

THE ULTIMATE GUIDE TO INDEPENDENCE

FIVE PRINCIPLES

TO HELP YOUR
LOVED ONE WITH A
DEVELOPMENTAL
DISABILITY
GROW THEIR
INDEPENDENCE



WRITTEN BY ERIC GOLL



USING THE GUIDE:

As a person with a loved one (son/ daughter/ sibling/ grandchild/ friend) with a developmental disability, I want to acknowledge that this road we travel as families comes with additional challenges and barriers that other families do not face. COVID has amplified our challenges even more! If you are feeling overwhelmed, stressed, or tired - you are not alone! My family has been there, and so have all the families I work with inside the Empowering Ability (EA) community. This guide supports the growth of your loved one's independence and will begin to decrease dependence on you, the caregiver, relieving some of the pressure you feel.

The people featured in this guide are members of the Empowering Ability (EA) community of families and have all benefited from the 5-practical principles you will learn. I've included real photos and stories in this guide to show you what is possible for people with developmental disabilities when these principles are put into action!

As you read through the guide, you can use these 5-principles as a checklist to help you make progress, even during COVID. It is essential to realize that growing independence takes time! There are immediate decisions and actions that you can take to get quick wins, but other things take time. So, you'll need to practice consistency and patience!

WHAT DO WE MEAN WHEN WE SAY "INDEPENDENCE"?

Independence is a word that we talk about a lot. So, let's understand what we mean when we say we want our loved ones with a developmental disability to be more 'Independent.'

I asked parents that I coach in my Empowering Ability (EA) communities, "What does it mean for your loved one to be more 'Independent', OR to have their 'Independence?'"

On the next page, you'll find what families said...

Here's what parents said 'Independence' means to them:

“ To be making more choices and decisions.

“ To do more everyday things on their own.

“ To not be as dependent on me, or others.

“ To be living their own life, not just a participant in my life.

We all want our loved ones to have more of their own life. In this guide, you'll learn how to help your loved one grow their 'Independence,' or as I prefer to call it, Capability, and live into their own Awesome 'Ordinary' Life!

You might be thinking, what is an Awesome 'Ordinary' Life?! It is simply enjoying the everyday ordinary experiences, choices, routines, relationships, and lifestyle that the rest of society enjoys. When we support our loved ones to grow their 'Capability,' we are helping them live into their Awesome 'Ordinary' Life.



**Greater 'Capability' and an
Awesome 'Ordinary' Life is
possible for your loved one!**

In my work as a coach to now over 150 families, I've come to understand that there are five (5) essential things we can do to support our loved ones with a developmental disability to grow their Capability (i.e., Independence) and to move toward living an Awesome 'Ordinary' Life.

Let's dive in, starting on the next page.

#1: BELIEVE THE IMPOSSIBLE



It starts with thinking differently.

When thinking about your loved one's Capability (i.e., Independence), how many times have you thought, "they can't do that," or said, "But... the problem is..."

I've thought many things weren't possible for Sarah (my sister), including; making meals, self-care, getting a paid job, taking public transportation, living on her own, and the list goes on...

I had to question myself. Why do I think these things are impossible for Sarah? Well, I hadn't seen examples of other people with a developmental disability living an Awesome 'Ordinary' Life. But, once I started looking, I found many people with disabilities doing the very things I thought were impossible for Sarah. The seed of possibility was planted. I began believing my sister could do what I previously thought was once impossible.

To plant the seed of possibility for you, the next page shares a picture of my sister Sarah in her place. Sarah lives with her cat, Annabelle, for who she is the caregiver. 5-years ago, my parents and I didn't believe it would be possible for Sarah to live on her own, and today it is reality.

Yes, it took a lot of work to support Sarah (right) to get where she is today. But, the joy shared in this picture is invaluable.

Too often, people with developmental disabilities have low expectations placed on them. And the reality is that people live up to the expectations placed on them.

We have to raise the ceiling of what is possible for our loved ones with a disability. We do this by increasing our belief in what is possible, and by dreaming bigger.



Society has taught us to believe people with disabilities are incapable. As families, we are guided into this incapability trap by the medical system, the school system, and our social networks. And we remain stuck in this incapability thinking until we can see our loved one in a different light.

To get out of the incapability trap, we must break free of the 'Special Needs' narrative and open our mind to the possibility of an Awesome 'Ordinary' Life.

