Editor’s Letter

Life is cyclical: it brings beginnings and endings, commencements and conclusions. Most of these life events are blurred—as one moment ends, another begins. Our most significant beginnings and endings are marked by ceremony, commemorated in some way so you and those important to you can hold it in your memory.

In this issue, we address a significant commencement for our students and their families—their transition from The Camphill School into adult life. The school takes special care to ensure that our Transition Program graduates are as prepared as they can be for life “post-21.” Their families prepare themselves as they dive into the world of adult placements and the multitude of options and barriers. The struggle comes with finding a place that can support them as they move on and all of the legal, legislative, and fiduciary confusion and uncertainty that comes along with it.

The journeys of our families should concern and be of interest to not only families of those with special needs, but all of us—all of you—who support them. You are receiving this newsletter (and reading it) because you have chosen to believe there is a better world to be had for our students and their families, whether they are currently here, were here, or are yet to come. You believe in the importance of providing those with intellectual and developmental disabilities with options that best suit their needs. You believe that all human beings deserve to lead lives with meaning, where their contributions are valued and celebrated. This means so much to The Camphill School community, and we look forward to sharing more with you about this important issue in future publications.
At the beginning of this journey, as Charlie grew and missed all of his developmental milestones, I immediately sought help, confident I would figure out what was going on. The days of early intervention and giving him “more time,” morphed into years and exhausting visits to specialists all over the country looking for an answer. But there was never an answer. Every conceivable test could not explain why Charlie was non-verbal, had severe fine/gross motor delays, and apraxia. All the while it was clear he had solid receptive language skills, a great sense of humor, and loved being with others.

I will never forget the feeling of utter devastation when I was told that I might never know the cause of this debilitating condition. At age five, he received a diagnosis of Pervasive Development Disorder/Not Otherwise Specified (PDD/NOS), which is an official diagnosis for... no explanation. I stopped searching for the WHY and shifted my focus to the HOW—how to support him at home, how to find the best therapies, and how to find an appropriate school setting.

I live in a very small town, and given the complexity of Charlie’s needs, he became an “out of district placement.” Over the next ten years he attended four different schools across the state, and none of them worked for reasons ranging from staff inexperience with a non-verbal student with severe fine-motor issues to their rigid applied behavior analysis (ABA) practices to which Charlie did not respond.

During this time, I routinely brought him to Children’s Hospital Boston to meet with his metabolic doctor. In his 35 years of practice he had never encountered a patient like Charlie and was committed to trying to find a reason that would explain his symptoms. He suggested having his DNA sequenced, which was a relatively new and innovative technology that aims to provide answers to...
families with undiagnosed diseases. This first round of testing was inconclusive. It would be six years later, per the doctor’s suggestion, that a repeat DNA sequencing would confirm a diagnosis for Charlie—SynGAP 1.

As Charlie grew, so did his frustration, and with that his behaviors became worse both in school and at home. He was not making any progress in toileting, dressing, feeding, or communication. My school district raised the possibility of a residential placement, which literally nothing was working. In retrospect, a residential placement was one of the best options; I had tried everything, and I made me physically ill to even contemplating, dressing, feeding, or communication. My school district raised the possibility of a residential placement, which literally nothing was working. In retrospect, a residential placement was one of the best options; I had tried everything, and I made me physically ill to even contemplate. At the same time, it had become extremely agitated for unknown reasons, and the resulting behaviors are heartbreaking.

And so, it was this past August, roughly four weeks into the summer break on a particularly bad day filled with frustration and tears, I made a commitment to myself and to him, to explore the SynGAP diagnosis. I had done some research, but it was not a priority due to COVID and the need to focus on Charlie’s upcoming transition to adult services. I also had doubts about the significance of this diagnosis at his stage of life, and I questioned the potential impact. But on that day, I realized if there was something, anything, I could do to improve his quality of life, I needed to do it. Four days after bringing Charlie back to Beaver Farm, I sent the email on page 5 to the SynGAP Research Fund.

