really comes down to that group support. If you have that group, you've at least got someone to fall back on.



24:39

In any community, you need anchors in the community that are your friends and associates and people you can count on to and places you can go and things you can do, and by living independently, he's developed those on his own.



24:52

because people start you know just just understanding who he is, as a person and respecting him as a human being and he feels that he has a purpose. In, in the community and in this life.



25:07

It's really important with this model that the individuals have choice so they have choice where they live, how they want to live and who they live with and choice around their roles and community. The most important thing, I feel that makes this model work are the eight families themselves. We're dedicated to having each other's back in the future, we make decisions together, and we get together socially and informal meetings, and you don't feel alone anymore.



26:03

All right.



Eric Goll 26:06

Pretty awesome. Right. I love. Darlene comments here. Oh my god, cheery mess here This is amazing. I hear you there, it, it makes me smile every time I see this video so you might be wondering like how right like how did this, how did these eight families make this happen. So we're gonna start to dive into that so I'm gonna hand it over to Vicki here. Vicki you've got some slides so I'll get those up. Just give me one



26:41

sec.



Eric Goll 26:43

Vicki, let me welcome you in here so like to welcome Vicki McCallum back in. So Vicki, the floor is yours. I just need a second to get the slides up.



26:54

Okay. Well, I can start talking about our bodies.



26:59

There we go.



27:01

So we



27:02

got together over two years ago, and we wrote a proposal for this model, and right from the beginning. We've obviously been thinking about it a long time before that, but we

decided that we needed to decide on what our values would be. We knew that we didn't want congregate living situations. We were trying to save money as much as we could. So we didn't want to work with any expensive builds. We wanted the funding to be individualized. The families on knew we, we pulled the families from our larger network that community park, we found eight families that were all ready to go. And they knew that they had to be involved that this was going to be a lifetime group effort. We all wanted our sons and daughters to have as much autonomy and choice as possible. We wanted to make sure they had the right kind of support not too much, not too little. And ultimately we really wanted to create rules and community and relationships, mostly unpaid for our sons and daughters so that they could like all of us have a sense that they're contributing. And they, they do contribute to have a sense that they belong in the photo there is my son Julian at his job and underneath this Karen's daughter Jacqueline at the, at her ski club. So the next three slides are just a little bit more information about our model. There are three major components for our model. First one is the family, the family group the families themselves. Next is community and the importance of community and third is facilitation. So we saw on the video some of the formal meetings we have we have mum chats and, you know, most of them were together before the pandemic but we're still doing all of them online so we're staying very connected. We have, we're having face to face social gatherings and we will do that again at some point. And we have formal and informal meetings where we talk about our successes are challenges. We help each other make decisions. We're really always learning from each other. I've gone into some of the mom chats or family meetings sometimes feeling dejected and I know the others have as well and, and they're always the first to remind me though what progress, Julian has made or that we have made together as a group and I always feel so much better by the end of it, and we're all not going through the exact same thing but very very similar things at the same time so it's such a such, it's such a big support, and in the future with this family network we want to start pulling in some siblings, cousins whoever might be taking over for us when we're unable to do so so that they also have this other family network larger family network to depend on and have oversight, as well. So next slide our next major component is the community support. So you can see the list there. We've made and are starting to make a lot of connections and community. We're also working with the region on portable housing subsidies we connected with other family networks. We have our, our members join programs but we also through our larger network have classes like the one their American sign language classes where we have great numbers from the community in such a wide variety of people from the community join in. So we're really looking at a macro approach to the community. We're trying to soften community spaces, make them more well, welcoming and have a sense of belonging for everyone, not just our family members. So the last key component to this model is the community facilitator. So the role of our facilitator is that well, there's many roles with the facilitator, but at the very beginning. He sat down with all of our, our family members, and for one of the first times it

was to discuss positive things in their lives. It was to discuss, where they want to go what they want to see in the future for themselves what they love to do what would be a great, great vision for their life. In the short term and long term.



31:28

So, after a great vision is built for each of the eight people in our group, we all found homes, and the facilitator helped us to transition. It was, as you can imagine, challenging but also wonderful at the same time. And then the facilitator's role is also to find valued roles in community that would hopefully even sometimes lead to leadership roles. The facilitator also helps us with decision making it might be one to one, it might be with this individual's family or the Oak Park family group helping out, and the facilitator can also help to train supporters so that they're also looking out for relationships and community, and the end, he facilitates all our formal and informal meetings, and that role is also another oversight role, it helps between the roles and community and facilitation and getting other family members involved. We've also set up support circles that the role of facilitators also oversees going forward for our sons and daughters and it helps to make this sustainable model. So thanks for listening, and I'm going to pass it to Karen Alexander now.



