

Circles of Support respond to parents' fears, child's dreams

by Wendy Singer

One of the most troubling questions that occupies the mind of a parent of a person with a disability is, "What will happen to my child (young or adult) when I am not here or able to care for them?" This includes, "Where will they live, who will take care of them and understand their needs the way I do?"

Creating a "Circle of Support," also known as "Circle of Friends" or "Support Network," is one way that many families are addressing these questions. Simply put, these models start with the person at the centre (the focus person) and use their network to form circles of individuals who, together, provide support over the individual's life-span. Members of a circle usually include people that have developed a relationship with the person at the centre, be it a friend, teacher, therapist, neighbor, co-worker or relative. Support

provided can range from day-to-day issues, staying at a friend's home for a weekend, finding resources and living arrangements to planning in the event that something happens to the parents. Most uniquely, the network aims to build supportive friendships and relationships with the focus person, listen deeply to their dreams and find ways to realize them.

A brief history of Circles of Support

Judith Snow and Marsha Forest, both life-long advocates for inclusion, introduced their model of Circles of Support to Canadians in the 1980s. Snow had a master's degree in clinical psychology from Toronto's York University and founded the university's Centre for Handicapped Students.

After graduating in 1976, her mobility deteriorated and by 1978 she was only able to maneuver her wheelchair with her thumb. Snow had multiple diagnoses, including congenital progressive atrophy of the skeletal muscles due to spinal muscular atrophy.

Forest, Snow and Jack Pearpoint, president of Inclusion Press, created Snow's Circle of Support to ensure she was able to live independently with her care team and fulfill her dreams, from marriage to spiritual, social, art, relaxation and health. The result was Snow's ability to fulfill her life vision and provide a model of support that people replicate worldwide. (Read more about Snow's life story on p. 38).

Circles of Support: Moving from exchange to participation

In Snow's book *What's Really Worth Doing and How To Do It* (published by Inclusion Press in 1994), which she typed with her mouth using a breath operated Morse Code system, she shares a diagram of four concentric circles that represent the various types of relationships in our lives. These circles are:

- 1. Intimacy:** People or things closest to you that you could not imagine your life without, such as family, pets, computer, smart phone.
- 2. Friendship:** Good friends and relatives who you enjoy socializing with.
- 3. Participation:** People you interact with in groups, organizations, clubs or work colleagues.

4. Economic exchange: People you pay to be in your life, such as a therapist, hair-dresser or accountant.

Snow explained these circles: "When someone has been labeled into the 'special' world we see a very different pattern emerge in their relationships. In circle two there will usually be fewer people, often none or one or two. In the third circle again there will usually be none or one or two. There will be an explosion in the fourth circle with more than 10, often more than 30 people paid to be in this person's life. As the third circle remains barren, the person gains no new relationships, interests or opportuni-

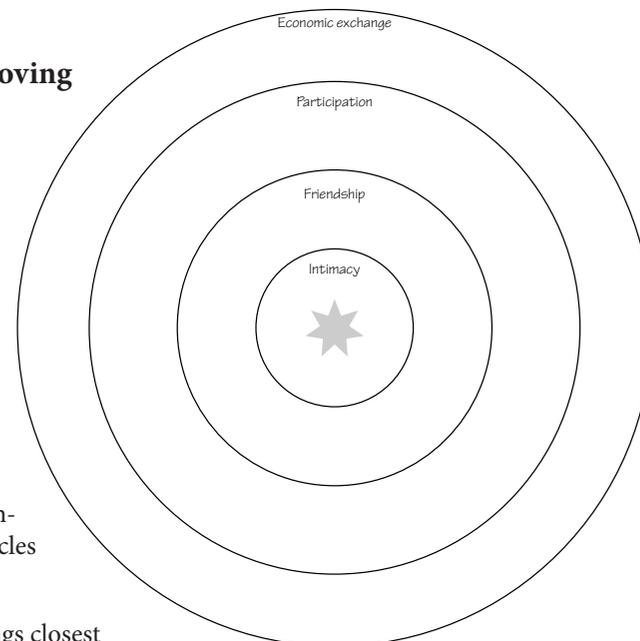


Image: Inclusion Press ©2015 |

ties from which to build a fulfilling circle of close friendship and intimacy."

