

SAIL CONNECT







CELEBRATING 2 YEARS OF FRIENDSHIPS, CONNECTIONS AND EDUCATION

A Seasonal Newsletter from SAIL Solutions for Adult Interdependent Living

LETTER FROM THE PRESIDENT

SAIL ends its second year of providing opportunities for families to connect, develop friendships, and learn what it takes and means to launch a loved one. It has been a tremendous year with membership surpassing our 2023 goal in just the first three months of the year. Clearly, there is a need for SAIL.

SAIL will continue to provide programming in the FALL with SAILing Lessons, as subject matter experts present on various topics that are of interest to the SAIL community. Friendship Connect will continue to host Friday night events, offering fun activites for our loved ones in conjunction with purposeful conversation with the parents.

I would like to take this opportunity to thank all of our volunteers who have worked hard to bring quality programming and events to our SAIL members. Whether you have helped on a committee, or promoted SAIL at events and in the community, or been a part of planning and executing a SAILing Lessons, your contributions have brought together a group of people who have found community and, hopefully, inspiration to develop a housing solution that will address the needs of their loved ones while providing a robust and full life.

For those who were able to attend our Friendship Connect event on Friday, June 2, it was nothing short of spectacular. To see our kids engage with other kids and our parents socializing with long time friends but also new friends who were brought together through SAIL was why SAIL was created.

Wishing you a safe, healthy and wonderful summer.

Kathy Remski

President, SAIL



- ARCHITECTURAL RENDERING OF RHS CONDOMINIUM BUILDING

ROCHESTER HOUSING SOLUTIONS (RHS) HITS MAJOR MILESTONE

The Rochester Hills City Council granted preliminary site plan approval for two of the inclusive neighborhoods that RHS is developing in Rochester Hills on May 22, Walton Oaks and South Oaks. City approval of the site plans is a major milestone for RHS and paves the way for final approval and permitting over the next 90-120 days.

Plans for RHS's third location, Auburn Oaks, are now under review by the Planning Commission and should be presented to the City Council this summer.

If all goes well this summer, RHS expects to break ground this Fall on all three locations, which will provide safe, inclusive, independent living (with supports) for up to 50 adults with disabilities when completed.

RHS is now accepting reservations for units for adults with special needs at our South Oaks and Auburn Oaks neighborhoods. There are opportunities to own and rent.

For more information, or if you are interested in making a reservation, please visit the RHS website, RochesterHousingSolutionsMi.org and complete the form on the "Contact Us" page.

People with intellectual and developmental disabilities (IDD) and their families often must find a way to save without losing public benefits that a person with IDD receives. Special needs trusts are one tool that can be used to help people pay for the things that they may need and want in their lives.

-THE ARC

TIP CORNER: Letter Of Intent

The question of "what happens when I am gone" can haunt a parent who has a loved one who is differently abled. Planning and preparing is one of the keys to ensure your vision and the vision of your loved one is realized by those who follow.

CHECK OUT OUR SAIL CALENDAR
LATER THIS SUMMER FOR UPCOMING EVENTS

MY SON SAM AND WHY I VOLUNTEER FOR SAIL.

-JOE SKORNICKA, SAIL BOARD MEMBER

My son, Sam, is now 23 years old. He is a very loving person and has a good sense of humor. I'll admit that I am a little partial in describing his sense of humor as "good," however, as I've been told that it is similar to mine. Similarities between us extend to our love of music and dancing. For the record, he is a much better dancer than I am. Sam has had intractable epilepsy since the age of three. As a result of his seizures he is cognitively impaired. He also battles poor appetite, fatigue and often has low motivation due to all of the seizure medication he has to take.

Last fall I was asked if I would consider getting involved with SAIL. After doing some research on their website, I immediately fell in love with their mission. My only hesitation was wondering what I could bring to the table to help this dedicated group of parents. Kathy Remski, SAIL's President, assured me that they had plenty of things that even an awkward dad (not her words), with limited volunteer experience, could add. So I signed on!

After six months of volunteering at SAIL, I would highly recommend to others who might be interested to step forward. First of all, volunteering and helping others gives me a sense of fulfillment. It's nice to give back. Secondly, SAIL has connected me with many fantastic parents who are facing the same issues that my wife and I face having an adult aged child with IDD (intellectual or developmental disability). Finally, even though we don't believe that Sam will be ready to move into his own place for a few years, we believe that working with SAIL (with their helpful website, Sailing Lessons and Friendship Connect) will better prepare us all for when that time does arrive. I am grateful for the opportunity to be involved with SAIL.



- JOE AND SAM

ACKNOWLEDGEMENTS:
SAIL WOULD LIKE TO THANK FIRST
PRESBYTERIAN CHURCH FOR GRACIOUSLY
ALLOWING US TO HOST EVENTS AT THEIR
CHURCH.

