

ARISE ADAPTIVE DESIGN



Enabling individuals to achieve success in all areas of life
www.ariseinc.org

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and the adaptive design process.



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In loving memory of Matteo Lester
10.13.14 – 10.02.18

ARISE ADAPTIVE DESIGN



Welcome to ARISE Adaptive Design! The intent of this booklet is to provide a brief overview of the origins, process, and uses of adaptive design, and to present a few examples of adaptations that can be developed using this technique. We hope that you enjoy learning more about the amazing potential that lies within adaptive design.



“Adaptation is the link between can’t and can.”

- Alex Truesdell

Who are we?

ARISE Adaptive Design (AAD) is one of the many programs offered to individuals living with disabilities by ARISE Child and Family Service, Inc., one of New York's eight independent living centers. The ARISE mission is to work with people of all abilities to create a fair and just community in which everyone can fully participate. AAD plays a crucial role in the participative piece of this mission by acting as a grassroots community dedicated to designing and building tools for inclusion, access, and participation. AAD partners people with all types of abilities, their families, friends, and

clinicians, with an eclectic group of volunteers within the Central New York community. Our volunteer team consists of clinicians, therapists, designers, engineers, architects, hobbyists and makers, students, as well as individuals who simply want to help others within the community. Participants that take part in the program along with their families are equal members of the design team set up to assist them in the building of their specific adaptation. Together we identify solutions to provide access and full participation in a wide range of activities and settings.



What is Adaptive Design?

The adaptive design approach utilizes simple materials to create highly customized equipment for individuals with disabilities. These adaptive solutions are low-cost, flexible, quick to create, and the design process itself is self-directed by the end-user. Whereas traditional durable medical equipment is often extremely expensive and can feel generic and industrial, our adaptive solutions are driven by the unique needs, interests, and personality of the device user. The goal of these affordable adaptive designs is not simply increased mobility, but rather to help individuals to achieve success in all areas of life including physical, social, academic, and vocational activities.



Why does AD exist?

The majority of those who live with a disability need more adaptations than they currently receive. According to the U.S. Census Bureau, nearly one in five people in the United States have a disability. Further, the World Health Organization estimates that 15% of the world's population, or about 1.1 billion people live with some form of disability. Of that, 2-4% experience significant difficulties with functioning within a traditional environment.

If provided with appropriate adaptive technology, or the necessary tool to perform an intended task, many would be able to reach their full potential in activities of daily living,

“Perhaps worst of all, some people never receive necessary equipment due to others’ preconceived notions of the capabilities of individuals with disabilities.”

education, work, and recreation. As Alex Truesdell, the founder of the Adaptive Design Association proclaims “Adaptation is the link between can’t and can.”

So, why is it that so many individuals living with a disability are going without the equipment they need?

Here are a few of the many reasons:

- The individual has no insurance or no access to insurance.
- The individual has insurance, but the insurance company does not cover the medical equipment they have requested.
- Many pieces of equipment are simply too costly to purchase out-of-pocket.
- Children often go without necessary pieces of adaptive equipment due to the time it takes for insurance to approve and pay for an item. By the time the much needed item is received, the child may have already outgrown it and the family must begin the process all over again.
- The individual is not aware that an adaptation could be available to make certain activities in their life easier and more fulfilling.

Perhaps worst of all, some people never receive necessary equipment due to others’ preconceived notions of the capabilities of individuals with disabilities. It is our hope that through adaptive design, we can challenge such assumptions, and recognize the untapped potential of those living with a disability.

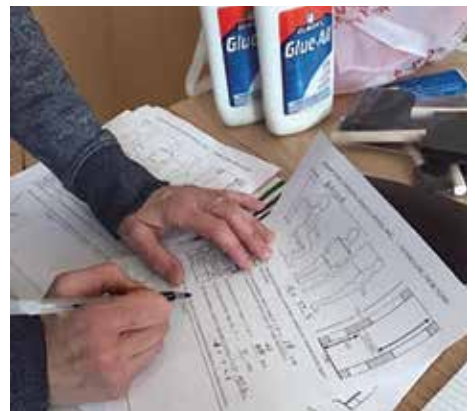
How does the process work?

Individuals who enter our program first identify a barrier that is keeping them from a meaningful activity that is important to them. They then partner with our volunteer teams to design and build the solution.

An initial assessment is completed with the participant to take measurements, gain a full understanding of what activity they would like to achieve, and to learn more about their interests, goals, likes and dislikes. The participant and/or their family then work along with their build team to help guide the development of their adaptive product from start to finish. This is how each product becomes such an intimate and unique item to that specific individual.

Those living with disabilities, as well as their families, have long been great innovators in creating design solutions when faced with adversity. Participant-centered co-design takes families'

ingenuity one step further. We bring together design teams that include people with a variety of personal and professional skills and perspectives. This approach builds on families' skill sets and enables a cross-pollination of ideas by exposing clinicians, designers, makers, and students to collaboration. The adaptive design construction process provides the means for individuals with disabilities to reinstate control over their environment, gain further independence, improve their quality of life, and learn new skills. The participant isn't the only person to benefit from the process of adaptive design either. The hands-on experience of building adaptive products is tremendously satisfying! It is not just about the end-product. Creating solutions, learning new skills, and working together builds community and is an extremely moving experience for all those who take part in it!