Circles of Support address this imbalance and help the person at the centre participate in community life where they contribute and are appreciated for their gifts, enabling them to develop and expand relationships in the other circles.

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Judith Snow.
Photo: Inclusion Press

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A paradigm shift from disability to giftedness

Circles of Support not only provide the space for a person to share their dreams (“Inclusion holds the fundamental that all people are dreamers,” wrote Snow), they shift the conversation away from deficits and towards each person’s unique gifts.

Wrote Snow: “Believing in disability allows us to have assumptions that people are hampered by limitations. In disability, resources are expended to overcome limitations, creating much activity but no participation. In Giftedness, resources are directed to foster participation.”

Mike Green, a student of Snow’s, supported her during the writing of *What’s Really Worth Doing and How To Do It*. A father of a child with a disability, he added: “People labeled with disabilities and their loved ones are often so conditioned by the disability paradigm that they cannot see gifts or possibilities. It can feel impractical, embarrassing or foolish to have dreams for a ‘labeled’ loved one who is surrounded by case workers and plans. When people begin to see gifts and begin to participate in the Giftedness paradigm, it is as though a fog has lifted from their eyes. To see gifts after being conditioned to see only deficits and problems is a wrenching, heart opening experience. This different view leads to a

new world, it is as simple as a new pair of glasses. We see what we believe.”

How to begin a Circle

1. Find a facilitator who will:

- › Determine who the circle is for (parents and/or child);
- › Make a list of potential Circle members (Snow suggested 20 to 40) that the family knows and trusts;
- › Issue the initial invitations;
- › Keep meetings going;
- › Get back on track – in case meetings stop or the focus moves to “fixing” activities.

2. Circle members will:

- › Listen to the dreams of the focus person and find ways to realize them in whatever way is possible;
- › Plan for the future;
- › Provide support whenever possible.

Note: Not all members participate at the same time. This is meant to be a dynamic group that evolves with each member’s life situation. While supporting the focus person, members gain support and inspiration as well. ■

For information about Circles of Support, visit www.inclusion.com.

PLAN sets up Support Networks across Canada

Planned Lifetime Advocacy Network (PLAN) is a Canadian organization established by and for families that is committed to future planning and securing a good life for a relative with a disability.

Originally and currently based in British Columbia, PLAN was created in the 1980s by Al Etmanski, who was the director of The BC Community Living Movement, which focuses on the inclusion of people with disabilities in community life.

PLAN’s mission is “to give parents peace of mind about the future, knowing their children with disabilities will be safe and secure over their lifespan.” The “Support Network” aims to empower people with disabilities to live good lives as part of the community, have financial stability, make informed decisions, find good places to live and plan for the future. As with Judith Snow’s Circles of Support, these networks identify the person at the centre of the network’s gifts and build on them.

Nancy Rother is a psychologist living in Montreal who, throughout her career, has supported people who have a disability and advocated for inclusion. She has been active nationally in the Community Living Movement and

worked with PLAN in BC in the early days of its development. The impetus for PLAN stemmed from the realization that the best way to ensure a good quality of life for a vulnerable family member when their parents were no longer able to care for them was to create a loving network of friends and family. “We recognized that the biggest handicap for people with disabilities was their social isolation and loneliness. Individuals, in particular those who were educated in segregated settings or worked in sheltered workshops, might have been learning concepts and skills but they did not have the opportunity to participate in community life where they could contribute and develop meaningful, caring relationships with strong friends. They were surrounded by service and paid relationships,” said Rother.

A visit to PLAN’s website will reveal innovative ideas, opportunities for training, consultation, research, publications and organizational support related to family leadership, social network facilitation, social enterprise, caring citizenship, dialogue and social sustainability. ■

– W.S.

For information about PLAN, visit www.plan.ca.

Building Circles of Support through art

Models of community care are evident through history, most evidently in Indigenous cultures. While Judith Snow or PLAN’s models take root in the family’s network, others can be structured in less formal ways.

Dr. Janis Timm-Bottos is an associate professor of Creative Art Therapies at Concordia University and principal investigator of the university’s engAGE Creative Living Lab. Throughout her career as an art therapist, she has developed a tremendous body of work that centres around building relationships through the collaborative creation of art. She is known for coining the term “Art Hive:” a creative, welcoming space that fosters inclusion, community, respect and learning through the creation of art.