SynGAP 1 is a rare neurodevelopmental disorder caused by a random typo in a person’s DNA. Because of this typo, people with SynGAP 1 are only capable of creating 50% of the critical protein (SynGAP), which is required for proper brain function. This causes all the manifestations that characterize SynGAP patients: intellectual disability, features of autism, gross/fine-motor delay, limited speech (most are non-verbal), sleep and behavioral disorders, epilepsy, low muscle tone, and global developmental delay. It is considered a spectrum as patients present with a wide range of symptoms that vary in degree of severity. Some symptoms may be absent altogether, for example Charlie has never had seizures.

Having a diagnosis has been transformative. In connecting with the SynGAP Research Fund (SRF) I found other families who have a “Charlie,” and not just in terms of the presenting symptoms, but who share many of his idiosyncrasies such as a love of elevators, fast rides, music, and animals, as well as proficiency using technology and possessing a remarkable visual memory, to name a few. The first time I spoke with another mom who has a child with SynGAP and heard how extremely similar her son was to Charlie and how her journey paralleled mine, I was in tears.

I found a community of amazing families who offer support and share information and ideas across all aspects of life regarding what it is like to have a “syngapian.” Simultaneously, SRF is committed to raising awareness of this under-diagnosed disorder and to fundraising for research in order to find a cure utilizing genetic therapies. And they are making incredible progress. The thought of a cure after all these years is something I’m still processing, as there are too many unknowns for me right now. But for the second time in Charlie’s life I have hope—and for the first time I am not alone.

Despite this progress, when he returns home for holidays and vacations, life remains a significant struggle. Charlie’s issues are still there. The level of care and support he needs to get through each day combined with his inability to effectively communicate his needs is both physically and mentally exhausting. Written schedules help to manage his expectations, but there are times when he becomes extremely agitated for unknown reasons, and the resulting behaviors are heartbreaking.

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Turn your Pennsylvania personal or business tax dollars into tuition assistance!

The Pennsylvania Education Improvement Tax Credit (EITC) program enables you to redirect your Pennsylvania tax dollars — almost dollar for dollar — to The Camphill School, for tuition assistance for our students from Pennsylvania.

To qualify for the program, businesses must pay one of the taxes listed below. Individuals qualify if their Pennsylvania state taxes exceed $3,500 annually. Effectively, you or your business can donate to The Camphill School instead of paying taxes to the Commonwealth of Pennsylvania. Eligible businesses and individuals can receive a tax credit equal to 75% of their contribution.

Any business authorized to do business in Pennsylvania subject to one or more of the following taxes may be eligible:

- Personal Income Tax
- Capital Stock/Foreign Franchise Tax
- Corporate Net Income Tax
- Bank Shares Tax
- Title Insurance & Trust Company Shares Tax Insurance Premium Tax (excluding surplus lines, unauthorized, domestic/foreign marine)
- Mutual Thrift Tax
- Malt Beverage Tax
- Retaliatory Fees under section 212 of the Insurance Company Law of 1921

For businesses, application deadlines apply. If you want to support the school by giving directly, you will get a tax deduction, yes, but the majority of that donation is still a cost to you. If you make a gift to the school through this EITC program, it can offset almost your entire Pennsylvania tax bill — in other words, the donation comes at almost no additional cost to you. You are basically redirecting who gets the money when you pay your state tax bill, which you have to pay anyway.

Even more good news is that the Pennsylvania budget, passed in June, includes $40 million to the Educational Improvement Tax Credit program, (EITC), representing the biggest expansion since the program’s inception two decades ago and increasing the total to $225 million.

To learn more, contact Courtney Coffman (ccooffman@camphillschool.org) or visit camphillschool.org/ways-to-give.

Thank you to these businesses and individuals who have participated over the last year:

Craig and April Adams
Scott and Jen Althouse

My next adventure
By Talya Dovas

This past summer, I packed up my life in Detroit, Michigan, drove 10 hours and arrived at Beaver Farm on August 26, 2021. When I pulled into the driveway I began to cry and laugh simultaneously as I didn’t really know what to expect or what I was truly getting myself into. I was overwhelmed with gratitude that I had the opportunity to live in such a beautiful community.