But, here is the catch; no one is going to do this for you. It is your responsibility. You must believe in the possibility of an Awesome 'Ordinary' Life for your loved one and raise the expectations for what is possible. Because if you don't, who will?

We have to believe an Awesome 'Ordinary' Life is possible. This is a life-changing decision that you can make right now that will unlock tremendous growth and possibility for your loved one with a developmental disability.

Use the stories in this guide to inspire the possibility of an Awesome 'Ordinary' Life for your loved one, no matter their disability.

#2: GET OUT OF THE WAY



Step aside.

I need to be respectfully blunt with you; you are standing in the way of your loved one's growth! Let me be clear, I am not placing blame or shame on anyone. We have good intentions, but the truth is that we get in the way of our loved one's growth.

How often have we said that our loved one is incapable of _____ (fill in your blank). Too often! Here are some examples, my loved one cannot; make their bed, do their laundry, make a meal, make that decision, get a job, have their own place, and the list goes on. These are often conclusions we have come to without even giving our loved ones the opportunity and support to try.

And how often do we do things for our loved one because it is just faster, easier, or don't want a 'mess'? Too often!

Even when we have this realization that we are doing too much for our loved one with a disability, and we have the intention to let our loved one do more, it is tough to change. Why?

I'm going to share the main reasons I see families struggling to step aside.

First, we've been doing things a certain way for decades! Our behavior patterns are deeply ingrained in our brain and we go about our routines on autopilot. Second, we are scared that our loved ones may fail or might not meet our raised expectations. And third, we are afraid to lose our identity and the value we feel as a caregiver. For all of these reasons, we can be hesitant to move forward. But, what has worked for families is taking small manageable steps.

This is your opportunity to pause, and reflect on how you might be getting in the way of your loved one's growth. Again, there is no judgement here, but I invite you to reflect. We might be led to believe that if we step aside, it means letting our loved one go. But, as Connie Lyle O'Brien has said, it is actually about letting your loved one grow.

"It isn't about letting our family member go, it is about letting our family member grow."

- Sourced from Connie Lyle O'Brien



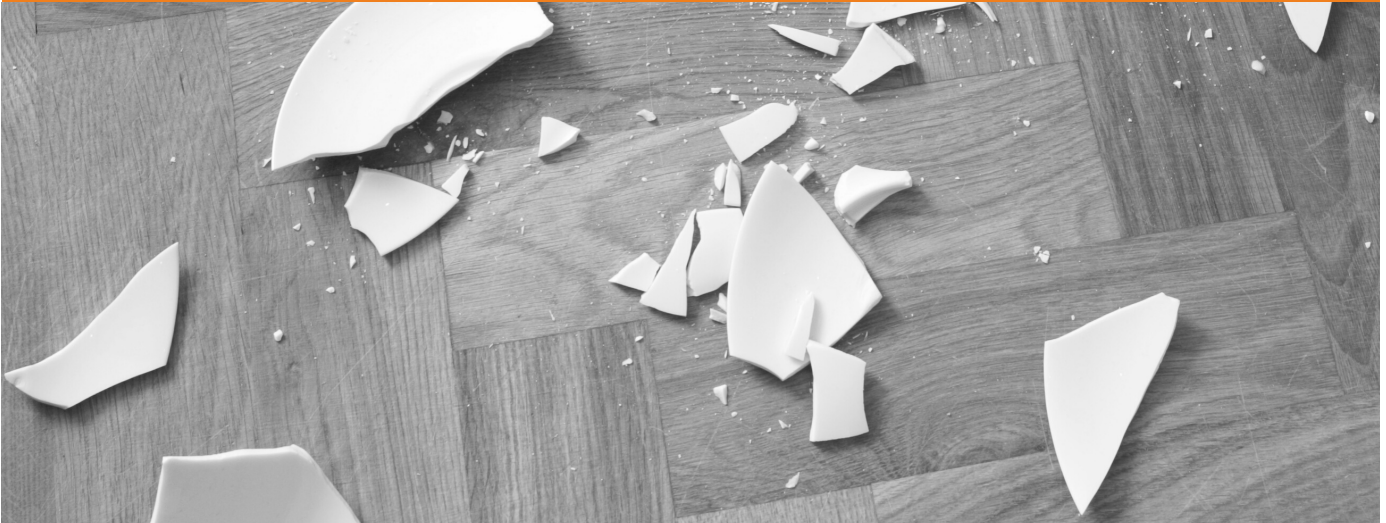
Melodia realized she was doing almost everything for her daughter, Sarah (left). With this new awareness, Melodia understood that continuing down this path was not sustainable. As a result, Sarah got opportunities to help out around the house and to take more responsibility.

