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CREATING REEL DESIGNS:

Reflecting on Arthrogryposis Multiplex Congenita in the Community

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STUDENT AUTHOR BIO SKETCH

Iris Layadi is a rising junior in biomedical engineering at Purdue University with interests in clinical and biomechanical design, human factors, and the medical device industry. Iris is from Jakarta, Indonesia, and was inspired to pursue a career path in health care engineering and medicine through her time serving underprivileged communities around the world and her interactions with pediatric oncology patients. In this article, she critically reflects on her experience on the EPICS Assistive Technology team building an assistive fishing device for a project partner with arthrogryposis multiplex congenita.

ABSTRACT

Because of its extreme rarity, the genetic disease arthrogryposis multiplex congenita (AMC) and the needs of individuals with the diagnosis are often overlooked. AMC refers to the development of nonprogressive contractures in disparate areas of the body and is characterized by decreased flexibility in joints, muscle atrophy, and developmental delays. Colton Darst, a seven-year-old boy from Indianapolis, Indiana, was born with the disorder, and since then, he has undergone numerous surgical interventions and continues to receive orthopedic therapy to reduce his physical limitations. His parents, Michael and Amber Darst, have hopes for him to regain his limbic motion and are very open to trying out new assistive devices that would promote independent utilization and potentially help him participate in activities with minimal assistance.

This reflective essay aims to elaborate on and evaluate the human-centered design project I worked on with my EPICS Assistive Technology team and the community impact fostered by it. Our service-driven and product design project places emphasis on a family hobby that

Colton wishes to be able to take part in—fishing. As a result of his condition, it is difficult for him to engage in this and similar activities, preventing him from connecting with his family and peers at a more physical level. By conducting prototyping of different autonomous systems on a device, implementing hardware programming on electrical control systems, and engaging in research and experimentation of computer-aided designs, my team and I were able to engineer and tailor to Colton's specific needs a high-functioning assistive device that compensates for his lack of muscular mobility, allowing this project to serve as a medium through which I could integrate and channel my knowledge of physiology and mechanics and take a step forward on the journey toward innovating and revolutionizing health care technology.

Additionally, this essay discusses a variety of aspects related to the bridges between empathy, innovation, service-learning, and human-centered design, and, despite its limitations, the ways our service project is helping to alleviate the problem that not only Colton, but so many others are currently facing. Similarly, the essay also outlines the impact this experience has had on me,

in the context of my direct contribution to improving quality of life and raising awareness of arthrogryposis multiplex congenita at the emotional, societal, and professional levels. Given the promising impact that we all can make, it is important to contribute to paving the way and helping lead Colton and those like him toward empowerment, inclusivity, and opportunity.

INTRODUCTION

Wrestling, soccer, and firefighting—from simple every-day tasks to grueling outdoor activities, Colton Darst wants to do them all. Our team believes he could, and we are committed to helping him do so. But with arthrogryposis multiplex congenita (AMC), an antepartum genetic condition causing multiple joint contractures to develop in various areas of his body, it is difficult for him to even walk across the halls of his Indianapolis home without assistance.

I first joined Purdue University's EPICS learning community in fall 2019, when I was placed on the Colton Fishing team within the Assistive Technology lab. EPICS is a service-learning design program in which students collaborate with both local and global organizations to develop engineering-based solutions for some of the most pressing community and environmental issues (Zoltowski & Oakes, 2014). Students work in multidisciplinary teams alongside human service, governmental, and educational institutions to integrate creativity and innovation and produce real systems and resources, allowing for valuable learning experiences that benefit both students and the community partners (Coyle et al., 2005). The Assistive Technology lab focuses on providing caregivers with assistance through devices that allow those with disabilities to live a more independent life. We aim to forward quality of life through design and development concentrated on health care delivery, fulfilling the unmet needs of patients and the community. The Colton Fishing subteam started in 2017 and partnered with Colton Darst, a then five-year-old boy who has reduced limbic motion due to his genetic disability.

Despite AMC's nonprogressive nature, Colton is affected greatly with regard to his impeded movement, lack of joint flexibility, and inability to contract his muscles. Colton has undergone several surgical interventions throughout his childhood and continues to receive orthopedic therapy to reduce his physical limitations. His parents, Michael and Amber Darst, have hopes for him to regain his limbic motion and are very open to trying out new assistive devices to help him participate in various activities with minimal assistance. Our team's

partnership with the Darsts places emphasis on helping Colton gain physical independence with the aid of assistive devices.