Prior, I worked as a collaborative assistant in an early childhood classroom at the Rudolf Steiner School of Ann Arbor (2020-21). I also completed a 200-hour yoga teacher training in the fall of 2020, and immediately following the certification I sought to teach yoga to kids with special needs. The director of the early childhood program told me about Camphill. She knew I had been working with kids with special needs, and obviously I was interested in Waldorf® education and wanted to pursue a Waldorf® teacher training. Once I began my research about Camphill I became very intrigued. Working on a farm has always been a dream of mine and studying in the Academy was very enticing, aligning perfectly with my future intentions of becoming the lead teacher in a Waldorf® classroom and deeply studying Anthroposophy and Rudolf Steiner’s work. I didn’t hesitate to apply, as I knew this was my next adventure in life, as it encompassed so many of my interests.

I grew up spending my summers in Israel, often living in a kibbutz, a communal settlement first founded in Israel in 1909, typically agricultural based, in which all wealth is held in common. I have been a coworker at the farm for nearly five months now. I have absolutely loved working the land and all the farm duties, especially working with the animals. I have had incredible opportunities to guide the students, I am equally receiving. As much as I am here to support and guide the students, I am equally receiving.

I am challenged to grow and learn as a person each day, and am absolutely better for it. My time at Camphill will change me. I will be a different person by the end. I already am, and I wouldn’t trade that for anything.
From the moment you become a parent of a child with special needs, the advocacy journey begins. Whether it is educating the plethora of people in your child’s orbit of what their needs are or explaining to a stranger on the street, Camphill parents are tirelessly blazing the trail to provide the best for their children.

After years of navigating the special education system, many families breathe a sigh of relief when they arrive on the doorstep of The Camphill School. Finally, there are allies who can help in the process of providing a meaningful education and opportunities for growth and friendships in a deeply supportive community setting.

However, all too quickly, the panic sets in as their thoughts turn to the inevitable: “What happens after my child turns 21?” This answer is different and unique for everyone. Transition outcomes have direct correlation with eligibility requirements, personal preferences, level of need, finances, admissions, and what is realistic for each family. By nature, post-secondary transition is highly complicated and deeply personal. It is much anticipated that the experience of transition will be a cathartic and a pivotal point in one’s life, wherein the line of demarcation is drawn between childhood and adulthood. What makes transition especially poignant is that parents are turning to their own mortality and recognition of the need for quality advocacy and care for the years after they are gone. While nothing makes transitioning particularly easy, having a vision and grasp of the system by the time the child reaches the year before graduation is very helpful; that way long before a student’s last school year, parents will have already made important determinations about what strategies and options will work best for them.

Age 14, when the transition section appears in the IEP, is a great time to start this process. I stress the word process because post-secondary transitions are years in the making until they are months, days, and minutes away. In the case of post-secondary transition and the families who are orienting themselves to this change, that means transitioning from the auspices of school/educational...
funding into the adult world of Medicaid waivers, which are governed by an entirely new set of laws and criteria. The most important difference between school and adult funding is that in Pennsylvania you are eligible, but NOT entitled to adult services. It is important to note here that all states operate a bit differently. Some states such as California and Vermont have full entitlement and fund educational years until age 22!

The general timeline for transition in Pennsylvania is as follows: age 14 register with your county for services through the office of Mental Health and Intellectual Disabilities or MH/IDD. This office is called different things in different states; for example, in New Jersey it is called Department of Developmental Disabilities or DDD; and Massachusetts it is DDS, short for Developmental Disability Services. Whatever it is called in your home state, getting registered is essential.

Once you are registered you will be assigned a caseworker or support coordinator; sometimes both! The level of involvement of the coordinator will vary from state to state, county to county, as well as the associated vocabulary and timelines. Some Pennsylvania families are able to establish a relationship with a coordinator, yet others get little to no involvement until the last year prior to graduation. However, if planning to collaborate with an in-state service provider, this support person should be your number-one best resource towards meeting the objectives of a transition timeline, such as finding available programming, arranging visits, understanding required supports, and submitting paperwork.