What are items built with?

The building supplies used in adaptive design are typically low-cost, easily modified, and readily available. Believe it or not, the main building material used in adaptive design is cardboard! Tri-wall cardboard is an eco-friendly material that is available all over the world. It is light weight, yet durable and strong. It can be easily cut, bent, glued, and painted, all with basic hand tools. It is the perfect material for making custom designs. Why is this important? Each participant has unique positioning and mobility challenges.

This is especially true for children, who are always growing and changing. Manufactured equipment can be very expensive and may not be readily available. Designs that are made locally with cardboard can be used right away and are easily modified as the participant's needs change. When necessary, we will also use more sophisticated materials and building techniques, such as thermoplastics and 3D printers. Each item is unique and so are the tools and materials used to create it.



Our Story

In June 2016 Syracuse University School of Design hosted Central New York's first Adaptive Design event. Children and families from Jowonio Preschool and Upstate Golisano Children's Hospital were invited to attend a three-day workshop led by Alex Truesdell, founder of the Adaptive Design Association, and others from her New York City team. On Friday evening, Alex and her staff led a four-hour Introduction to Cardboard Design session followed by two full days of co-designing and building. Volunteer designers, clinicians, and makers put in twelve-hour work days collaborating with four families to learn, design, and

construct pieces of equipment to enable their children access to more opportunity. Over that initial weekend

"ADA Syracuse was gaining steam, but was missing one thing: a home base within the community. This is where ARISE Child and Family Service, Inc. stepped in."

a total of 15 pieces of adaptive equipment were created. After this first workshop, the adaptive design movement in Central New York never slowed down. A core group of

volunteers continued to meet regularly to work with new participants and families, and to develop new adaptive solutions. These building events took place in various locations around the community, and became known as "pop-up builds". Depending on the month, our group might be found in a church gymnasium, Upstate Golisano Children's Hospital, our local Home Depot or maker space, or even in someone's garage; wherever space was available to set up a makeshift workshop. Over the course of the next year, volunteers for the newly minted Adaptive Design Association (ADA)



Syracuse continued to grow the program, holding pop-up builds, speaking at conferences and events, and giving demonstrations at local occupational and physical therapy schools. Upstate Golisano Children's Hospital and children and families from Upstate's Center for Development, Behavior and Genetics helped guide the adaptive design movement every step of the way. ADA Syracuse was gaining steam, but was missing one thing: a home base within the community. This is where ARISE Child and Family Service, Inc. stepped in. ARISE, an independent living center

that provides numerous services to people living with disabilities, saw the potential that adaptive design could

“Upstate Golisano Children's Hospital and children and families from Upstate's Center for Development, Behavior and Genetics helped guide the adaptive design movement every step of the way.”

have within its community and agreed to take it on as a program that they would offer. ARISE not only agreed to serve as a location within the

community where people could visit to request adaptive equipment, but has also provided funding for a program coordinator, assistance with grant writing, and a physical space where build events can now consistently take place. Since the merger with ARISE, Adaptive Design Association Syracuse has officially become ARISE Adaptive Design. Our hope is that ARISE Adaptive Design (AAD) can serve as a pilot program for future adaptive design groups that may sprout up in other counties, cities, and states and act as a model for effective partnerships with local independent living centers.



Examples of Adaptive Solutions

Workshops and custom designs were created by and for families of children with physical, visual or hearing disabilities.

Standing Frame

A standing frame allows a child who may not have the strength, function, or control to stand independently, the ability to be in an upright weight bearing position. This will help develop muscle and core support, minimize bone density loss, and help to improve digestion and circulation. To help encourage longer periods of standing, an activity tray can be attached onto, or in front of the standing frame. While standing, the child can use the activity tray to play, read, and/or use a tablet, making the act of standing feel less like therapy, and more like play!



Focus Chair

The focus chair can be a perfect solution for an over-stimulating environment. For individuals who may have autism, attention deficit disorder or attention deficit hyperactive disorder,

or obsessive-compulsive disorder, crowded settings such as a classroom, or a party can be distracting or stressful. By blocking out much of the outside stimuli, this device can allow

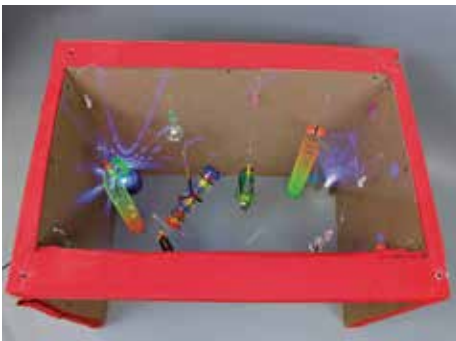
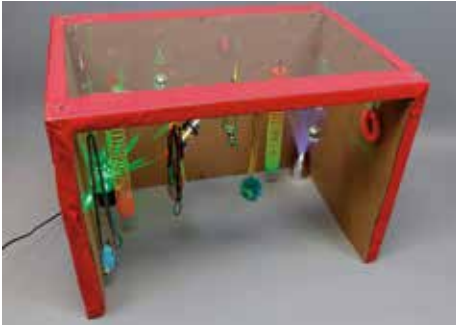
the user to focus more easily on what is visible directly in front of them. The focus chair's encompassing walls can also be used as a safe space during stressful and over-stimulating moments.