32:47

Thank you, Vicki, there's been so many benefits to what we've done but with respect to quality of life. Our family members' lives have improved exponentially. Each one shows where with who and how they live their capability and pride and being responsible for their home and life is just something to behold. That's Julian in the photo on the left, helping to teach sign language. And on the right is Nick at a potluck dinner that he helps run. Other roles held include working at a drop-in program, the food bank ski group, assisting seniors, and being a good neighbor. Some have support circles set up with people who want to be part of their lives and help support their decision making, whether it's pursuing goals tackling challenges or transitions and circle members can also provide continuity of support when parents can't. So not only do our sons and daughters, enjoy their responsibilities, increased relationships and valued roles that the community benefits from each individual's gifts contributions and diversity. They're able to live full lives while reducing the entire family stress and helping avoid future crisis. And next slide please. Yeah, so there's also health and safety benefits so having their own homes and roles and community it mitigates the potential for isolation dissatisfaction and disease that can occur and congregated living relationships improve one's mental well being and helps keep people safe, as there are more people who know, and look out for them. So the

benefits include safer, happier lives better health and lower medical costs for the individuals and their entire family. Next slide please. So our call to action is to share the merits of our model as an option for other families to support their loved ones have choice, a home of their own and live life fully, and to inspire families to consider working together, so they can benefit from each other's learnings inspiration, support and sustain each other's journeys. And we also want to encourage the government to provide direct funding to families so they can apply resources in the manner that best supports their family member. It's worth noting that our model costs less than 50% of traditional residential services, and this does not take into account the cost of a future crisis. We're taking a proactive approach, because if we don't, we will also end up in crisis. And when that happens, the entire family is devastated. Next slide arc. Here's some of our family members in this collage, going from top left to right there said doing some cleaning. And next to him is Richard in his new home. And there's Jacqueline doing her laundry. Below is Julian learning to take the bus, Nick volunteering at the weekly Park run and Ben loving himself into his first apartment. They've all worked so hard to make big change in their lives and they're starting to enjoy their successes. Eric I'll turn it over to you now for the next part of the meeting Thank you everyone.



36:41

You're on mute are



Eric Goll 36:42

talking on mute. All right. Thanks Vicki and Karen. Hopefully that starts to give you a bit of an idea or a bit more of an idea of really how these eight families. Worked kind of within their own family but also worked together. And there's some great questions going on in the chat so we're gonna have a question and answer period but keep using the chat keep keep answering questions. Vicki and Karen and some other folks might pop in there and answer some one off questions but keep asking your questions, and we're going to have a question and answer period so if you can just stay on mute. For now, that'd be helpful. There'll be a time where you can unmute yourself we'll let you know. Okay, so I want to welcome cam and Deb on so you're going to hear from three families, and they're going to share a little bit more about their experience over the last two years, and kind of what they've done with their own family, and give you some more insights so I see you're unmuted there so welcome can and death, or is it just cam or just death I think I saw both of you. But welcome



37:53

cam will do the talking Debbie I'll make sure that I get everything right. Okay, I've got a few pages of notes here about our story and I think I've got way too much, but I'll try and focus on stuff that hasn't already been talked about in terms of how the Oak Park family group is structured and whatnot. Our story is that our, our oldest son Ben is 28 years old, and he has a developmental delay. My wife Debbie and I are now retired and Ben has a younger brother. Mitchell who's 25, and Mitchell is a typical guy, and he's finishing a university program right now. And if I guess, to sort of start at the beginning of our experience in Oakville, we moved to Oakville, when Ben was about nine years old. So we, it's really his hometown he went to school in Oakville, his friends are there. He knows the community Well, he can get around on transit. Ben drives a car and he knows how to get around the community that way as well. You can tell from the picture I think that he's a bit of a funny guy, and he's very friendly. One of the issues for our kids with disabilities is social isolation, but that's not really an issue for Ben. He's very gregarious really likes to get out there, has a wide circle of friends.



39:32

Advocates for himself, all the time,



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and has a real social orientation. His disabilities are primarily intellectual and academic, he, he was diagnosed at an early age with a global developmental delay, but with no known cause, so he doesn't have, he was, he doesn't have cerebral palsy. He doesn't have any major physical disabilities, he walks in, he talks and he drives a car, but he was slow to hit his developmental milestones and continues to struggle with some intellectual



40:13

handicaps



40:16

in 2018 when we first met though part family group, or what became the old part family group. Ben was living at home with us and his brother. And we had moved from the Oakville community, not too far away about 30 minutes away we live in Carlisle, which is just north of Burlington, and Ben was living at home, but driving almost every day into

Oakville to see his friends, and to occasionally work. Ben has stroke he struggled to keep a regular job. But he really likes doing odd jobs, and he occasionally finds those and works with people and helping out usually in a sort of casual labor. Kind of circumstance. I know that probably sounds risky but he's actually quite good at it.



41:16

We knew that we wanted to help band to live in his own place. But we didn't know when that was going to happen. And whatever it was, we didn't really think too seriously about what he would need either. And it wasn't until we started going through the process with the park family group that we began to take an inventory of what it was that Ben wanted and what he would need. And up until that time we hadn't really thought seriously about that and I think that that would have led us without becoming involved in this group, we would probably still be thinking about it the same way, and never having really considered what it would take and the Oak Park family group, really represented a bit of a challenge for us because the question was, are you ready to help your child, move into their own home. And we said yes and off we went.