SAIL VISION:
WE DREAM OF A DAY WHEN ALL
INDIVIDUALS, WITH THEIR UNIQUE
ABILITIES AND TALENTS, CAN ENJOY LIVES
OF INTERDEPENDENCE, EMPOWERMENT,
AND PURPOSE IN THE COMMUNITY OF
THEIR CHOICE

BOARD MEMBERS:
SUSAN CHAPLIN
DON COURTRIGHT
SARA FENTRESS-GANNON
HEATHER MINGLE
TOM MUELLER
SUSAN NANRY
JIM AND KATHY REMSKI
JOE SKORNICKA
DENNIS AND RO VARLEY
TIM WEED

CREATE YOUR LETTER OF INTENT

No one knows your child the way you do, and no one ever could. A lifetime of support, education, medical care, experiences, and traditions make up the full life of your loved one - and only a parent really knows the details behind that life. You may have already determined who will care for your child if you are unable to. However, even if they have been involved in your child's life, they do not know your child and their needs to the extent that you do. Writing a letter of intent (LOI) for your child with special needs can provide continuity to your loved one's life and support those who will care for them in the future. The LOI is not a legal document, rather it is a document to memorialize your knowledge of your child's loves, preferences and needs so that future caregivers, guardians and trustees may provide the best possible care for your child. The letter can contain any information you would like but should be explicit about the areas of your child's life that need specific, detailed attention including financial plans, trusts, estates, and benefits received, medical and therapy needs, and the contact information for key professionals and family members. Additional information may include family history, school and employment history and critical life events that may have influenced you or your child in a big way – which may allow caregivers to develop a deeper emotional connection with your loved one.

The LOI allows parents to paint a detailed picture of their child's current life, including schedules, likes and dislikes, religious preferences, and behavioral information, which will help to ensure continuity in the parent's absence. The LOI should also contain the parents' vision of the future for their child. Where they will live, what type of job or program they might attend, social environments and activities, even religious observances, and traditions to be maintained.

A few additional tips about your LOI:

- · Every child is unique, and your LOI will be unique.
- · It should be flexible, clear, and personal.
- · Share it with people in your and your child's lives today and make it a living document.

The SAIL Website contains <u>links</u> to some examples of Letters of Intent as well as resources available to help parents prepare this important document. You can also find a link to a Letter of Intent template <u>here</u>. Your family attorney or trust attorney will also likely have suggestions of where to start.

NOT A SAIL MEMBER? JOIN SAIL TODAY!

BY JOINING SAIL, YOU WILL HAVE FULL ACCESS TO THE SAIL WEBSITE INCLUDING THE FRIENDSHIP CONNECT PLATFORM.

THE HOUSING ROADMAP AND ALL SUPPORTING RESOURCE DOCUMENTS.

TIP CORNER: STEPS TO INDEPENDENCE

DO: While preparing your loved one to live independently, work to have tasks, no matter how big or small, mastered by your loved one. The tasks can include taking a plate to the sink or folding towels or hanging a coat...it can be anything. Make a chart and celebrate victories that are achieved.

DON'T: Do tasks for your loved one because it is quicker or easier. Independence is achieved step by step and not in one big leap..

PS. Celebrate your victories, too! Letting go or giving up some control is hard.

RUNNING A TIGHT SHIP

"Running a Tight Ship" refers to the stage after your adult child has moved into a living situation on his or her own or with roommates. In the May 10 SAILing Lesson Jim Remski and Sara Fentress-Gannon addressed the parents' or guardians' role before and after this point for about 40 participants. Speakers recommended making a list or log of the

day-to-day necessities before your loved one moves out, such as:

- Monthly expenses
- Medications
- Medical supplies and when to reorder
- Chores that loved one handles
- Preferred groceries
- Sleep habits

In addition, once the individual moves out, you will want logs for the following to help with continuity between care givers and to document any issues:

- Care giver shifts
- Night shift behavior patterns and sleep log
- Incidents or concerns log

Examples of worksheets for all of the above are available on SAIL's website under "Running a Tight Ship" and in the slides from the meeting.

The second half of the session dealt with a "Letter of Intent," which states your wishes for all aspects of your loved one's life after he or she moves out and particularly after your death. The "Letter of Intent" article in this newsletter takes a deep dive into this topic.

Parenthood is about raising and celebrating the child you have, not the child you thought you'd have. It's about understanding your child is exactly the person they are supposed to be. And, if you're lucky, they might be the teacher who turns you into the person you're supposed to be. ~The Water Giver

HAVE A GREAT RESOURCE, BOOK, OR QUOTE TO **SHARE? SHARE IT ON FB:** SAIL - SOLUTIONS FOR ADULT INTERDEPENDENT LIVING



- SAIL'S FRIENDSHIP CONNECT MARCH 2023 Friendship Connect Hits New Record

In March, SAIL hosted its tropical themed event. Participants danced, limboed and enjoyed wearing leis that they grabbed from a tree of leis. Parents gathered to discuss why their loved one would make a great roommate. Over 80 people attended and all left with smiles on their faces.

On June 2, 90 people participated in SAIL's Friendship Connect at Springdale Park in Bloomfield Township, more than any prior event. New families and regular participants mingled happily, enjoying conversation, kickball, parachute games, art projects, water balloon toss and other games. The theme for this last event until fall was "red, white and blue." Event organizers were pleased with the turnout despite the near-record temperatures, which were moderated by a large supply of ice cream treats enjoyed by many, if not all! SAIL thanks the many volunteers who helped set up, clean up, greet guests, organize activities, serve ice cream, supply water and keep the games going!

Check out the SAIL Calendar on the website for a calendar of Fall events.