

MAKE JUST RIGHT

STOP TRYING TO GIVE ME FINGERS

**A guide to designing prosthetics
*from youth with upper limb differences***

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OVERVIEW AND PURPOSE

This document is a primer for designers, engineers, and makers who are interested in creating a better or more accessible upper limb prosthetic. We have been excited to see a growing interest in prosthetic design and innovation, especially with the rise of 3D printers. We see a world of opportunity for how prosthetics can improve. But - we feel like most of you adults have been missing the mark bigtime.

We're three kids, ages 14-19, with congenital upper limb difference. Since we were born with our limb differences, we each have 11+ years of experience using prosthetics. We recognize that solutions can't improve without users like us sharing our insight. We see a lot of incredible energy and skills being focused on prosthetics these days, and few who are moving in a direction we're excited about. We want to help align that energy and those skills with our actual needs.

Thank you for the work you're doing - we DO need your help. Prosthetics will only get better with a lot of passionate, talented people like you working on them - and working WITH end users like us to create empowering and meaningful solutions.



TERMINOLOGY

Congenital Limb Difference: a condition from birth where an extremity is atypical

Traumatic Limb Difference or Amputee: resulting from an illness or accident

Disability / disabled: A lifelong condition. Identity as part of a vibrant and strong set of communities that have a huge range of lived experiences. United by living in a world that was not built for them.

RBE/LBE/RAE/LAE: Used to describe the location of an amputation. Stands for either Right (R) or Left (L), Below Elbow (BE) or Above Elbow (AE).

"Inspiration Porn": Saying people with disabilities are "superheroes" or "an inspiration" for doing normal, everyday tasks. We're just trying to live our lives.

While there is some language we recommend staying away from due to their history and connotations (crippled, handicapped, superhero), there is no universally "correct" language to use around disability. It comes down to whatever an individual is comfortable with. If you're not sure, ask!

MINDSET

Designing FOR looks like...

- "I see you have this problem, I'm going to fix it"
- A medical device
- Limited options and input (e.g. pick a color or character)
- "Here's what we made for you" (this is like a wheelchair user designing running shoes based only on his experience)
- Lacks custom fit / was not designed for "my" body
- Generic product with no specific intended user or function
- Fits, but doesn't *work*
- Prescribing a "solution" with a lot of embedded assumptions (eg creating a prosthetic with 5 fingers)

Designing WITH looks like...

- Developing tools to adapt to mismatched environments
- A dignified, fashionable accessory
- Getting the perspective of your end user throughout the process (and especially early on in your process!)
- Made with intention around its usage, and based on a person's lived experience
- Initially designed for a specific user/group, then can be expanded on for others
- Collaboration: expertise of the designer/maker matched with experience + needs of the user. Trust that the user knows what they need.
- Alignment between designer + user on the vision, including what they want it to do and how it should feel.
- Clear role of the designer + user during the design process (how involved is the user in the design process?)
- Some knowledge of, or interest in, the disability, its community, and the context of assistive devices within it
- Sensitivity to an individual's self-identity and self-image
- Inviting open-ended exploration of new ideas and uses based on lived experience (if you don't have a hand, what could it be? You have a blank slate to work with!)

Design WITH, not FOR.

MINDSET

Reframing Your Perspective for Empowerment

Common Assumptions Around Disability	Consider, instead...
A disability = a problem to be solved	A disability = a lifelong condition, an identity to celebrate, a community to be a part of
Assistive devices look Medical / User looks like a “patient”	Assistive devices look trendy and stylish (eg glasses) User looks dignified, independent, fashion-forward Opportunity for self-expression
People with disabilities (PWD) are in need of help / Recipients of aid	PWD are capable of creating their own solutions, and know their needs best.
PWD understood to be “Need knowers” and “End users”	PWD seen as designers + makers Designer who is also end user
Missing or lacking something, disadvantaged	Whole just as they are. Unique perspective + capabilities such as creativity + adaptability
Assistive devices, prosthetics	Body mods, enhancements to the natural body (blur distinction between prosthetic + exoskeleton)
Assistive devices as functional, efficient	Assistive devices as expressive, beautiful, dignified
Focus on what a body lacks	Focus on what a body has
Focus on body	Focus on experience

KNOW YOUR AUDIENCE:

Congenital vs. Traumatic Limb Difference

While our conditions may appear similar, there are two major groups of people with limb differences who tend to have much different perspectives: those of us born with **congenital limb differences**, and those who **lose a limb** due to an accident or illness. This document is from the perspective of kids with **congenital** limb difference.