42:18

And



42:21

all of a sudden we were on the clock, we were trying to find a place and do so as quickly as we could. And when we, when we started looking for it we found it. So, we, we found an apartment. That was a that we thought was a real friendly setting for Ben. It was in our old neighborhood in Oakville. So Ben knew it well and so did we, the landlords lived on site, and they were a family similar age to us with kids similar age to our boys, their kids are off at school and work and whatnot. And then would be living in an apartment in the basement. And we just we thought it was great because it had the kind of support and oversight that we gave us some comfort. And yet it was independent enough that Ben felt like he was on his own. But we thought Ben was going to need a ton of help, because living at home. If he had work to do. He would struggle to get up and out and get out the door. He wouldn't do any food preparation or feed himself. He was always late it was always an argument to get him out the door on time to get anywhere. And it just seemed like that was going to be a really big need. And once he got into his own place. He very quickly changed his behavior, set his own alarm. We tried to get him to set up a home and we just couldn't get him to do it, but once he had to do it. Once it was up to him while he started

to do it. And the next thing we know he's bragging about being to work it ahead of the other guys. And so he's there early, instead of late which he was when he was living at home, and all of the. All of the supports that we thought were that we were sure he would need. He hasn't needed. That doesn't mean he doesn't need any support. But all of the challenges that we face are ones that we hadn't contemplated. And the ones that we did contemplate Ben showed us that he didn't actually need that. And I think that was that's mostly a sign of. When he was living at home. We took a lot of responsibility for his life, and consequently he didn't take as much. And now that he's on his own. He takes a lot more responsibility for his well being. And we're left out of the picture a little bit more. And that kind of gets us to where we are today with Ben he's doing fine. As I say it's not there aren't It's terrible. There are bumps in the road. But they would be there anyway and they're new bumps and many of the ones that we struggled with when Ben was living at home. We don't struggle with anymore, because he's grown and developed and become more independent. As a result.



Eric Goll 45:36

Yeah. Awesome, thanks CAD CAM for sharing and and Deb for being I put up a picture of Ben here beside me. So you might have seen that earlier on another slide but this has been cooking, when he was in his apartment, but, um, I think that's one of the things I've heard, I've heard you say a lot cameras that Ben always rises to the occasion when given the opportunity, and I think that's kind of a common theme that we've had as a group. When people are given the opportunity they rise to the opportunity so.



46:09

And I just want to say too but he's a 2% cognitive ability so he has intellectual disabilities quite substantial. And so we just thought this would never happen. And as, as much as I went to for years to groups like this to listen to what they had to say. And people were preparing for years I thought, you know, I never thought that we'd ever get to this point and if it wasn't for the support of others who are on the same page as I am. You know, and without expectation set by Eric, it wouldn't have happened for us I don't think



46:44

it was good to have the deadline. Yeah. Then we made a list and stuff started to happen.



Eric Goll 46:50

Yeah. Right on. Awesome, thanks for sharing Cameron Deb. Okay, so let's go to another family to hear from so you're gonna hear from two more families, and then we're going to jump into a breakout room so let's hear from Blair Blair if you're there, feel free to unmute yourself I got a picture of Nick up here in his role as a tail Walker



47:15

at



Eric Goll 47:16

his local walking group so Blair if you're there if you can unmute yourself left.



47:24

Okay. Can you hear me now.



Eric Goll 47:26

Yeah, we got your Go ahead.



47:27

Okay. Okay. Next, Nick 31. Today, and his journey started back in, let's say 2018. Nick has global developmentally delayed issues he's never been diagnosed to the school system, although every year they were trying to label neck, but we started back in 2018 beginning of the year. And we simply as a family just made the decision that we needed to act. At that time, Nick was 29 years old. And we as parents were, I guess at that time 57 and 59 nearing our 60s. So. Additionally, there were also things happening in our family as Nick's older brother was moving to Winnipeg and his younger sister along with her two kids, and her being a single parent. She was moving into her own place. So, while not really knowing how we were going to get Nick into some sort of Independent Living we simply just needed to decide to move forward. And we thought we'd be able to figure it out figure it out as we move, move forward. As I guess all of us in our own family we're making those life changes, or some life changes. I should point out here that my wife's oldest sister from Saskatchewan has always been telling Coleen since Nick was about 18 or 20, years old,

that we should consider some form of independent living for Nick, as they themselves have an adopted daughter, who has Down syndrome. And she's five years older than Nick, And back in the day when my wife Colleen was pregnant with our firstborn. We used to actually babysit Nina when she was a baby. So, there was a little bit of push from that end as well, but also the fact that we are from out of province have no family here in Ontario, being both from Saskatchewan and our family network is basically spread out from Manitoba to BC or all four provinces. We've been in Ontario since 1992. So, at that time we quickly jumped we found a one bedroom apartment, through a friend we knew. Move Nick in July of 18. July of 2018 without really having a plan again. But knowing we had to figure it out ourselves or do something here in life Timing is everything and perhaps with a little bit of luck came our way, when I actually I met Vicki through one of their we the community Oak Park meetings. At that time, there was discussion about trends



50:15

housing.