Little Room (Multi-Sensory Environment)

Little rooms, or multi-sensory environments (MSE) as they are otherwise known, can be a perfect item to provide relaxation, encourage cause and effect understanding, and enhance sensory stimulation. These rooms create a safe space with items that provide visual, auditory and tactile feedback. Little Rooms encourage young children with vision impairment/blindness, deaf children, and children who are deaf-blind to begin safely exploring the

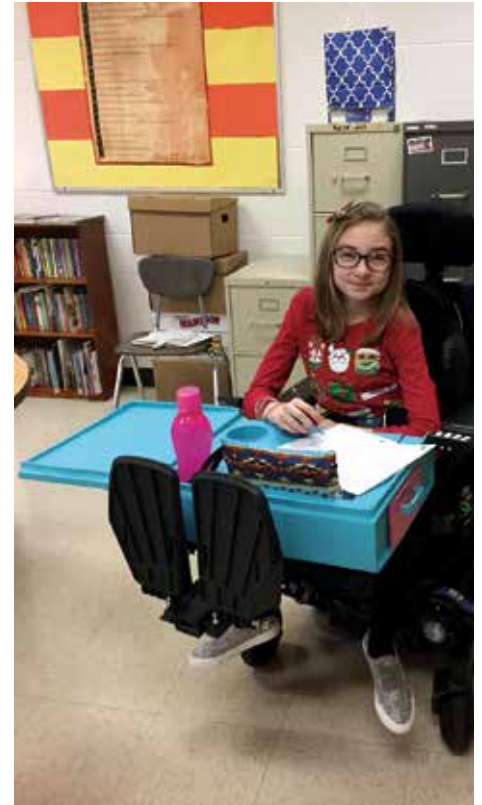
space and environment around them. Items like soft multi-colored lights, metallic beads, fuzzy toys, carpet swatches, and bells can allow children to explore different textures, materials, sounds, shapes, and visuals. Little Rooms can also help ease anxiety and stress for children with disabilities such as autism spectrum disorder, and other disabilities that create sensory difficulties.



Activity Tray

An activity tray can be a great piece of adaptive equipment for a child who uses a wheelchair who may have trouble gaining access underneath a typical school desk. A custom tray can be a fun cooperative project between the end user of the product and those helping to make it. For children with vision impairment/blindness, deaf children, and children who are deaf-blind an activity tray can be custom built to allow them to learn and play without losing any of the items. This can be accomplished by building a ridge around the perimeter of the tray so that items do not fall off or become out of reach. Specific compartments are included to keep commonly used items organized.

Tactile and visual stimuli can also be included in the features of an activity tray. A slant board can be added for children who have lower visual field neglect, which is common among children with cerebral palsy. The child shown in the photos here enjoys arts and crafts activities, and gave specific requests as to some of the adaptive features she would like it to have, such as the pencil/cup holders, a pull out side drawer, and a hidden pencil tray. She also took over when it came time to decorate the item. Choosing bright colors that matched her new wheelchair, this tray quickly became a unique product that specifically reflected her fun and bright personality!

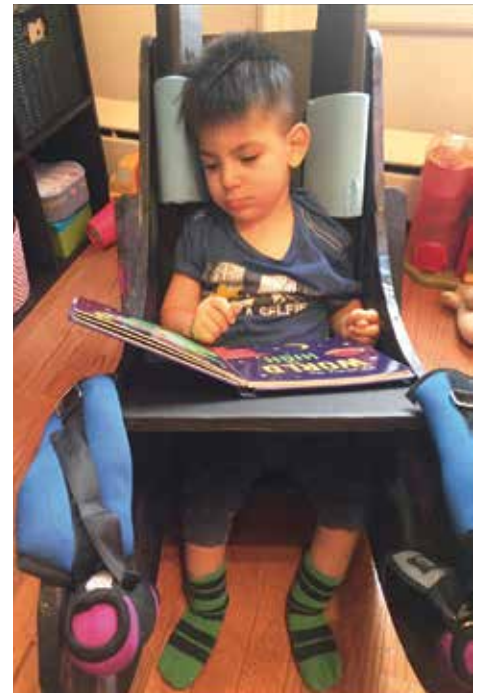


Rocker

The fun kidney bean shaped rocker offers many great benefits for any child who may have a disability that affects stability and/or motor functions. This adaptive product can give a toddler who may have limited mobility the ability to begin strengthening their legs. By pushing themselves to achieve the fun rocking

horse type motion created by the rockers curved outer walls, the individual begins to build muscle and limit muscle atrophy. The side walls can also be enlarged to provide seclusion from over-stimulating environments, and help with focus. For children with vision impairment/ blindness, deaf children, and children

who are deaf-blind this rocker provides a safe place for play and a chance to begin exploring movement. Self-activated movement through rocking oneself in the chair can also begin to teach cause and effect. An activity tray can also be attached to the front lap area for more fun and play while moving!