One of the main functions of support coordinators is to submit paperwork, including getting your child on the list for the PUNS (prioritization of urgency of need). The budgeting for Medicaid waivers is based off federally dispersed funds that are allocated to states, so each year there is a finite number of new waivers granted. This is why it is a good idea to get on the PUNS list as soon as possible even if the transition is still years away; because when the state does its projected annual budgeting for Medicaid waivers, your child will already be part of that equation. Families can expect that in the last six months prior to aging out of the educational system, the individual will be bumped up to emergency status on the PUNS, which is when supports coordinators can actively start to make referrals to various service providers. The waivers typically come available around June in the final school year.

Something else to keep in mind is that Pennsylvania is an employment first state, meaning quite literally that this is the first option. Each Pennsylvania student must be referred to the Office of Vocational and Rehabilitation (OVR) for an evaluation to determine whether or not the student is deemed eligible or deferred from competitive or supportive employment (i.e., a full- or part-time job in the community). If the student is eligible for supportive employment, the waiver dollars can cover job coaching after a certain number of months when the OVR funds are depleted. If a student is deferred from OVR, it is possible for the waiver money to kick in for cover costs associated with a day program or other volunteer jobs in the community.

There are several types of Medicaid waivers for people with IDD/autism, but the three most commonly utilized are the Person/Family Directed Support or P/FD, Community Living, and Consolidated. Most people who have IDD/autism pursue one of these three aforementioned waivers because they have higher caps and qualify for more services than autism waivers. The caveat with receiving waivers for IDD is that the IQ must be below 72, and the disability must have manifested between the ages of 0–8, with the exception for folks on the autism spectrum, as there is frequently a discrepancy between IQ and adaptive behaviors. If a student has an IQ over 72 and does not have a diagnosis of autism, the student would be ineligible for these types of waivers and the process for them looks a bit different.

Your plans and vision have an impact on the type of waiver you will receive. For people who plan to stay living at home without round-the-clock supports, or who plan to get a job in the community through OVR, the P/FDS waiver is generally what they receive. It has a modest cap of $33,000 per year and can be applied to transportation, day services, and TSS care. The Community Living waiver has...
the next-highest cap of around $80,000 per fiscal year and can be applied to life-sharing circumstances. Finally, the consolidated waiver covers costs for highest levels of needs and services for both day and residential staffing (there are caveats to what is covered, so do your research), without a cap for life. This is considered the most highly desirable waiver. You can find a full list of what is covered by the various waivers at https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Intellectual-Disabilities-Services.aspx.

Another frequently asked question is, “How does my student get into an adult Camphill or community-like placement?” Unfortunately, in Pennsylvania and many other states there are restrictions due to settings criteria. Settings criteria is a Community Medicaid Service (CMS) guideline, as explained in the final rule which forbids application of Medicaid dollars to congregate settings where people live AND work. Each state has a slightly different interpretation of this final rule; Pennsylvania is one of the more restrictive. This explains one of the reasons why settings similar to Beaver Farms are challenging to replicate for adults given the current policy interpretations. In states where this is allowed, communities are considered high-structured settings. Community life is the hallmark of most Camphill villages, but according to the state, people should live amongst non-disabled peers to the fullest extent possible, and there are actually restrictions on living nearby too many disabled peers if receiving state funds.

Want to seek out a desirable program in a different state that permits waivers? The general rule is that waivers do not follow a person out of state. To be clear, there have been exceptions to this in some states, but in recent years it has become more difficult to do so. Therefore, if considering moving, it is often necessary to establish residency in a desired state and reapply for Medicaid funding. This can take up to one year to accomplish, with no guarantees of being accepted into the program. Just because a student attends The Camphill School, it in no way guarantees admission to an adult Camphill or Camphill-like placement. Each program has its independent admissions process for acceptance and the possibility of long wait lists. Because adult placements are meant to be lifelong, when sought-after programs fill up, it may be many years before an expansion happens to allow for new openings.