50:18

That was part of the objective. genda. So, this is where things really gain traction for NEC and ourselves. I call it a pilot project, obviously one of each of the selected participants, so also having keeping in mind. Nick was always dependent upon us. My wife and I, or his siblings, for most of his 20s. When he was done High School. Once we were in the old part family group program or project. This is where Eric really came into play on a regular weekly basis where let's say the effectiveness, or efficient planning of goals and objectives worked greatly, insofar as creating many desired end results. Eric's assistance guidance coaching understanding and encouragement along with next weekly support worker, this being paid supporter otherwise. Nick had basically blossom. This opportunity basically gave Nick the tools and what was created was an environment conducive to allow Nick to make his own decisions. Eric spent a lot of time with Nick and through community living Oh Phil job shadowing etc. Nick actually landed a part time job with Martino's he's been working there since April, 2019 now and where he works anywhere from 10 to 20 hours. He. Um, I should know here that when Nick was nearing time to vacate high school we took Nick to community living tabs, thinking that that might be a good place to start after high school. But it was funny Nikki, she had no desire whatsoever. Anyways, the other thing to mention as well as with Eric's ongoing support. It took Nick quite a while and coax into us and learn let's say the bus system here in Oakville or the public transit and Eric did a remarkable job and was very patient with Nick and overcoming all kinds of obstacles. In a nutshell here, we really as parents, at times become the obstacles for our own children's

growth where we are overprotective at times Nick would resist or he would be scared to try new things, but through these last two years. When I say we, being in this case Eric old Park family group, we as parents and Nick, more importantly, himself, have opened up so many new avenues which have allowed Nick himself to flourish where he has also shown us where he can actually do it. Nick has been a regular volunteer at Oak Park neighborhood center with weekly Food Bank and seniors program initiatives. He was an active member with the, with the local community park run, it's a global thing. It's a weekly five kilometer walk and run, obviously, now it's COVID has stopped, some of that. But pre COVID he was an active participant in local community, gym, swimming pool, yoga classes, and through opmc Nick has led two programs one being the drop in, and the other a monthly community potluck which was touched upon in the video to some degree,



54:05

and



54:07

funny thing Nick keeps on asking today. He so looking forward to doing it again, keeps on asking when is this COVID stuff going to stop. But all in all, Nick is doing his own thing now his own choice his own decisions he makes. It's been a remarkable journey, and I should also mention it support worker was great. She got Nick into Facebook where Nick now keeps in touch with his cousins out west of the prairies, Nick is also taking online Spanish classes, as both Nick and his supporter are so support worker Marissa still continued to this day. We took Nick to Mexico back in January, 2019, and he wants to learn more Spanish before making that neck trip next year back to Mexico. The support worker also or neck support worker also got Nick into some additional cooking recipes, which to this day. Nick's five year old and seven year old niece and nephew, say, uncle Mickey makes the best race in the world. A few key learnings quickly to point out, we as parents assume that Nick could not do things by itself, we have to learn to expect that our expectations were or perhaps are not necessarily really Nick's expectations. We needed to learn to let Nick do things allow him to fail and try again and again and again and yes repetition is required here. Most times Nick has shown a willingness to fail. And through that failure learns more many hard lessons learned and although there's more for Nick to learn and accomplish two of the most recent successes, actually include finally Nick is able to now start using his debit card. And he's doing his own laundry by himself. Also to close out here, I should say that from the start of the program here. We were looking at eight to 10 hours weekly of support for Nick, where necessary or required, and we've got that down to no more than four hours a week, which is a significant improvement. And although there's

always more need or continuing need for more support. Nick's basically got it to the point point where he loves where he's at today. And of Nick's story.



Eric Goll 56:37

Awesome, thanks Claire, it's, it's been awesome to watch, Nick flourish as you mentioned and become his own person, and just watch his confidence rise so thanks for, for sharing. You're welcome. Awesome. Okay, we will go to the last family that's going to share their story and then. Yeah, and then we'll go to the next part so let's welcome, Jeff and Natalie I'll put a picture up here, of Noah, so you can see Noah here at his front door and Jeff and Natalie welcome.



57:09

Thank you. Thanks Eric.



57:12

I'm obviously Jeff and this would be Natalie, our son Noah is 28, and he has an older brother, 30 who went off to university at right after high school. And so he's been out of the house for the least the last 10 years. I think know is always been interested in the independence that Nathan demonstrated. And now they recognize that as well. I certainly was slow to the table, not wanting my, my, my card playing buddy and game playing pal, know what to leave. But with Navis determination. We realized that this is quite an adventure. Noah has a dual diagnosis development delayed and autism. He's very physically active. He plays six Special Olympic sports. He gets around quite well on his bicycles. And he was working part time. And thanks to the contribution of our facilitator. Eric developed a better work regimen, where he was working consistently three days a week. So I think it. Seeing Noah's growth and and his desire to move, move on. Sort of paved the way for us to start looking and thinking we certainly had a hard time with putting it all together, And we felt that for Noah fairly social guy who may need some, some guidance in terms of domestic functions, maybe having a roommate or two would be a great way to motivate him to participate and to keep his place and himself in some form of hygiene. So, as I say, Natalie and I knew that they were ready. I think over the wild we've learned that he's certainly capable he's has his own set of rules, and enjoyed the independence that he got when now that I would go out, you know for overnight so we knew we have the ability. Yeah, and and i think Natalie sort of paved the way by having assistance. Teaching Noah, how to keep, keep his laundry organized keep it clean, start doing some cooking. So that was already in place before we really got hooked up with a

with a place for Noah, again with that backdrop of we thought we would benefit if he had somebody in the home with them. In terms of economics that was certainly an advantage to have two of us. Renting a property. And then we took on a student rental. That also helped and to encourage the student. We offered well if he if he participates with the, the, the roommates. He can work towards getting some of his rent decreased from the hours that he contributes in the home, assisting the young men to to get things organized and stay clear. In terms of our learns. I think certainly patients, was one of the biggest ones. I was be known that would be there three to four times a week at the beginning. Now it's three to four times a month. And we're often begging him When are you coming home Noah He is such. You know embraced his independence, his ability to shop for himself to look after for himself. So we asked him when he's the next coming around and he'll always sort of, you know, you know, I'll let you know, just like his big brother. So, Natalie Would you like to add anything to that,