DESCRIPTION

It is one of Colton's biggest dreams to be able to fish with his family. But with his disability, it has proven to be a difficult challenge to overcome, especially with no products on the market that can satisfy such needs. When our team first started with this design project, we received design iterations from past semesters' teams. After discussing several concerning factors in relation to safety, durability, and design efficacy, we decided to proceed with a complete redesign of the fishing device.

Over the past two semesters, we have developed a newer model of the assistive fishing device design that would optimize user abilities and perform according to Colton and his family's preferences. We took into consideration Colton's minimal grip strength and his significant reliance on core and neck strength. Within our current design, our team has determined three main functions that the device centralizes in addition to infrastructure—casting, reeling, and controls. During the fall of 2019, we acquired an off-the-shelf electric spinning reel. It was built by and for the handicapped community and provided us with two key advantages: (1) we were able to utilize the specifications from the commercial product and avoid having to size motors for the purpose of the reeling functions—after preliminary testing, the motor proved to be of power and the motorized reel met all our and the project partner's requirements; and (2) we were able to save an extensive amount of time by purchasing the fishing reel, allowing us to focus on completing the other pivotal aspects of our design.

At the fall 2019 midsemester design review, we discussed moving the fishing rod to a base that is separate from the chair. Past semesters' design iterations were limited to a rod-armrest complex that brought up numerous safety concerns, including weight imbalance, as well as issues regarding expandability and versatility. After conducting tests with different fishing systems, we discovered that attaching the rod on a cart next to the chair would be the optimal design.

Colton and his family were receptive to the idea and believed that it would be a safer, more transportable option that would be user-friendly and intuitive. Based on their suggestions and advice from stakeholders, we developed a prototype of the fishing rod-cart system using swivel casters and plywood and placed the rod in

Figure 1. Exploded CAD view of the cart-fishing rod base prototype.

Figure 2. Physical prototype of cart.

a stationary sleeve that is yet to accommodate rotating and angular casting mechanisms.

When we spoke to Colton, we received input on his predilections for the operation of the disparate functions. He highlighted the ease with which he can push and maneuver buttons on standard video game controllers, so we adapted our plans for the controls system of the assistive fishing device to match his wants and needs. We began to explore the idea of programming a Game Cube controller to perform all necessary fishing functions; however, after research and testing in the EPICS lab, we discovered that the plan was not realistic given the time constraints and our current technical skill level. As an alternative, we built an initial prototype of a

Figure 3. Initial custom controller box prototype.

pseudo-controller made of plywood and a variety of large buttons that performed reeling operations at different speeds.

Following a conceptual design testing visit to the Darsts, we drafted a custom controller design that would replicate the parts of a video game controller that Colton likes. This new controller is 3D-printed out of nylon and carbon fiber and utilizes the same button design that Colton preferred from earlier testing.

The new controller is designed in a triangular shape and equipped with soft tactile switches to make it easier for Colton to hold between his legs and allow him to grip the sides in a more fitted way to actuate the buttons. The controller is programmed with an Arduino circuit code that enables him to reel in quickly by holding down either of the top buttons and reel in slowly by holding down both buttons. Our original plan was to add a joystick on the controller surface that would allow Colton to move and rotate the swiveling rod base and the rod to his liking in various fishing locations.

As we approached the end of the spring semester, our team progressed to working on the casting mechanism of the multipart assistive fishing device. Preceding the completion of a decision matrix weighing a pressurized air system vs. a loaded spring system for bait casting, we decided to move forward with an air propulsion device. Mathematical modeling and an FMEA safety analysis test showed that this launch system would be best for integration with our existing cart and controller prototype. Additionally, it would ensure maximum efficacy and satisfy project partner needs most

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Figure 4. Exploded CAD view of the final controller design.

Figure 5. 3D printed controller casing.

favorably. Presently, the team has transitioned into developing test protocols to evaluate the safety, functionality, and usability of the current prototype, with plans to visit Colton and his family in the near future for secondary design validation and user testing.

COMMUNITY IMPACT

With our assistive fishing device, Colton can deviate from traditional forms of physical activity, including fishing, while still espousing his desired level of recreation in a safe and comfortable setting. During our preliminary testing, Colton expressed how much he liked the self-reeling and controller portions of the system. He enjoyed reeling objects of varying weights and commented on

how intuitive and ergonomic the mechanical and electrical design was. He was able to maneuver the controller with ease and seamlessly navigated between the button options, noting how similar it was to his current video game controller and how easy it was for him to operate the assistive device independently. His parents were also able to load the multisystem device onto their family car relatively easily and was pleased that the device was transportable and sturdy, design requirements that were of top priority, especially as they would need to travel to their fishing location. Colton and his family were excited at the prospect of utilizing the device outside and fishing over summer vacation, but unfortunately, with the ongoing global COVID-19 pandemic, Colton has yet to take the fishing device outdoors and test it in the water; we are all eagerly looking forward to the opportunity for him to do so!