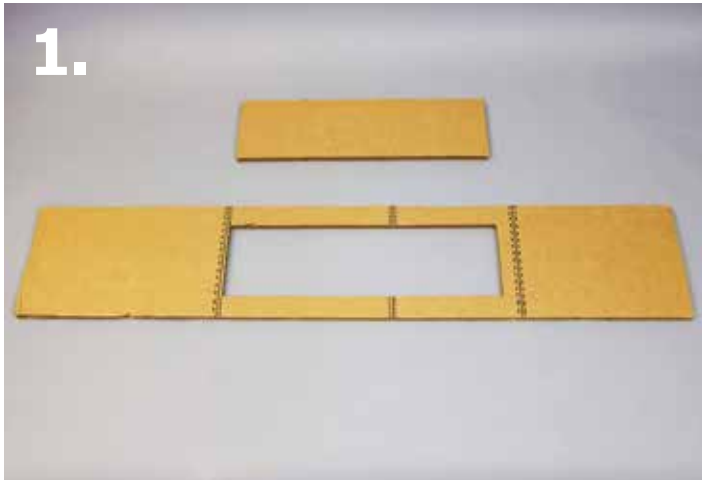


Build Breakdowns

Build Breakdown:

STANDING FRAME

A standing frame allows a child who may not have the strength, function, or control to stand independently, the ability to be in an upright weight bearing position. This will help develop muscle and core support, minimize bone density loss, and help to improve digestion and circulation.



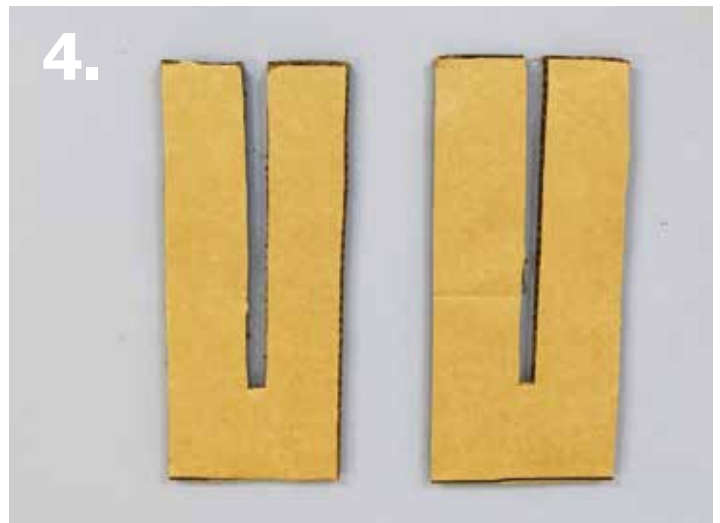
Measurements are taken of the product's end-user to create an ergonomically correct pattern from. The pattern is then drawn onto a sheet of tri-wall cardboard, and cut out using either a utility knife, jig saw, or band saw. Lines are marked on the template to show where bends, scores, and grooves will be made.



Bend marks are indented using the back edge of a spoon. The pattern is bent in the appropriate spots using a straight edge ruler or the side of a table. A groove is created by removing two layers of cardboard with a precision knife to create a male/female joint.

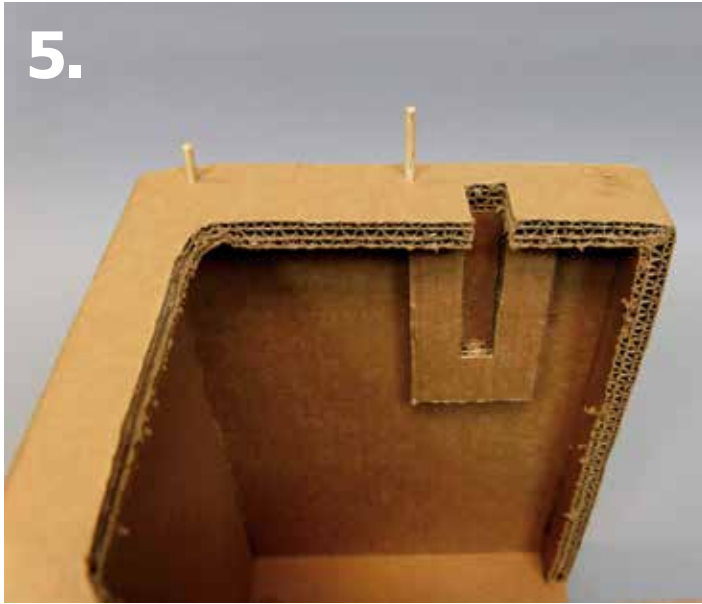


The template is then folded into its appropriate shape. The multiple parts of the standing frame are then assembled and reinforced using Elmer's glue, hot glue, and sharpened wooden dowels that are driven down into the cardboard.