1:01:23

yeah just through the whole process. I mean we were looking for that then we knew that Noah wanted to have his own place and you have to voice that so when we found the park group, and they suggest rock gave us this opportunity we jumped on it I got I couldn't get to the back of the room, fast enough to put our name on the list. And, yeah, and from there the transition wasn't easy. I mean, it took time, we probably had a good whole year where we had workers coming into the home to help prepare Noah to become more independent learning his laundry skills learning how to cook and and take care of himself. And during that time you know there was some anxiety at first he was really keen to move out and then he was sort of like oh it's time got closer he wasn't really sure. And then he was and then he wasn't and then he was and so off he went but the transition was actually slow he didn't move in as soon as we got he got his home, he didn't. He moved in slowly, and we had to reassure him that you know what we're here for you where it's not jumping you off and in selling our house and moving away that we would still remain in our home and we'd be close enough to him that he could ride his bike back home and he would. And that really that really helped in his ability to sort of move forward and and follow his dream of living on his own and we're very, very proud of, of how he has



1:02:47

progressed grown and progressed through this whole process.



Eric Goll 1:02:52

Yeah. Thanks Eric. Yeah Thanks Jeff and Natalie and again it's just been awesome to see Noah's growth and I think one of the things that stands out in my mind is maybe Natalie you're sharing with us and I think it's okay to share this but you're sharing how Noah invited the both of you over for dinner and like he fully prepared dinner and you're like, wow, like, first time that happened that was that was really cool moment.



1:03:19

And it was delicious I was blown away it was it was excellent and just the way he, I guess he's watched us entertain. And so he just the way he entertained us was quite nice you know he made sure he had, you know, the wine for me and the beer for Jeff and he wanted us to to enjoy well he cooked and then he served us dinner and he had dessert and it was a really lovely evening and we are quite Preston. Yeah, it's been great.



Eric Goll 1:03:43

Yeah. Awesome. Cool. Thanks for sharing, Jeff and Natalie, and we will probably hear for some of these families again so you're gonna have an opportunity to ask them some questions. I'm just going to put this picture of Noah down here. So, um, I want to give you the opportunity to connect with some other families and the purpose of that is just to share a little bit about yourself, your family, learn a little bit about some other families. And so we're going to jump into breakout rooms so you're gonna have six people in your breakout room, and we're going to be in a breakout rooms for 12 minutes total. So, each person is going to get two minutes of airtime right so I know it gets really easy to talk and you know we could talk for an hour I'm sure we could all talk for an hour about our family at least probably days, but you're at two minutes. So with your two minutes to share your name. A little bit about your family, and your situation. And if you can share also maybe what your biggest question is around creating a home. So, so your name, your, a little bit about your family, and the biggest question you were trying to answer around creating a home. Yeah, I as I said we could all talk for a day right so not enough but hopefully it gave you the opportunity to connect a little bit, and share your questions, everybody back on mute. So, this is where I'm calling on the note takers. So, the notetakers. I want you to look down it's hopefully you wrote the notetakers wrote down some questions. I'm guessing not all of you did your job, though. It's too easy not to do that job you get just sucked into the conversation so okay so for the note takers if you did take questions write them in the chat, what are some of the main questions that came up. So while you're doing that, there's I've been kinda sort of keeping my eye on the chat here. And one of the questions that that's come up is around the funding side of things and how does that all work so Vicki maybe you'd be the best person to answer that question maybe how that was

structured. And what support the group had so Vicki I'll hand that question over to you.



1:17:29

So we received a ministry fund from the Ministry just a two year grant it's it's it finished in April, so we have no funding at all right now for this group. But the funding that we were given through the modernization grant gave us money for facilitation and money for support in the home. The families use their odsp funds and some funds of their own to pay for rent but as I mentioned, we're also advocating for portable rent subsidies we're hoping that that will happen, but families are kind of keeping it together on their own, as mentioned some of the families have found that they've actually needed less support than they did and as they as they develop more rules and community they're, they're needing less again.



Eric Goll 1:18:17

Yeah, great. So, kind of looking at different areas for funding right so looking at different ministries of the government. And look, trying to, you know, kind of piece a solution together it's not just a one size fits all. Here you go. And it's the families, kind of working together to build that and put it together. So thanks Vicki. Okay. There's another question around.



1:18:45

Maybe,



Eric Goll 1:18:47

how to find a place, so I'm not sure if it was around renting or buying. But I think maybe it'd be interesting to hear from cam and Deb around how to find a place and maybe a bit about your experience, trying to work with Ben and find that place to to rent that first apartment that Ben rented Can you share a little bit about that and maybe any tips you have.