Sarah and her family then joined my course, the Plan My Future Coaching Program. Since starting the course, Sarah's Capability has grown exponentially, including making many of her own meals, learning to take public transit, and gaining part-time employment!

I invite you to find one opportunity for your loved one to grow. Starting in the home is a great place.

What things at home can your loved one take responsibility for? Here are some ideas for you; making the bed, setting the table, doing the laundry, grocery shopping, yard work, making meals, watering the plants, cleaning, etc.. Work together with your loved one and allow them to select the opportunities they would like to take on!

#3: GET COMFORTABLE WITH BROKEN PLATES



Growth takes practice... (and patience).

One night in the family support group I lead called Empowering Ability Club, Shannon, a mother, told the group of families, "As families, we need to get comfortable with broken plates... so go to IKEA and buy \$1 plates."

Shannon explained that we couldn't expect that there won't be the odd broken plate while learning to do the dishes. Broken plates are part of the learning process. So, buy the \$1 IKEA plates, so you're not upset when the fine china is in 100 pieces on the floor.

When our loved ones have the opportunity to grow, we can't expect perfection.

When we are learning new things, mishaps will happen, so expect the mishaps. Also, don't make the mishaps a big deal! And give positive affirmation for any progress made, even if it is only one of ten steps completed!

Of course, this idea applies more broadly than just doing the dishes. The key here is to design opportunities for growth where the mishaps can happen, and it's no big deal.

To the right is a picture of Gabby, Shannon's daughter. Gabby is an energetic young woman who strives to contribute to her home and community every day. Gabby has the role of a dog walker, and is soon to be dog owner! Gabby is also giving back in her community by leading a warm clothing drive, leading into the winter months. Despite her significant disability, Gabby has the opportunity to contribute to her household and community, and she is given the right level of support.



Gabby has a big vision for an Awesome 'Ordinary' life, and because of that she does many things that other people thought would not be possible for her.

For Gabby and Shannon, there have been many broken plates along the way, but luckily they only cost \$1 each!

**When our loved ones have the opportunity to grow,
we can't expect perfection.**

When we are helping our loved ones to grow we need to show up in a supportive way, and our approach is important.

We can support our loved ones growth by designing opportunities where the costs of mishaps are low, and by providing the right level of support; not too much or too little. We also need to bring a calm and supportive mindset to the opportunity, and to remember to give positive affirmation.

By taking this approach, you will create a learning environment where your loved one will grow their Capability.

#4 LOOK OUT FOR THE 'SHERO' / 'HERO'



Stop enabling the disability.

What happened!?! Things were going so well.

Okay, so you're loved one is growing their Capability! Things are working because you believe what you once thought was impossible (step 1), you've stepped aside, and you're letting your loved one grow (Step 2), and you've 'gotten comfortable with broken plates' (Step 3). Then, the progress your loved one is making gets derailed, and things quickly go back to how they were before.

It is only a matter of time before this is going to happen. Someone is going to enable your loved one's disability by playing the 'Shero' / 'Hero' (i.e., the enabler). What do I mean by this? Well, someone is going to think your loved one can't do the thing(s) they've been learning, and they are going to play the 'Shero' by doing it for them. The 'Hero' isn't going to be able to help themselves. They have heroic (i.e., good) intentions, even though it turns out they are the villain in this situation, robbing your loved one of the opportunity to grow. When the 'Shero' steps in and does everything for your loved one, your loved one's learned helplessness kicks in.

So what do we do? Communicate! Communicate! Communicate!

Support your loved one to communicate what opportunities they are learning, and the right amount of support is needed. This communication is essential with your loved one, other family members, and paid supporters. This communication also creates shared accountability. Work together as a team and be consistent in your team support approach.