Separate pieces are cut out for the slot mechanism that will be used to hold the child upright within the standing frame.

STANDING FRAME CONTINUED



5. The slotted cardboard pieces are joined to the standing frame with Elmer's glue and dowels. Slots are also carved out of the top of the standing frame to allow access to the slotted cardboard pieces aligned below.



6. A plate that will fit within the slotted side wall pieces is also created. Multiple pieces of cardboard can be layered together on one side of the plate in order to offer various amounts of support depending on which way the plate is facing.



7. Heavyweight paper applied with Elmer's glue is used to cover the exposed corrugate edges of the device, holes where dowels were driven through, and any other torn or punctured areas of the cardboard.



8. The entire device is then primed, painted, and polyurethaned to add to its aesthetics, rigidity, and resistance to water and wear and tear.

Build Breakdown:

TACTILE CALENDAR

A Tactile calendar is a simple device that can describe a schedule for an individual who may be blind, or deaf/blind. Tactile cues/symbols can describe to the user what activity they are doing now, and what activities to expect after. These calendars can be used for part of the day, or for the entire day based on how they are designed.



The pattern of the calendar board is drawn onto a sheet of tri-wall cardboard and cut out using either a utility knife, jig saw, or band saw. Lines are marked on the template to show where bends and scores will be made. Bend marks are indented using the back edge of a spoon. The pattern is bent in the appropriate spots using a straight edge ruler, or the side of a table. A groove is created by removing two layers of cardboard with a precision knife to create a male/female joint.



The template is then folded into its appropriate shape and glued into place. The front and rear faces of the calendar frame are at an angled, upright position. This will bring the visuals that will eventually be placed on top into the user's field of view where they can be seen more easily.



Heavyweight paper applied with Elmer's glue is used to cover the exposed corrugate edges of the device and any other torn or punctured areas of the cardboard.



The exterior of the calendar frame is coated with an adhesive spray and a wide-loop woven nylon material is wrapped around the exterior. The ends of the nylon that extend beyond the sides of the calendar frame are tucked inside and stapled into place.

TACTILE CALENDAR CONTINUED



5. Tactile cues are cut out from tri-wall cardboard. The edges of the cardboard are edged with paper and Elmer's glue.



6. An item that will represent a specific activity is chosen to be placed on the tactile cue. The silhouette of that specific item is drawn onto the center of the cue. That pattern is then carved out of two layers of the cardboard cue. The cue is primed, painted and polyurethaned, and the chosen item is hot glued into its corresponding hole.



7. Adhesive backed Velcro strips (hook side of Velcro) are placed on the back of the cue to allow it to stick to the calendar frame. Large black and white labels describing the cue's activity can be placed at the top. Braille labels can also be included as an additional educational feature.



8. Cues can then be organized in various patterns on the frame to accurately represent the activities that the individual will take part in that day. One side of the frame can be used for morning activities, while the other side can represent the afternoon/evening activities. Vertical lines created with masking tape can also be added between where each cue should be placed to further distinguish one activity cue from the next.

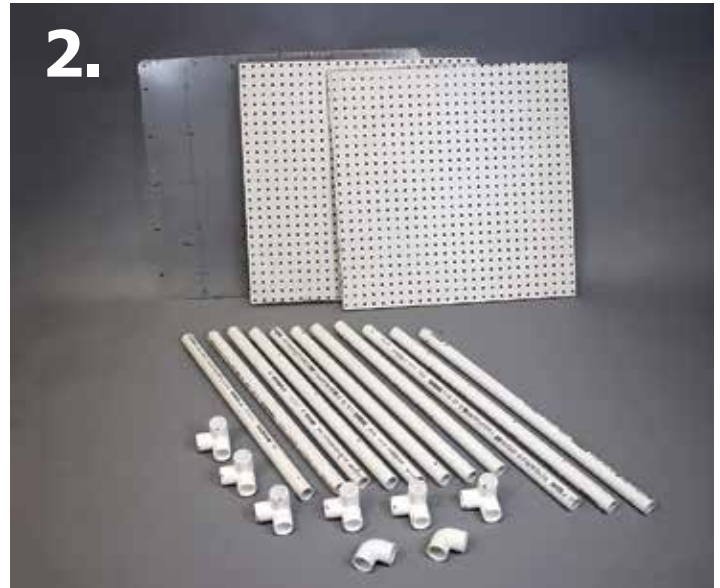
Build Breakdown:

LITTLE ROOM (MULTI-SENSORY ENVIRONMENT)

Little rooms, or multi-sensory environments (MSE) can be a perfect item to provide relaxation, encourage cause and effect understanding, and enhance sensory stimulation. These rooms create a safe space with items that provide visual, auditory and tactile feedback.