Art Hives embody many characteristics of Circles of Support. They bring people together despite financial situation, age or ability. Timm-Bottos sees how people who might not otherwise have met can easily connect and support each other through a third element, in this case, art. “Healing, health and well-being are relational. The work doesn’t happen just within each of us, it’s between us,” she said.

“The studio relationships created are important and deep, but it happens at the studio. You don’t have to become best friends or be intimate with someone you create art with. But when you meet regularly with people in a creative space it’s a comfort to know that you have a place to go when you need help. It’s a deepening of the Circles of Support model,” said Timm-Bottos. ■ –W.S.



Melissa Sokoloff, left, and Natali Ortiz at the Concordia University Art Hive (Loyola Campus) in September.
Photo: Rachel Chainey

For information or to find an Art Hive in the Greater Montreal area, visit www.arthives.org.

Hannah's Network supports family, fosters friendships

by *Wendy Singer*

Over 20 years ago, Evelyn and the late Charles Lusthaus were invited to set up a Support Network through Planned Lifetime Advocacy Network (PLAN) (see p.13) by their friend, a former student of Evelyn's, psychologist Nancy Rother.

The Lusthaus' accepted Rother's offer, realizing this would be an excellent support for them and their daughter Hannah, now 44, who has Down syndrome. As the network facilitator, Rother began by recruiting people that Hannah had already formed strong relationships with, including her elementary school special education teacher Linda Mahler and her educator from social services Pamela Celani. The group began to meet and start thinking about Hannah over her lifetime.

"We can't just rely on social services to care for people with disabilities," said Lusthaus, now 75 and formerly a professor of Inclusive Education at McGill University and an inclusion advocate who worked closely with Judith Snow, the creator of Circles of Support (see p. 12). "We need community networks in order to give the person who's vulnerable the friendships and support they need and enable parents and families to be less worried about what's going to happen to their child after they die."

Lusthaus describes her daughter as highly motivated with huge dreams. The network helps Hannah find ways to tap into those dreams at a level that she can achieve. Hannah attended Elizabeth Ballantyne Elementary School and Westmount High School of the English Montreal School Board (EMSB), John Abbott College's voca-

tional training program and enjoyed a work placement at Concordia University's radio station. While at the university, she fulfilled her passion for basketball by becoming the Concordia Stinger's much loved scorekeeper, a role she held for many years. She now attends the EMSB's Wagar Adult Education Centre.

Hannah moved back home to live with her mother during the pandemic, and dreams of returning to her apartment in Lachine. The network is actively working to realize this dream. They also have driven her to and from Wagar and supported her while her mother recuperated from surgery this summer.

The network has been "a life-saver" for Lusthaus, especially since her husband passed away three years ago. "I cannot even begin to tell you in words what it means to me to have this extraordinary support," she said. "They love Hannah, partly because she is a loving person, but people learn through their involvement and identify the beautiful parts of the person. This is quite different from a social services model, where professionals are trained to see the needs and the deficiencies."

To begin a Support Network, Lusthaus encourages parents to find a facilitator to recruit a core group of five or six people, with other members coming in and out as needed. Group size will vary depending on the needs of the individual at the centre of the network.

As Hannah's Network's facilitator, Rother initiates group meetings, keeps in close contact with Lusthaus to discuss any necessary action needed and advocates on the Lusthaus' behalf.

According to Rother, it can be very hard for parents to ask for help. "Reaching out reveals our vulnerability, and we worry that



Hannah Lusthaus, left, and Nancy Rother enjoying an afternoon together in September. Photo: Evelyn Lusthaus

what we ask will pose a burden to others. Having a facilitator do the asking can be a great support to families," she said. In Rother's experience, typically, everyone says yes!

"This is about being part of a web of relationships and engaging with the person at the centre of the network in a way that is reciprocal, authentic and deeply meaningful. All of us need to belong, contribute, be acknowledged and appreciated for our contributions and to experience the love and care which flows from relationships. In a network, we all have the opportunity for these kinds of enriching experiences," she added.