If you are thinking that the laws and regulations that govern Medicaid-eligible adults are restrictive, then you are not alone. It is important to recognize that the interpretation of these policies is to ensure that physically or mildly disabled people have full inclusive access to society. However, there has been an acute resistance on the part of policy makers to acknowledge that many people with low-incidence disabilities have a very different set of needs and required supports. If you would like to help effect policy change, there is an active group of parent advocates, which can be found on Camphill’s Parent C.O.N.E.C.T. Facebook group. There are many active members of this group who have partnered with an organization called “Together for Choice.” This group is lobbying in Harrisburg to change current policy so that families can CHOOSE.

While post-secondary transitions are daunting, there are also success stories and happy endings. The main thing to remember is that the process of transition is not “one size fits all” and, just like comparison to typically developmental peers can seem irrelevant, no two young adults with developmental disabilities are the same, which is why educational plans are individualized. It is time society starts treating post-secondary transition the same way. In order to improve transition outcomes, we need a variety of settings, activities, programs, and supports for our citizens with intellectual and developmental disabilities. We are grateful to the parents, teachers, and policy makers who take time to listen and advocate for the vulnerable and strive to create a brighter future for all.
**Advocacy Workshop: May 14**

Together for Choice, an organization whose mission is to unite to protect and advance the rights of individuals with intellectual and developmental disabilities (I/DD) to live, work, and thrive in a community or setting of their choice, is planning to host an all-day Advocacy Workshop. The aim of this workshop is to educate, train, and prepare like-minded advocates to have a better understanding of the current regulatory and political challenges in Pennsylvania and develop strategies to effectively advocate for their loved ones with I/DD. The tentative date of the workshop is May 14. Location will most likely be in Phoenixville. Please be sure to register early!

Visit togetherforchoice.org for more information. You may also reach out to Ashley Kim Weiss, Together for Choice’s National Coordinator, if you have any questions, comments, or suggestions. Phone 310.889.8800 or email ashley@togetherforchoice.org.

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**2022 CAMPHILL GALA**

**HAN D-CRAFTING OUR FUTURE**

On Friday, June 3, 2022, we will host our first hybrid gala!

Guests may join us at historic Loch Aerie Mansion in Malvern for an evening of dinner and dancing or participate virtually from the comfort of their own home.

Whether you’re in the ballroom or watching the livestream, you will enjoy musical performances from Almost Minnesota and our students, have the opportunity to bid on unique, student-made items, and be a part of handcrafting our future.

Brighter days are ahead, and we look forward to hosting you in person or from afar.

Visit camphillschool.org or bidpal.net/camphill2022 for more information, purchase admissions, to preview and bid on silent auction items, purchase much-needed items for our students, donate, buy an ad, or sponsor the event.

**Questions?** Contact Sarah at sdowns@camphillschool.org or 610.469.9236 x133.
The Joy of Playing
by Ginny Thimme, Second Grade Teacher

There's the thrill and excitement of something new and the challenge of pushing yourself. There's the fun that comes with swinging, sliding, jumping, climbing, and balancing. There's the joy of playing alongside your friends and classmates. Then there's the deep inner satisfaction and peace that comes when your sensory needs are met. All of these things live on once playtime is over. They reverberate in the children's muscles, joints, lungs, and hearts, and show themselves in deeper breathing, twinkling eyes, rosy cheeks, coordinated limbs, and more-focused learning in the classroom.

These thoughts came to me whilst watching my second-grade student, Jett, negotiating his way across the wobbly bridge and up and over the climbing web on our new playground, which arrived at the end of October. The playground was built for us in three weeks by three men, Willy Atz, Luis Atz, and Alex Maslach. They worked hard every day: digging holes, pushing wheelbarrows, unpacking crates, and building structures.