Here is an example from my family; my parents always took Sarah's shoes off. So, Sarah learned that someone had to take her shoes off. She developed a deeply ingrained belief that she couldn't take her shoes off. A paid supporter noticed Sarah's increasing capability and encouraged Sarah to try to take her shoes off. With a lot of encouragement, Sarah had her shoes off for the first time in 35 years in under 2 minutes. It seems like a simple thing, but it means that Sarah doesn't require a supporter to be there for her to enter her home. For a week, Sarah took her shoes off until she got a drive home from Dad. Dad helped Sarah inside, Sarah sat down, and Dad took her shoes off like always.

What do you think happened next? Sarah again believed that she couldn't take her shoes off. For weeks afterward, Sarah refused to take her shoes off, even though she could. All because Dad unknowingly played the 'Hero' by taking Sarah's shoes off and reminding Sarah that she was incapable.



You might have your own version of this story. The 'Shero' often is just doing what they've always done or is just trying to help. But, when they help too much, they can undermine your loved one's capability and it can result in taking steps backward.

Alert: You might be the 'Hero'! The 'Shero' might also be another family member or paid supporter.

Communicate what you're working on with the 'team,' and be mindful of your loved one's energy! If energy reserves are running low, your loved one might need additional intentional support!

#5 WE ALL NEED SUPPORT



It is truly about Interdependence.

Let's be real; no one does it all themselves! It isn't a fair expectation to think that a person will do it 'all' on their own. Western society places a high value on individualism, but the reality is that we are all interdependent with other people.

I know, you're probably thinking, wait a minute Eric... You've been talking about 'Independence,' increasing expectations, and increased Capability, and now you're saying our loved ones can't do everything independently? Aren't you contradicting yourself?!

Let me explain...

Your loved one with a developmental disability can increase their Capability (i.e., Independence) when they have the right opportunities and they have the right level of support. AND there is also a significant opportunity to be more interdependent with other people. Even when a person increases their Capability, there are still things they will need support with. Let's think about this for a minute; how do other people currently support you? It could be a partner, your children, your parents, friends, colleagues, or people you pay in exchange for their services. There is a ton of things you are supported with, isn't there! You likely have many interdependent relationships.

However, as family members (mom, dad, siblings, grandparents, etc.), we often think we can do everything and provide all of the support to our loved one with a disability. When we feel this way, co-dependent relationships form with our loved one with a developmental disability.

We need to look for opportunities and nurture interdependent relationships. You can do this in many ways, not just paid support. We often treat paid support as a hammer and try to hit every nail with it.

When thinking about interdependent relationships, think about; friends, neighbours, roommates, extended family, and people in your local neighbourhood! Most often, Interdependent relationships don't just happen for people with a developmental disability, so we need to think about these relationships intentionally! Think Interdependence, not just 'Independence'. Interdependence leads us toward an Awesome 'Ordinary' Life, and it is the answer to 'Who will be there when I can no longer care for my loved one?'

Lastly...

Take Action

You've learned about the five essential principles to support your loved one with a developmental disability to grow their Capability, and more significant than that, how to start helping your loved one to live into their Awesome 'Ordinary' Life.

Use these principles to support your loved one to grow. Find a win-win opportunity with your loved one, and support them with the opportunity to learn and grow. Remember to keep it simple and provide your loved one the right amount of support. There are only \$1 IKEA plates to lose and an Awesome 'Ordinary' Life to gain!

Together, let's take a small step forward!

I'd love to hear from you, send me an email to eric@ericgoll.com and let me know how you use these principles. I will reply to you personally!

very best,
Eric Goll

About the Author



Eric Goll is a family member and family coach. Eric began by helping his sister, Sarah, move out of mom and dad's and into a home of her own. Eric has gone on to coach over 150 families to support their loved one with a developmental disability to gain more independence, including; gaining employment, increasing their capability, building more relationships, and creating individualized homes. Eric now supports families with the Plan My Future Coaching Program and Empowering Ability (EA) Club.

Together we can create a world where people with developmental disabilities have the opportunity to live an Awesome 'Ordinary' Life!

One last note...

Share

P.S. Many people have asked if they can share 'The Ultimate Guide To Independence,' with other families.

Yes! Of course, you can share this free guide. My goal is to get this guide in the hands of every family that has a loved one with a developmental disability. When sharing this guide with others, I ask that you share the link below so that others can download their free copy.

**Use this link ↓ ↓ ↓ to share this guide with other families.

www.empoweringability.org/independence