Rother describes the experience of being in Hannah's Network as deeply meaningful: "I love Hannah. Our relationship has grown over many years. She's introduced me to Zumba and Hip Hop! She enlarges my life.

And it gives me hope when I see how eager people are to help and contribute when we put out the call."

Lusthaus said Snow shared powerful words with her some 25 years ago that impacted her life and decision to start Hannah's network: "Judith Snow challenged me, saying, 'You don't like to ask for help, do you?' That went straight inside. That opened me up to the possibilities of support. After that I learned to ask for help." ■

To learn more about network facilitation, read Rother's publication *Reaching Out: A Portrait of Social Network Facilitation in Canada* at www.planinstitute.ca/wp-content/uploads/2018/02/Reaching-Out.pdf.

Listen to our podcast with Evelyn and Hannah Lusthaus and Nancy Rother at <https://soundcloud.com/inspirationsnews>.

Jonah's Circle brings his community together

by Wendy Singer

Jonah Davis Yanofsky's Circle of Support was created in March 2021, three months after his father Joel Yanofsky passed away at the age of 65. While his parents had been interested in creating a circle after learning about Judith Snow's concept of Circles of Support, it was the gravity of this loss that made Jonah's mother, Cynthia Davis, take action.

"I have the day-to-day plus the long-term concern about what will happen to Jonah if I can't take care of him. After losing my husband, I find when I get sick, even if it is just a cold, I start to panic about Jonah's future," said Davis.

Before she created "Jonah's Circle," Davis analyzed who and which organizations populate Jonah's four circles (Intimacy, Friendship, Participation, Exchange – see p. 12). She clearly saw the need to develop Jonah's intimacy and friendship circles. "Jonah has no peers who he can call, so there's room for improvement. Until a few

years ago, his intimacy circle included six family members. Only two, including myself, are still alive today. This speaks to the necessity of building a little village around him," she said.

An active 22-year-old who has autism, Jonah attended Hampstead Elementary School of the English Montreal School Board and Summit School. He now attends the Filion Adult Education Program of the Centre de services scolaire Marguerite-Bourgeoys.

He has diverse interests including outdoor sports and music, and participates in many programs, including the Centre of the Arts and Human Development and the Shira Choir.

Jonah's Circle currently operates as a private Facebook group which, in August, had 19 members. Members include people from Jonah's Exchange Circle that he has strong relationships with: family, trustworthy friends and a legal team.



From left, back row: Jonah's cousins Noah Davis-Assil and Emmanuel Davis-Assil, Jonah's uncle Sym Davis, Jonah Davis Yanofsky; front row: Jonah's mother Cynthia Davis and his grandmother Carole Davis sitting on a bench on Côte St. Luc Road that is dedicated to Cynthia's late father Alex Davis for his environmental contributions to his community.
Photo: Nigel Dove



Jonah Davis Yanofsky, left, and Jonathan Shrier enjoying a music session at Cynthia Davis' art studio in NDG in January 2021.
Photo: Jonathan Shrier

As the group's facilitator, Davis has begun introducing and engaging members online with Trivial Pursuit nights (a game she and her son play regularly). "Jonah is involved in so many groups, but the only thing connecting them was me," she said. "Now if something should happen to me, people will know each other and Jonah's connections."

Davis is figuring out Jonah's Circle as she moves forward. "It's a work in progress, but we're off to a good start," she said. "It helps me to know that we're not alone."

"The more overwhelmed you are, the more you need the support of caring people," added Davis, understanding how it feels to be completely overwhelmed. She encourages families to read Judith Snow's book *What's Really Worth Doing and How To Do It*, and analyze your child's circles (with a caution that circles can overlap, and it can be confusing at first). See where the needs are and speak about them with the key people. "This is not an academic exercise. It's something to do to help your child and gather resources around you," said Davis. ■

Being a circle member makes a huge impact

Jonathan Shrier is a member of Jonah's

Circle. A professional musician and music teacher by extension, Shrier first met Jonah Davis Yanofsky at Camp B'nai Brith's Avodah program in the summer of 2019. One evening after watching him perform at camp, Jonah's mother Cynthia Davis asked Shrier to teach her son once a week. "My friendship with Jonah blossomed and since then we've developed a close relationship that is focused on music," said Shrier. Together, the duo has written nearly 10 songs that express Jonah's thoughts, worries and what he's excited about. "Jonah inspires me every day to be better at what I do."