1. One inch PVC tubing is measured and cut to length to make a custom sized rectangular prism that will fit around the child. Three out of the eleven PVC tube segments are cut longer to create a wider shaped rectangular prism instead of a perfect cube where all the sides are the same length. Six three-way elbow fittings, and two two-way elbow fittings will be used to join all of the straight PVC tubing segments together.

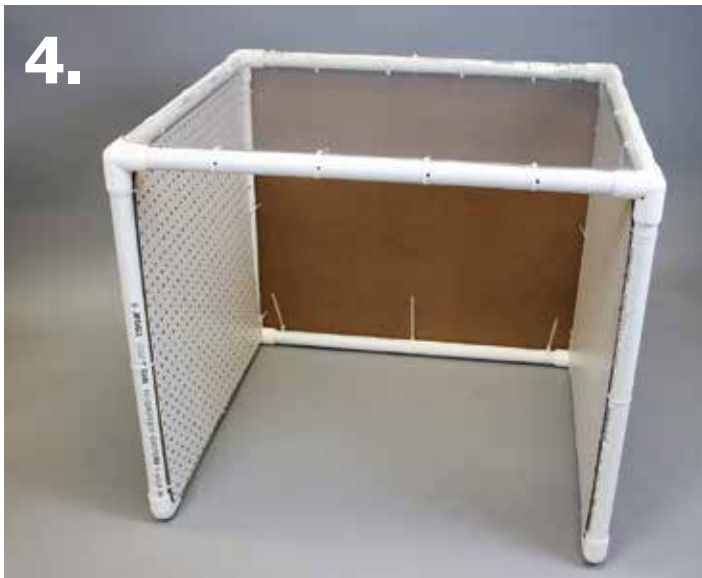


2. Four walls are created from pegboard, hardboard, and plexiglass. These walls will make up the left, right, rear and top of the rectangular prism. Holes are drilled along the outside perimeter of both the hardboard and the plexiglass to allow for these walls to be mounted with zip-ties. Smaller holes are also drilled in a linear pattern throughout the plexiglass to allow for items to be strung down through from above once it is mounted.

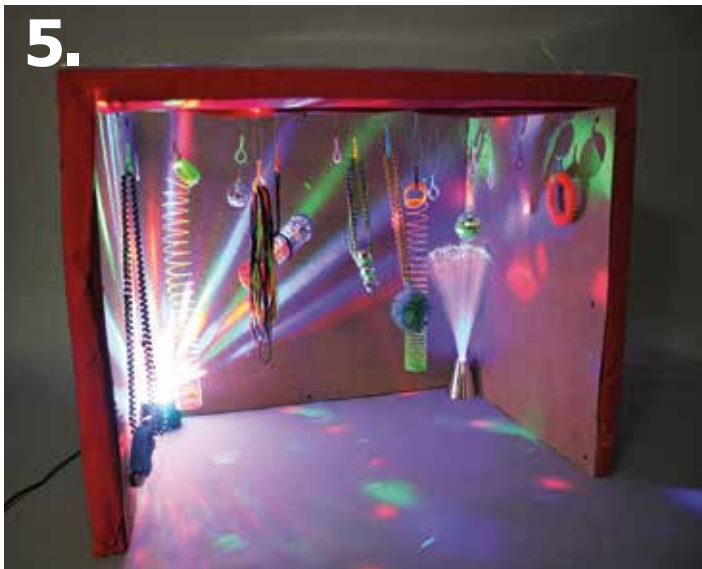


3. All of the PVC tubing segments are joined together with the proper fittings. PVC cement is used to secure the PVC tubing segments into the fittings so that they do not come apart. The front, base segment of the rectangular prism does not include a PVC tube. This will allow the child to enter into the little room and be able to lie on their back underneath without having to lie across a tube.

LITTLE ROOM CONTINUED



The pegboard, hardboard, and plexiglass walls are attached to the PVC rectangular prism using zip-ties. We decided to use two pegboard walls, and one hardboard wall, but this can vary depending on what items the child will be using within the little room and how those items will need to be mounted. Pegboard offers the greatest amount of versatility in most cases. The plexiglass will be used for the top of the little room so that string lights can be viewed from underneath if they are placed on top of the little room.



Tactile, auditory, and visual items are strung down from the top of the plexiglass using fishing line or string. Lengths can be adjusted to allow easier access to an item, but can also be shortened to encourage the child to reach out further and further, learning to go outside of their normal comfort zone. As shown here, heavier duty frames can also be built out of 2 x 2, or 2 x 4 wooden planks. These planks were then wrapped in fabric to decrease the risk of any user getting splinters.



Rope lights or Christmas lights can be placed on top of the little room for an added visual feature. This can be combined with a push button inside of the little room. By having the ability to turn the lights on and off the child can begin learning cause and effect. In order to block the view outside of the little room, which can be too distracting or overstimulating, a fabric sheet can be cut to length and attached to both the top and front of the little room (not shown here).