This EPICS project alleviates some of the struggles the Darst family experiences because of Colton's disability, fostering increased inclusivity within the family and promoting familial connection at a more physical level. The mobility-improving device my team developed will also be of use to other children with physical constraints similar to Colton's and promote improvement of self-esteem by allowing them to engage in activities as "normally" as possible. Similarly, we have researched and interviewed experts on arthrogryposis multiplex congenita, determined best movements that would contribute to enhancement of physical therapy, and implemented and mapped out such movements to be included in our device, which would help improve the physical abilities of those suffering from AMC long-term.

From an economic point of view, our product is low cost, durable, easy to manufacture, and safe, which is beneficial to the AMC community, especially with a lack of similar products on the market. Through rapid prototyping of product and following device constraints and design specifications, the fishing device we designed met Colton's specific needs and increased his comfort in engaging with this outdoor activity. With regard to community regeneration, advocacy, and activism, the impacts of our design and work will contribute to driving real change beyond simple product touchpoints to systems and behaviors.

STUDENT-AUTHOR IMPACT

Even with numerous volunteering experiences before, I have never been able to contribute to improving quality of life this directly. Being able to apply my knowledge and design a device that would help children in need and

give back to the community has been a very rewarding experience. Collaborating with my peers on this design project has given me the opportunity to hone my skills and interests and expand my creativity in areas that I am passionate in, including making health care more accessible through human-centered design. By having the Darsts so involved in our project, my team was able to achieve equity and combine the disciplined and creative capacities of design to create a profound social impact. Undergoing the human-centered design process also taught me the value of an extroverted design process, where I am able to advance my thinking around others with different frames of reference and fresh thinking to elevate the work we are doing and move forward from feedback. By first empathizing with and understanding our project partner, defining clearly what we can meaningfully design, converging stakeholders to better understand their needs and opportunities and how they align around one shared problem, ideating and experiencing the creative process to generate more collaborative ideas, and creating a prototype and testing with others to gain actionable criticism, I was able to use design to make sure that not only does society adopt the solution, but that the solution creates lasting impact along the identified goals of making things better.

Important key takeaways I have received so far from being able to work on this design project include the value of fostering a close relationship with the project partner, how to succeed in being a first-time people and project leader, ways to become comfortable with failure, and how important it is to always hustle with passion, lead with intent, and design with purpose.

I have learned the importance of being self-aware—how to practice humility, empathy, and risk-taking, how to navigate conflict and empower others, and how to stay human and intentional, and the value that doing so brings to me, my team, our project partner and stakeholders, our designs, and the community. The human-centered property of this project has taught me how to design more empathically, how to focus on the more human side of engineering, and how to drive a more thoughtful approach to expanding creativity in technology and science. This EPICS project has served as a medium for me to stay innovative and find ways to refine my thought processes constantly through the cultivation of a design-driven approach to development using human-centered design methods. By focusing on Colton and remembering to take into account broader cognitive and social biases, we created a device that will be very beneficial for him and others with similar constraints in the long-term setting. Ultimately, working on the Assistive Technology

Figure 6. The AT Colton Fishing team with Colton Darst.

Colton Fishing team this past two semesters has taught me the importance and many values of human-centered design—repeating methods for creating problem solving and innovation toward alleviating global-scale and specific challenges that takes inspiration from real people and a real project partner, works within technological and market constraints, and considers our designs and prototypes as an opportunity to surprise and deliver benefits to our project partner. It has taught me the merits of compassionate design practice and what caring, giving care, and service really mean. Designing to drive social impact is really all about learning and understanding the experience of our project partner and others facing intense human challenges, using the knowledge as a launchpad for creativity, and rethinking traditional modes of creating social change to make greater impacts in society.

CONCLUSION

This design project aims to alleviate limbic limitations through a mobility-improving fishing device with an electric reeling system and corresponding movement-promoting casting and controls methods. Although Colton and his family were big proponents of our

project's first deliverable, there are many more aspects of the assistive fishing device necessitating additional refinement.

Through further rapid prototyping of product, our team hopes to be able to compensate for Colton's lack of muscular mobility and contribute to helping him participate in fishing activities. Similarly, by integrating knowledge of physiology, mechanics, and electrical work, this project allows us to explore assistive technologies and deliver a life-enhancing device to better assist individuals affected with AMC.

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