We've always lived a one-handed life. Adapting to make things work for us is second nature. Having one limb is as much a part of who we are as the color of our hair or the town we're from. For us, it's normal. We like how we are. We don't view our limb difference as a "problem" that needs to be "fixed." We don't generally use prosthetics - they can often be more of an obstacle than helpful for us.

When we *do* use prosthetics, it's usually for two reasons:

- 1) To do a specific task (like ride a bike safely)
- 2) To prevent/reduce chronic pain and other health issues

While we can't speak on their behalf, we suspect that people who *lose* a limb may have a different perspective. The "normal" that they were used to was life with two hands. They have suffered a loss. They might identify differently than we do. We encourage you to get their perspective, but we would guess that this group generally might be more interested than we are in the "two-handed ideal" and prosthetics that attempt to look and function like a natural limb.

Prosthetics are generally designed by people who live with two natural hands. It is easy to assume that anyone with a limb difference would want to have two hands that look and function like a natural limb.

We're here to let you know - that's not necessarily true. It might be for some people.

But not for us.

Since our needs can be quite different, choose to focus your design on either congenital or traumatic amputations.

PROSTHETICS: WHAT'S WORKING FOR US

While we don't use prosthetics too frequently, there are two types of prosthetics we DO tend to use:

#1: Prosthetics for Specific Tasks

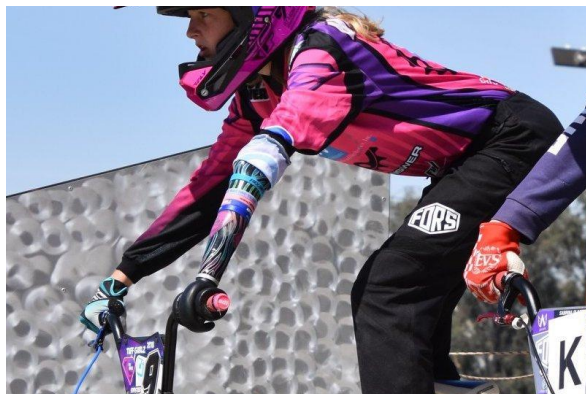
We like doing active things, just like any other kid. Prosthetics can be helpful for us to be able to participate in certain activities better or more safely. TRS Prosthetics has made a lot of progress in this direction for the industry. Here are some examples:



Archery arm
To help hold the bow



Volleyball arm
To help serve



Bike riding arm
To ride safely



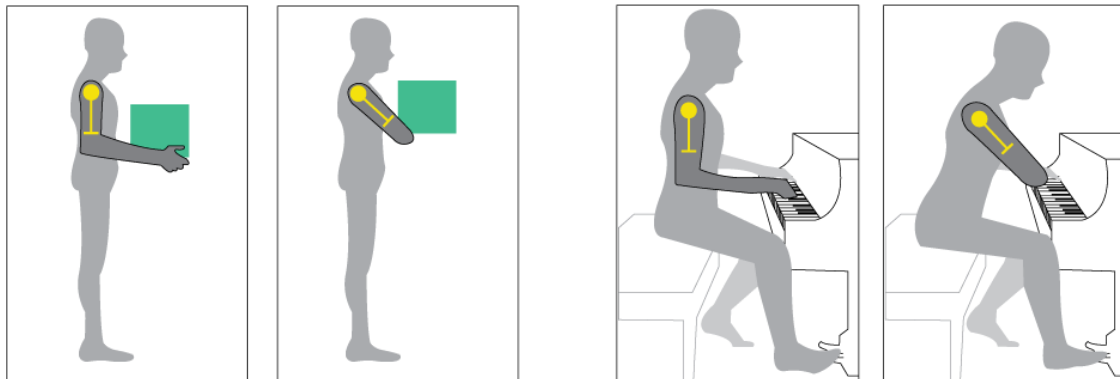
Violin playing arm
To hold the bow

Prosthetics designed for a specific function are more useful than prosthetics for general use.