There were exciting moments, like the one when the flatbed truck arrived with the huge tower and slide strapped to it; and then there was the pickup truck that dumped a mountain of woodchips onto the grass under the trees. The whole project, from beginning to end, was overseen by Bill Brunner, our Maintenance Supervisor; it was inspired by the adventure playground that Ivan Rynder created behind Catalpa a few years ago; and it was made possible by Guy Alma and the Development team and realized through the generous donations at last year’s Gala by the parents, grandparents, friends of our school, and a gift from the family of Caroline Chester.*

When Meadowsweet was built in 2015, it seemed to have everything: beautiful light-filled classrooms, a magical kindergarten space, a catering kitchen, a laundry room, a big dining room, and living area for the day-student population, but it didn't have a playground. It had a hill, a patch of grass, a teeter-totter and a sandbox, but no swings, no slide, and nowhere to climb. Now that the playground is here, Meadowsweet seems complete.

Since its opening at the beginning of November, children have been playing on the playground every day: Kindergarten and Lower School children, and, on weekends, I have seen families there with picnics and blankets, playing and having lunch together! One evening I saw the staff children playing on the playground with flashlights. It made my heart jump for joy.

The Camphill School is the Children’s Village, and now we have one more space where the children can play. As Oscar Wilde’s “Selfish Giant” said, in a story that we performed as a play a few years ago when our school turned fifty: “My garden shall be the children's playground for ever and ever.”

*Editor’s note: A key to making our playground a reality is the family of Caroline Chester. Caroline is an alumna who passed away in 2011. Her family made a generous contribution when Meadowsweet was being built and requested that a future playground be named in her memory. We look forward to a time when her family can come visit and we can dedicate the playground officially to Caroline.
A Tree Verse for Thursday

Thus speaks the broad leafed Maple, the tree of Jupiter.

O Human being, overcome the haste and hurry within you,
Seek hours of quiet, which bring goodness and wisdom to birth.

— J. Hemleben

Walking into the craft house on a cold snowy day you hear familiar sounds emanating from all the workshops: the trundling of the delivery cart emanating from the Store, the click of the pricing tool, the soft repetitive clack of a wooden beater in the Weaving workshop, the tapping of mallets on chisels, the scrape of the rasp, and the push-pull of a hand saw.

When you enter the Woodshop, your nose registers the smell of newly shaved wood and your eyes see an active workshop where students and adults are engaged with both their hands and their whole bodies. Most of all, you experience the peacefulness and order of a workshop focused both on the learning of skills for the students and the transforming process of working with wood.

The leader of this workshop is Carlton Noll, who has been teaching our students in the Woodshop since 2003. Carlton began at The Camphill School as
A process of exploration
(continued from page 21)

Carlton leads the students in a process of exploration; starting with walking in our abundant woods to see where raw material comes from, perhaps finding a branch that would make a good walking stick or a larger piece that might make a bowl or a spoon. For some students this can lead to working outside splitting the wood or making charcoal for the blacksmith’s forge. For others, it means bringing the wood inside and working with the actual shape to see what is trying to reveal itself. Is it a stool? Could it be a musical instrument? In this way students can experience the source of the wood as a natural resource, and there is lesson in ecology and appreciation of the natural world underpinning all of their work.

Both students and teachers love coming to the Woodshop. It is a place where they can find creative expression, and the door is kept open for all students to figure out their own way of using their hands to be makers. Carlton has always been a behind-the-scenes kind of guy, and almost every class play, midwinter festival, or puppet show reveals some piece of scenery or prop that was essential for the story.

The Lower School is busily engaged with crafting a variety of projects following the Waldorf® principals of working first with convex forms, then curvature, then concave forms, and finally the element of assembly. A highlight of the 3rd grade year is to construct a shelter or house somewhere in the landscape, which has resulted in playhouses, storytelling shelters, and an adobe house on the creek. All of these provide places to visit and play for the whole village.

Year after year, we look to Carlton to continue to share and pass on his love of wood and its transformation into both useful and beautiful objects.
The Camphill School's mission is to create wholeness for children and youth with developmental disabilities through education, extended family living, and therapy so that they may be better understood, they may more fully unfold their potential, and they may meaningfully participate in life.

The Camphill School does not discriminate on the basis of race, age, color, creed, gender, sexual orientation, national or ethnic origin, or disability.