3D Printing

THE PROGRAM

The 3D printing program is a collaborative effort between ARISE Child and Family Service, Inc., Health_eConnections, and Weedsport Central School District. This project is supported by the NY State Disabilities and Health program, funded by the Centers for Disease Control and Prevention (CDC). This innovative program was developed in an effort to increase access to equipment that promotes physical activity and healthy eating for individuals living with disabilities. Individuals and programs within the community can request items through ARISE Adaptive Design, who then works with the students involved in Weedsport's technology class to develop and print the products

using three-dimensional CAD software, and 3D printers. This program provides a dual benefit in that it not only produces much-needed accessible equipment at a low cost, but also provides an excellent learning experience for the students. By creating these unique products, the students are able to see how work they do can have real-world application and can benefit someone's life in a positive way. Pages 26-27 show some of the products the students developed in the spring semester of 2018. These items, as well as others can be requested through the AAD website, or by contacting the AAD program coordinator (information listed in the back of booklet).



BENEFITS OF 3D PRINTING

Three-dimensional printing has been around for decades, but only recently has it become so widely accessible and affordable. With many high schools, colleges, libraries, and maker spaces providing access to 3D printers, developing an idea into a one-of-a-kind plastic product in a few hours' time is no longer out of the realm of possibility. The large advantage that 3D printed products have over devices found in a medical catalog is that the product can be completely unique to the end-user's specifications, needs, and dimensions, instead of a one-size-fits-all approach. 3D printed devices can also be offered at a much more affordable rate than many items found in a medical catalog.

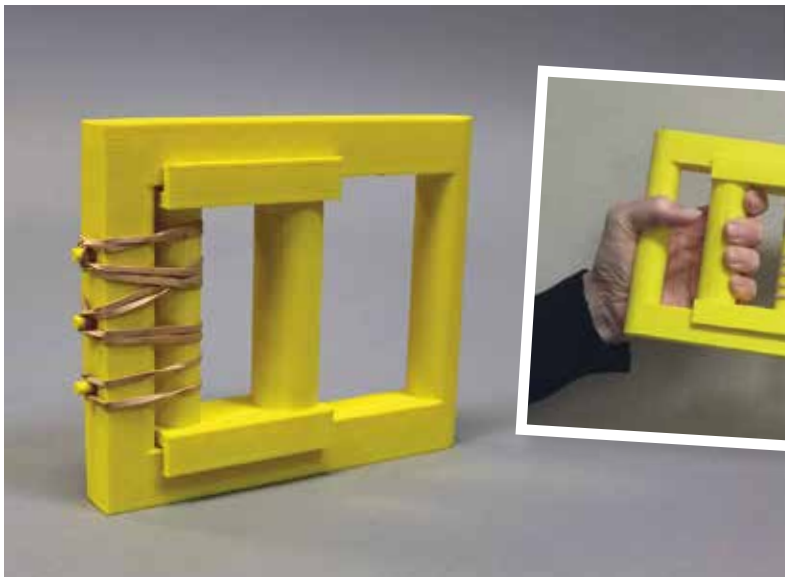


The Program Continued



Cup Holder

The cup holder mounts to the armrest of a wheelchair, allowing the user to more easily hydrate throughout their day. The cup holder can swivel in and out to allow for better access and reduce the chances of it breaking off in doorways or other tight spaces. The mounting mechanism can be customized in size and shape to fit a wide range of wheelchair types.



Grip Strengthener

The grip strengthener allows individuals to better improve their grip strength by squeezing the handle closed against resistance created by attached rubber bands. The handle can be custom sized based on the size of the user's hand, and rubber bands can be added or taken away for more or less resistance.



Sandwich Bag Holder

The sandwich bag holder allows a user who may have limited grasp, unsteady movement, or only the use of one hand/arm the ability to more easily hold open a sandwich bag while placing an item inside of it. The two vertical arms grip and position the bag upright so the user can pour or place something within it without having to hold the bag at the same time.



Cutting Guide 01

This cutting guide allows a user who may have limited grasp or unsteady movement to more easily brace and slice a fruit or vegetable item. By not having to hold the item near where they're cutting, and with the help of the cutting grooves used to guide the knife, this item reduces the risk of cutting oneself.



Cutting Guide 02

This cutting guide allows a user who may have limited grasp, unsteady movement, or only the use of one hand to more easily brace and slice a fruit or vegetable item. Through the device's ability to hold and steady a fruit or vegetable on its own, an individual is only required to hold onto the knife that they are using to cut with.