1:19:13

Well, I'll start and Campbell correct me and or moderate me then. I never lead with a disability first, that was important to me. What you see is what you get. And we met with

the landlord, and she out of five people picked him as a as a renter, and we wanted a place where he could share a home that somebody lived in so that there would be some similarities let you know. Parents looking after kids. And as it turned out, it was kinda like that.



1:19:51

We used a realtor to find rental opportunities. A lot of realtors work in this, and of the real estate business and can help you to keep abreast of new listings for apartments basement suites, all that sort of thing. That was really helpful for us we were able to get access to new listings each day. So we got emails and whatnot. And we went out and started to look. One of the other challenges we had was, Ben would either like. The first thing he saw, or he wouldn't like anything he saw. And when it came time to choosing getting Ben to decide in a timely way was a real challenge, so we just, we made the commitment. And while Ben thought about it. And once went and when we had the apartment secured. We told Ben that it was his if he wanted it. And by then he had, he had enough time to think about it. But if we had pressed him for the active decision in real time, he would have froze up on us. And so we sort of took a risk that we would have some explaining to do.



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But we made the commitment, and



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because you have to, you have, you know, you only have one chance, and then you're looking for another alternative. So, that was how we ended up being successful in finding an apartment for Ben. We subsequently Ben subsequently moved. He moved into a house, moved out of the basement apartment and moved into a home with two other roommates, and that home is a home that we purchased,



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which not everybody can do but.



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Long story short, we knew that that was probably how we were going to eventually do things. And in similar fashion to how we got the apartment we Debbie started looking and before we knew it, we had a spot.



Eric Goll 1:22:02

Awesome, thanks candidate. The other thing that comes to mind for me is some families did face discrimination. When we're looking to rent. So, you know, I'd say that it was almost to the point where it was common. So, there was, you know, maybe some creative ways to work around that by other people going to look at the place. First, and maybe not leading with, with the disability that was just, unfortunately, the experience and I've heard that from other families that are looking to rent apartments, as well the discrimination factor unfortunately is experienced and it is real. So there's a question that came in, we'll probably not be able to get to all these questions I'm gonna do my best to help us kind of pick out some of the big ones here. They're all important questions. I definitely acknowledge that there was a question around like how do we get our likes from a parent's perspective how can we influence our son or daughter to want to move out. So maybe any of the Oak Park family members here. You want to jump in on on that one. Maybe, maybe I'll put it over tonight.



1:23:26

Okay. Oh yeah,



1:23:28

thank you. I do we just found that time, no I, um, I mean he had an interest in moving out, and he definitely wanted to get his own place and when it came to the point where you know he was sort of ruling the roost around here thinking that he, you know, own this home and he was going to tell us what what he wanted to do and when he was going to do it and set the rules and expectations for us and his home, and we were you know we all came together and realize No, this is, this is not going to work but you know what you've been talking about wanting to get your own place so if you do get your own place and you pursue this, then you can make your own rules and have your own expectations and, and it would be a great way for you to live, but under our roof. You're gonna follow our rules and expectations and he didn't like that very much so, that was a way that like in a way to encourage him to say hey, yeah, I guess I do have to get out my own if I, if I want to really live the way I want to live.



1:24:23

Mm hmm.



Eric Goll 1:24:24

Yeah, for sure, that's that's great now the, the one other thing that comes to mind for me is for many people with developmental disability just having that lack of of life experience and not maybe not knowing or not understanding what it would look like to have their own place because they don't have that the experience or the context to maybe conceptualize that or understand it so to maybe visit other people that have their own apartment. They don't have to have a disability right but to spend the afternoon, like to have to what's, what's next. I always think of what's an experiment you could run well you know who's who's someone that your loved one knows that has maybe their own apartment, and maybe we could they go spend a couple hours together and talk about what it's like to have your own place and maybe share a lunch. Right, so to get more experiences like that to see what it could look like, and maybe the benefits. And, you know, maybe some of the work that it takes to have your own place. So there's a couple of ideas there for you. And some great stuff that Natalie shared as well. Okay, um, next question was around someone around supportive roommates, so maybe Vicki I'll hand that one over to you. Can you share a little bit more around like what a supportive roommate is. And maybe, like how it's helpful, and how did you find one.



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Okay so supportive roommate is just someone in the way that we want them to be we wanted them to really be as close to a typical roommate as as possible. And I think that's how it worked out. So as Jeff had mentioned earlier, the roommate, we gave reduced rent and the roommate you know we wanted him to get after the guys to clean up. And just like any other roommate would, you know, but ask them maybe we want to do it together how do you how do you want to work it out. We also want the supportive roommate to look for relationships in the neighborhood, you know, just say hey you want to watch a movie or make a meal on Saturday night, and things that they would be doing anyway in their home and by doing that they're getting a really really good good price on rent. And we just advertised all through the regular channels, we had a lot of people come and, and, and be very interested. And we found a guy, a guy who was very gregarious and the guys really liked him he's a student so he's left now and with the pandemic words, we've just put on hold. He may be back in January, we're not sure, but just like indeed and an all and word of mouth is actually really great. Even Kijiji obviously make sure you're going to vet

them well and ask for police checks which we did and so on. And it's, and let your own son or daughter decide who they have a good relationship with.