From what Shrier has learned, he is planning on bringing song writing to a greater audience.

Shrier describes Jonah's Circle as a group of close friends. "We meet and share information and the joy of being around Jonah. Between all of us we can always ensure that Jonah has a program to go to, fun things to do and people to talk to," said Shrier. "Jonah's Circle is filled with people to reach out to when things are okay and not okay, who are willing to step in should something happen." ■ – W.S.



by *Joanne Charron*

Support through shared experiences

Finding support: Where to begin? Sometimes it exists, sometimes we have to create it. We start on a journey replete with “we don’t know what we don’t know.”

The best place to start is in the health sector with a general practitioner and your local CIUSSS. They will provide direction and information on the support, programs and resources available to you given your particular situation.

Once we transition into the school sector we can seek guidance from the school administration as well as their student services and special needs department. They

will provide our children with the best support and programs they have to offer. The health sector and the education sector coexist and collaborate in the best interest of the child and family.

This process continues throughout the child’s schooling, transition into adulthood and beyond. It is a laborious process, one that we have to be on top of all the time. Through our journey we meet all kinds of people and families. We end up in a club that we might not necessarily want to be a part of but wouldn’t want to be without for only they can understand our realities.

These groups provide a wealth of knowledge and support; a small community that is with us throughout every stage of our

journey and with whom we create support that is not available otherwise – a group of people who fill the gaps of what lacks and doesn’t exist to meet the needs of our children as they age.

Nuclear families are in a predicament as their handicapped child ages along with the rest of the family. These families find themselves not only caring for their aging child but for their elderly parents as well. When we reach that point we can use the knowledge and resources we have gained in caring for our children in caring for our elderly parents.

The key to all this is to share our realities with one another and our families, and by default it creates a circle of support. By

sharing with one another, we help those around us who can learn from our experiences, and we gain knowledge from theirs. It creates a wealth of support and resources. It forges a path for those who follow in our footsteps, creates a better future for all of our children and advocates for their quality of life. It is hoped that this will, one day, be sewn into our national fabric.

Share your story. It could be a lifeline to someone else. ■

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Activating a village of support

by *Sarah Lynch*

After giving birth to my first child, I easily connected with other families and established a network of parents who were also experiencing sleepless nights and endless diaper changes. We found a pediatrician, knew which mom-and-baby classes to sign up for and which necessities to purchase. Looking back, I realize how much support was available to new families and took it for granted at the time.

My son Kian was born three years later and was diagnosed with Down syndrome. Instantly, our network vanished as we navigated the unknown with limited guidance. We initially found support in a community organization, the West Island Association for the Intellectually Handicapped, and we also began to educate others about our family’s needs. While we longed for more support from the health and social services network, it was the kindness of others that got us through the first years. Phone calls, home-cooked meals, asking direct ques-

tions, offering listening ears and having a shoulder to cry on were gestures of support that we most needed and appreciated.

It took time to accept that “support” would have a different meaning than it did with our first child, and that we would need to create our own network within our community, friends and family. We became active in the community, were present with Kian at events and integrated him into the local preschool and soccer team. We advocated for Kian and educated others about his needs and challenges. We normalized the conversation, often speaking about what they may “see or observe” when meeting Kian. Other children and families were sensitized to his feisty personality; he was embraced as he warmed the hearts of those around him.

Kian put life into perspective and with that came our support. Our network grew out of our own hard work, while connecting with those who gravitated towards our life.



Kian LeCouffe, top, and his best friend Cassius Qadri playing in the front yard in the fall of 2020. Photo: Tricia Flint

We are grateful for our “village,” for the kindness, warmth and acceptance that surrounds us. We have people in our lives who ask about Kian and who ask how we’re managing as parents. Many compassionate people take the time to get to know Kian, to think of him and his interests and spend their personal time engaging in meaningful activities with him.

We have learned to accept that support can be demonstrated in different ways, by unex-

pected people. It is now our turn to be there for others, offering help to those cultivating their own network. Allow yourself to trust in the kindness of others and, in time, you will be able to build your village. ■

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