PROSTHETICS: WHAT'S WORKING FOR US

#2: Prosthetics to promote our health

Especially for those of us with an above elbow amputation, we naturally use our little arms a LOT. We can usually find a way to do most things unassisted. This can take a toll on our bodies, though, and lead to chronic pain and other health issues. The biggest risk for us is overusing our shoulders, or putting a strain on our neck or back because we're favoring one side of our body. These diagrams show a couple examples of how we use our shoulders, where most other people would not. This type of shoulder use happens dozens of times each day for us, and that can lead to pain and problems associated with overuse in the long term.



There are a lot of instances like these where we do things just fine with our little arm - but it can result in overuse of our shoulder.



A device that extends the length of our residual limb can reduce shoulder overuse. This is much more useful than having fingers.

PROSTHETICS: WHAT'S NOT WORKING

And why we're frustrated with what's currently available

We have experienced a lot of frustration with prosthetics over the years. The issues generally fall into one of these categories. This is based on our experience to date (we are ages 14-19) and may not be universally applicable.

Aesthetics: The ones that try to look like a hand but never do. The size or color are off. It feels like it's trying to hide our disability, which hasn't been a priority for us. Sometimes these can end up attracting more attention to us, in a bad way.

Function: Fingers on prosthetics are generally not helpful. They can't do very much. Grip strength, reaction time, accuracy, versatility of movement - there's a *long* way to go. The standard open/close motion is super limited: try to notice how often you use a pinching movement in a day. (Probably minimally, unless you are a professional finger cymbalist.) Typical prosthetics often don't fit or work for us due to the location of our amputation (2/3 of us have little arms that end at our elbow).

Fit/comfort: There are so many ways that a prosthetic can be uncomfortable or poorly fitted - itchy straps, painful rubbing, falling off, creating sore spots... The ones that fit really well still get super hot and sweaty to wear and don't feel good.

Cost: Traditional prosthetics for kids that range from activity specific to full myoelectric arms can cost from \$3,000 to \$50,000 and it's always a question whether insurance will cover it. Open source 3D printable prosthetics are much less expensive (usually donated!) but the form and function are not useful for us.

Outgrowing: Typically, traditional prosthetics take 5-8 months to be made. We have sometimes already outgrown a new prosthetic by the time we received it. Think of how quickly kids outgrow shoes. We've had to get new prosthetics on average every 1-3 years because we've outgrown them and they don't expand or grow with us.

Adjustment/learning curve: Every time we get a new prosthetic, it takes time and energy to learn how to use it. We're used to doing things with our little arms. Imagine if someone strapped a device on to your body and expected you to use it for all of your daily tasks!

A CASE STUDY

Context:

Make Just Right worked with an engineer, A., whose vision is to design a prosthetic whose look and function is indistinguishable from that of a natural hand. In the early stages of his project, he wanted Make Just Right's team of youth with limb differences to test and provide feedback on a prototype. He chose the open source 3D printable exiii Hackberry as a starting point for his project due to his determination that it was one of the strongest open source options available.

Outcome:

To us, the exiii Hackberry is similar to other 3D printable prosthetics that are currently available. Which is to say: it's not particularly useful. While our team appreciated the opportunity to give input early in the design process, we felt that A.'s vision comes from a two-handed perspective, and that it is infused with a lot of big, unchecked assumptions. A.'s vision is to erase our differences and impose on us a "two-handed ideal." With it, he would erase a part of who we are, and our belonging to a community that means a lot to us.