Eric Goll 1:27:25

Awesome, thanks Vicki, that's helpful. Okay, so we're gonna keep going here rapid fire style. I'm thinking maybe Karen would be a good person to answer this next question there's a lot of questions Karen around. What if my family member needs more support so if they need, you know, closer to 24 seven support or, you know, higher support levels. How can we had, what do we do, how do we think about that.



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Okay, so my daughter needs quite a bit of support to stay safe and she's nonverbal as well. We were the last ones to join this group because we didn't think she could actually do it and I had a lot of fear. So the way we moved forward was to have a basement apartment so that you know you can only afford so much paid support that we're close by, so we can provide what else is needed, and you just continue to work on the goals we found that Jacqueline working with someone else learned quite quickly and was way more capable than we thought. And. And so she, she was doing more and she needed less support, although she still needed a lot, the pandemic when we lost our supporters for a while. I had to step back in, and I could see us moving backwards instead of forwards. But we started to work on other things and I started to really just let her be on her own without support in safe. You know periods of time. And then I expanded that and you know it's really me who's been holding her back because she pretty much does everything just the same way I do it she's been watching all these years. And so, I would have said she needed 24 seven support in the beginning and she doesn't she still needs quite a bit, but it's a lot less than what I thought. And she's still young enough we can just continue to work on this so I think the key thing is just get working on it. It's a process.



Eric Goll 1:29:42

Yeah, thanks Karen, I appreciate that. And, you know, just some a couple of other ideas like thinking about, you know, how could you help meet a person's needs and that paid support isn't the solution for for meeting every single need that a person has right those needs can be satisfied with, you know, kind of more natural solutions like maybe a roommate who might provide a little bit of support, or, you know, in Karen's situation it's, you know, the apartments attached to mom and dad's place to mom and dad, maybe provide a bit more support easily. It's thinking about, you know, if a person maybe has a

some personal care needs or some, maybe a physical disability, you might be able to access some more funding from the Ministry of Health. So, you know, you also think about friends and neighbors and support circles like how could they be involved in providing meeting some of those needs potentially so I'm thinking a little bit more broadly, other than paid support to fill a person's needs and needs and I think what Karen is mentioning as well as just Jacqueline self reliance her capability expanded exponentially, which I think she's meeting some of her own needs. Right, so it's thinking about how to, how to, how to satisfy a person's needs with not just paid support. Okay. There's a question around the first few questions on the facilitator role so maybe Vicki or Karen, whichever one he wants to pick this one up. Was it a full time role was it funded as a full time position. And how do you find a great facilitator, as well. and how do you pay for it. So lots there. So was it a full time role. Maybe what was the role, and how to find a facilitator, and how do you pay for it.



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I guess I'll start caring if you want to jump in.



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It was funded by for the two years by the Ministry with our modernization grant and it was half time, amongst all eight families. So Eric worked for. On average 20 hours a week some weeks, a lot more than that. You can pay for a facilitator, out of your passport funds. And I was lucky that I mean we went through an interview process again we advertised all the regular routes and deed and so on. I was lucky that I happen to know Eric and he took part in the interview process, and was hired. But there is the facilitation network, as well as it Ontario independent facilitation network.



Eric Goll 1:32:36

Yeah, so, oh, oh my fn.ca maybe Ontario independent siltation network. Last I heard they're working on a coming up the list of facilitators. So, so you can check out their website I don't know if they have that up there yet. I support families to create vision and and create plans and start to support families and implementing plan plans online. So you can connect with me if that's something you're interested in, as well. Um, okay thanks Vicki, there is a question. And I think this kind of come has come up a couple of times so it's a good one to answer. Does this really Karen you can answer this one does this program support slash Connect others in similar situations and come up in a with a plan in other areas.



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I'm not sure I understand the question.



Eric Goll 1:33:37

So there. So, what oak, the Oak Park family group has done. Are you helping other people in other areas to do similar things.



1:33:49

Oh okay so. So this is a, you know, a project that we have been working on the past two years and we're trying to set it up successfully and. But what we've been trying to do one reason why we made the video was to just share our learnings and the benefits of it with others and we we have shared it with the government we've shared it with our MPP the region and all sorts of agencies and other organizations. We're not capable right now of starting up a whole new group nor do we have extra funding for that, but we would support any group that wanted to start up we would be more than willing to speak with them and talk to them and it may be something in the future but that's where we're at right at this point, Vicki Do you want to add anything.



1:34:47

No, I think, i think that's great, and we are continuing to advocate for this type of model, that's family directed and and directly supported.



Eric Goll 1:34:59

Cool. Thank you. There's a quick question I'll answer here from Elizabeth. So, these families didn't want group homes but many young people want to live with roommates. Would you recommend for or against roommates, or groups. So I recommend, so I recommend to think about what would be the best home for the person so for your son or your daughter anybody has a developmental disability that we're helping to create their own home. What would be the absolute best for them and to start there, and to start about start creating a vision with them. And if part of what you're doing. So, if part of what a person wants what would be absolutely best for them is they want to live with other people, then start to think about who would be the absolute best person like characteristics, maybe, you know their interests and you know what they're good at and what they like like certain think about who that person might be. And when we're thinking

about that that person, you know, that person if it's a roommate like thinking about who would be a good role model to like who could they maybe learn from who could and model things off of. Right. So those are the types of things that, then I would coach a family through, through thinking about so so hopefully that's helpful for you. Okay, so we've got four minutes left here there's lots of questions around. So, what are the next steps like how do we how do we think about moving forward. So, maybe Vicky or Karen I'll throw this one to you maybe you could both comment on it, or any of the other families as well. What was,



1:36:45

like,



Eric Goll 1:36:47

how would you coach another family to move forward. And like, how what would your advice be in terms of, you know, if I'm a family thinking about how do I help my family member, how do I help my son or daughter create their own home, like what would what would what would you recommend some some good kind of first or next steps be.