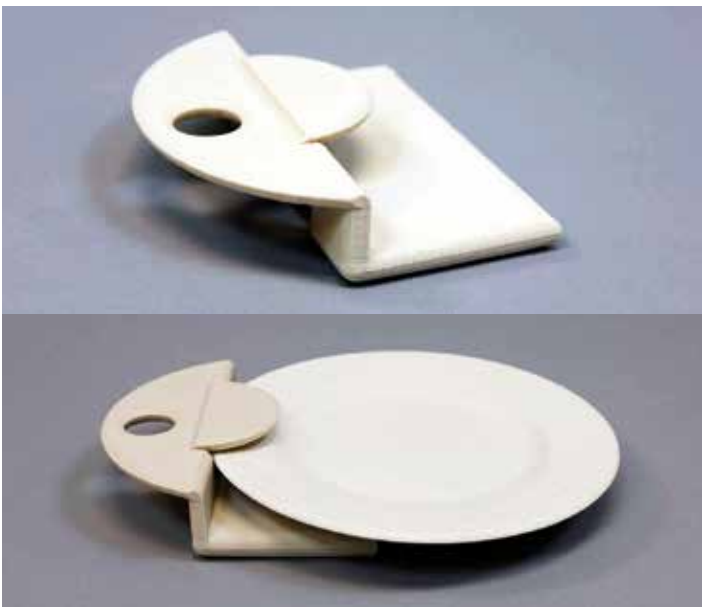


Plate Holder

The plate holder can be a helpful item for individuals who may be lacking grip strength, or have sensory difficulties in their hands, such as the inability to feel whether something is hot or cold. This plate holder can prevent the user from burning themselves on a hot plate. It also offers a large handle that is easy to grab, as well as a hole for your thumb that provides extra grip and stability.



Cell Phone Leg Mount

The cell phone leg mount is created for a wheelchair user who likes to have their cell phone on their lap without having to worry about it falling off. When placed in the leg mount, the phone is angled upright to prevent glare due to sunlight or overhead lighting. The leg mount is secured around the thigh with Velcro fasteners that can be adjusted to any leg size.

Resources

ARISE Adaptive Design

Connor McGough, Program Coordinator, 315-671-5104, cmcgough@ariseinc.org,
www.ariseinc.org/arise-adaptive-design

ARISE Child and Family Service

Independent living center providing services to individuals with disabilities
www.ariseinc.org

Adaptive Design Association – New York, New York

www.adaptivedesign.org

Adaptive Design Association’s Learning Library

<http://www.adaptivedesign.org/copy-of-learning-library-1>

Adaptive Design – Ibarra, Ecuador – Prótesis Imbabura

<http://protesisimbabura.com/>

Adaptive Design – Guatemala City, Guatemala – FUNDAL

An organization providing educational programs for children with deaf-blindness and multiple other disabilities
<http://www.fundal.org.gt/taller-de-disentildeos-adaptados.html>

Adaptive Design – Philadelphia, Pennsylvania – Temple University

<https://news.temple.edu/news/2017-09-25/project-creates-cardboard-adaptations-kids-disabilities>

EnableMart

Assistive technology provider
<https://www.enablemart.com/>

e-NABLE

3D printed prosthetics
<http://enablingthefuture.org/>

Go Baby Go

A national, community-based research, design and outreach program that provides modified ride-on cars to children birth to age 3 who experience limited mobility
<https://sites.udel.edu/gobabygo/>

Rehabilitation Engineering and Assistive Technology Society of North America

<https://www.resna.org/>

AbleData

Information on products, solutions and resources to improve productivity and ease of life’s tasks.
<https://abledata.acl.gov/>

Thingiverse

Digital designs for physical objects
<https://www.thingiverse.com/>

About ARISE Child and Family Service

Since 1979, ARISE has provided opportunities so people with disabilities can live freely and independently in the community. Everything ARISE does is based on the independent living philosophy: the belief that people with disabilities have a right to self-determination, the freedom to make choices and work toward achieving personal goals and systems change. Each year, ARISE serves more than 7,000 people from offices located in five Central New York counties: Onondaga, Oswego, Madison, Cayuga, and Seneca. All programs are consumer-directed, maximizing choice and opportunities for the people we serve. Services areas include:

- **Advocacy & Accessibility**
- **Basic Needs & Assistance**
- **Education, Employment & Skill-Building**
- **Health & Wellness**
- **Recreation & Art**

As a designated non-residential Independent Living Center, ARISE is organized and directed by people with disabilities. Many services are available to people of all ages who have all types of disabilities. Independent Living Centers (ILC) have five key characteristics. Those are:

- **consumer-controlled** – it is operated by people with disabilities who directly influence policies and service delivery
- **community-based** – it is located in the communities we serve and is dedicated to meeting each community's specific needs
- **non-residential** – we do not operate a residential facility and focus on helping people live as independently as possible
- **non-profit** – the agency meets the federal and state definitions of a not-for-profit organization
- **cross-disability focused** – we serve people of all ages with all types of disabilities

ARISE is at the forefront of advocating for access, choice, and self-determination for individuals with disabilities. We encourage you to get involved and give back to your community, either by volunteering to help ARISE accomplish its work, or by helping advocacy efforts that reduce the barriers people with disabilities face in their everyday lives.

For more information, contact the ARISE main office at:
315-472-3171 or go to: www.ariseinc.org

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