Here were our top insights for A.:

Our Top Three Insights:

- **Check your assumptions.** Not all individuals with a limb difference would want a prosthetic that resembles the functions or look of a natural appendage.
- **Differentiation.** What strategies will this project use to make itself differ from the other prosthetics on the market?
- **Use.** Consider building a design from the shoulder down rather than the hand up. This could provide more immediate benefits to some users and would be easier to develop.



OPPORTUNITIES FOR INNOVATION

These are some areas of opportunity that we'd love to see people working on. We believe solutions in any one of these areas could revolutionize prosthetics. The need is there, and there is currently not much competition!

Build from the shoulder down, rather than hand up.

Fingers are much less useful for us than a longer arm would be. This could also help to reduce the overuse of our shoulders. Drop the idea that a prosthetic needs fingers and see what opportunities open up.

Make it feel *great* to wear.

Figure out an interface between the device and our arms that feels *great*: the texture, the amount of pressure, the temperature inside (not overheating)... make us *want* to put it on.

Useful, but make it fashion.

Think of glasses: they're an assistive device that have managed to become fashionable, with styles for every look and personality. How might prosthetics make this shift from medical device to fashion accessory?

Have it give temperature and pressure feedback.

The lack of temperature and pressure feedback are part of what makes prosthetics so hard to adjust to, and cumbersome to use. It would be SO UNBELIEVABLY COOL - and make prosthetic use so much more intuitive - if it could give us this feedback.

Independent finger movement (if you must!).

If you *do* end up working on fingers, we would love a solution that allows independent finger movement, or being able to spread the fingers out flat (for example, to play some instruments).

A note on *osteointegration*: Osteointegration is not appealing to us - we don't use prosthetics all the time and since ours is a congenital condition we are comfortable navigating the world one-handed. This might be a more appealing option for people with acquired amputations.

OPPORTUNITIES FOR INNOVATION, CONTINUED

Grows or expands with us.

Kids grow quickly. Prosthetics don't grow at all. We would love to see assistive devices that can grow *with* us, so that we don't have to adjust to using a new device so frequently or worry about outgrowing a custom device before we receive it.

Engineers, consider this cry for help: The state of the art in the prosthetics industry right now is to use a thick sock or padding in a socket, and replace it with a thinner sock or padding when we grow. Seriously? That's the best we can do?!

Other kids react with "that's so cool, I wish I had one!"

Limb difference is not very common, so for most kids we're the first person they've seen like this. Reactions usually include staring, fear, concern we're hurt, or pity. Existing prosthetics can amplify these reactions when they look medical or attempt to look "natural." How might an assistive device be designed differently to spur a more positive reaction?

For specific tasks.

Some tasks that we would love to see assistive solutions for include cooking (think of chopping veggies or stirring a pot one-handed), a video game controller (we love playing them and they often require two hands), dog walking (obviously, we want to use our phones while walking the dog), and piano playing (better posture and reach).

Long sleeve fashion solutions.

Not a prosthetic, but something that would be really helpful for us. We usually tie our long sleeves into a knot, or just leave it hanging down. It would be really cool to have clothes that feel like they're made for our bodies.

Let someone with limb difference drive the vision

Since each of us has our own experience and needs, collaborate with someone with a limb difference to define what they need and what type of solution they would be excited about. Invite their participation in the design, and involve them much more deeply than user feedback.

OPPORTUNITIES FOR INNOVATION, CONTINUED

Here are a couple examples of devices that we've made in collaboration with some incredible designers. These ideas explore some of the opportunities listed:

Aidan's Lego Arm

Universal attachment, able to grow + expand. Available [open source online](#).



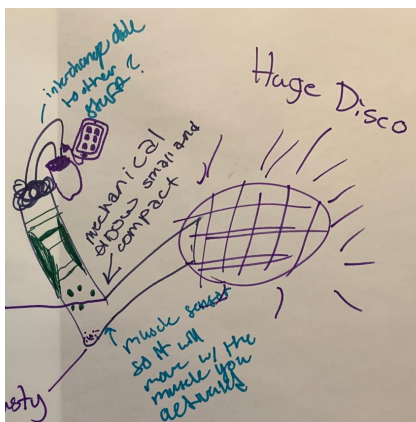
Jordan's Project Unicorn

A glitter blaster that looks like a purple unicorn horn. Invites a *much* different reaction from people than a traditional prosthetic would.