1:37:08

I think if you recognize you. You can't do this alone You can't raise neurotypical children on their own and you most certainly can't do it with children that have variety of disabilities so you have to realize that you have to reach out to people you have to start to connect whether it's a support network, whether it's getting a facilitator. I strongly recommend joining a family network. That's how our eight families all came together. Even if we didn't have any money whatsoever for any kind of support. We've dedicated to be there for each other to support each other as we grow older, it's it's just, you know, one of the most important things you can you, you can do. And if you can give yourself a bit of a timeframe because I tell you the last 20 years of my life have just flown by so quickly. You know, and I wish I'd moved a little earlier I thought I was but there you have to I think except that there's no easy answer a group home does become an easy answer for all of us. And I'm not saying that it's a terrible thing to do but we seen in the past few months safety concerns and so on. And the best that our sons and daughters really are kept safer through relationships, and especially unpaid relationships keep them much safer. So it's an ongoing effort but don't consider you have to do it yourself just reach out, wherever you wherever you can. And we can all advocate together to for our sons and daughters as well. And if



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I can't, if I can add it is overwhelming. And all I can say is my daughter in one year is so much more capable of helping herself now than she was a year ago. And if I hadn't started acting. I think 20 years could have slipped by. And so even if down the road, she ends up in a group home she's going to be in a much better position to take care of herself than if we hadn't done this, and I would just think of it as I know home can be really big for some people just look at where you're at right now and think of how you can move forward, just in growing independence and giving them more space and letting them have their own life experiences because when Eric mentioned earlier about the lack of life experiences to even make choices and decisions that just, that's my family all together I've decided everything I've done everything, and she's surprised me and I never, never could have known.



Eric Goll 1:39:59

Yeah. Awesome, thanks Karen and Vicki and, you know, I'll add my kind of two cents on this. I think it's really important to think through. As I mentioned, like what would be absolutely best So thinking about a vision and home is like home encompasses kind of a person's life so it's not just about the house. And it's not maybe even just about who the person is living with. There's so much more when you think about it like get to think about the person's life holistically and the home is is a piece of that so creating a vision, like, like, you know, I had the opportunity to work with all these families to do that and I think all the mentioned it kind of Natalie and Jeff and Blair and cam and Deb talked about like, thinking about what would be best for our loved one right and create that big bold awesome vision is a really important first step, and being connected with other families, I found that really powerful as well I mean, that speaks for itself with this group so there's a quick question here I'll answer. Is it too early to start if we're at least four years away. I think this group would give a resounding no start now. Even if it's 10 years away start thinking about it. So from my family experience it from starting the conversations in my family to help my sister create a home for Rome. It was five years. By the time, my sister had her own home. So, um so yeah so it's not never too early. Okay, um, we're a little bit over time, so my apologies on that but I'd love to maybe hear in the chat, what are some insights, what are you what are you taking away from, from this. This event this meeting here with the Oak Park family group let us know in the chat, what you're taking away. What aha moments what insights, did you have, maybe even what's your next action item. Let us know in the chat, what you're taking away love to know any Aha, or insights. And while people are doing that Vicki, how can folks get in touch with the community Oak

Park.



1:42:11

I think the easiest way is just to Google the community Oak Park, and you'll see right away it, you'll get a little more information about our larger network and you'll see right away how to contact us with any questions or if you want to sign up to be on our email list.



Eric Goll 1:42:28

Okay, awesome. Fantastic. All right folks. Well thank you so much for being here. If you're looking to get in touch with me or have questions for me, you got my email. So, the invite came from this so feel free to send me a note and I'm happy to try and help out as well so thank you everyone for being here. If we can give also give a big thank you in the chat to Jeff and Natalie and Blair and cam and dad, for sharing their family's story, and their journey, it's so helpful to hear the stories about their families. So, give them some love in the chat, and thank you all for being here.



1:43:05

Eric Can I just mention one last thing. If anybody wants to share our video, we would love for you to do it and I think it helps the cause of direct funding to families, you just go to YouTube and Google the Oak Park family group. And we would be thankful if, if you could do that as well. Thanks everybody so much for coming and hearing, everybody's stories.



Eric Goll 1:43:27

Fantastic. Thanks so much. All right everyone, thanks for being here. I'm gonna close down well I'll leave the meeting open for a minute. There's lots of Thanks, Kevin, so we'll soak in a little bit of that love. Vicki, feel free to post the link to the video in the chat for folks. If you'd like to do that. And, again, Jeff and Natalie, thank you for sharing your story and thank you for being here. Blair thanks for working out your tech issues, and being here and sharing your story. Your family's story, and Kevin Deb. It's always great to hear from you too and to hear your insights and for you to share your story as well so thank you.