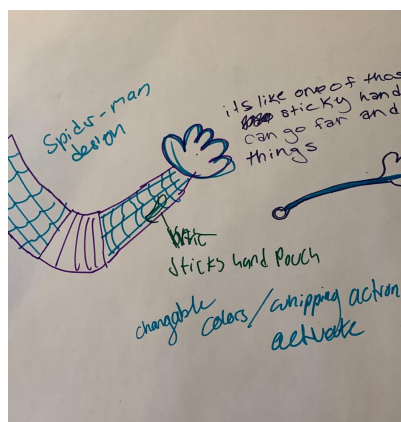


A PLAYFUL BRAINSTORM

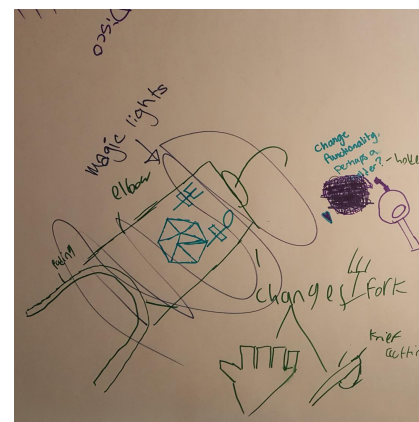
Our team did a quick, collaborative and playful brainstorm around the types of assistive devices we would love to have in our lives. We're not sharing these to suggest that this is what you should create: consider it an invitation to explore, play, and expand the possibilities for assistive devices with us.



A mechanical elbow with a disco ball and interchangeable parts. Because why not?



This action hero-themed arm is complete with sticky hands that shoot out and "grab" something far away.



Functional and stylish, this design features utensils and magic lights to give any dining experience extra pizzazz.

Have fun exploring the possibilities.
If it's not a hand, what *could* it be?

HOW TO ENGAGE KIDS IN YOUR PROCESS

Finding kids to work with:

- **Local Community Organizations.** You can try reaching out to an organization like [Helping Hands Foundation](#), your local [Shriner's](#), or [e-Nable](#) that have built a network of kids with limb difference. Explain what you are trying to do, and ask if they would be willing to put word out to their network to see if any families are interested in working with you.
- **Make Just Right.** We have heard many designers/engineers having trouble connecting with kids. We started [Make Just Right](#) to bridge that gap. We have been developing our design skills to co-create and collaborate with designers and engineers who share our interest in making our world more inclusive. Reach out!

Working with kids:

- **Get set up.** Make sure to set expectations with the family. Consider: frequency of contact/meetings, roles and expectations (on both sides), appropriate lines of communication (through parent for under 14 years old). How can you build trust with the kid and the family?
- **Respect as a collaborator and peer.** Listen and take their ideas seriously. If they are driving the design, you'll need to structure some initial brainstorming activities to get ideas flowing (asking "what kind of prosthetic do you want?" will not be fruitful).
- **Ask great questions.** Ask specific questions (e.g. "What do you think about how it fits?" will be more useful than "Do you like it?"). Avoid yes/no questions. Be aware that they might not have the language to articulate all of their ideas, and they might be afraid of hurting your feelings by giving critical feedback. Frame the challenge. Let them know the parameters you're working with.

Sample Questions: What do you want to see more of? What's comfortable? If it could do anything in the world, what would you want it to do? What do you think think kids at school will say when they see it? How can we make it even better?

MAKE JUST RIGHT

Information + Contact

Make Just Right is a design consultancy that specializes in helping products and services to be more inclusive. Our team of consultants are all young designers (ages 14-19) with physical disabilities. We have a heck of a perspective on living in a world that wasn't built for us, and what we can all do to make it just right.

Our Team



Caleb Tighe
Co-founder/Consultant



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We'd love to hear your questions or feedback! Reach out to **Kate@BornJustRight.org** or follow us **[@makejustright](https://www.instagram.com/makejustright)**

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