



Down Syndrome Association  
of Greater St. Louis

# Who is the Down Syndrome Association of Greater St. Louis?



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# WHO WE ARE

- Established in 1976 by a small group of parents
- Serve 2070 families in the greater St. Louis region (approx. 150 mile radius)
- Only agency in the region solely dedicated to serving individuals with Ds and their families from before birth through end of life and beyond.
- Headquartered in Brentwood
- 12 staff – 4 PT & 8 FT




## **Mission:**

DSAGSL serves, supports, and celebrates the lives of individuals with Down syndrome and their families, through every stage of life.

## **Vision:**

An inclusive community in which all people with Down syndrome can reach their full potential.


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# SERVICES WE PROVIDE

- New family support and resource navigation
- Family support and resource navigation throughout the lifespan directly and indirectly
- Workshops and support groups
- Early childhood therapeutic programs
- Community connections and community building activities
- Direct social and skill-building programs for teens and adults (in-person and online), including day programs and employment services



# SERVICES WE PROVIDE

- Community awareness raising and education / advocacy
  - Healthcare and educator outreach and education
  - School / student presentations and awareness campaigns
  - Social media and weekly newsletter resources and education
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# FAMILY SUPPORT

- Meet with families at the time of their prenatal/postpartum diagnosis and provide resources and vital information about Ds.
- Provide support, connection, and education for families of children with Ds beginning at time of diagnosis throughout life.
- Our goal is to help families feel confident, not scared, about their child's future.



# NEW FAMILY SUPPORT



- We work closely with area hospitals, who refer new families to us with the family's consent.
- Families receive a home/hospital/virtual visit where we provide a Celebration Basket and information and resources about Down syndrome.
- We talk to families about connecting to Early Intervention, Pediatric care guidelines, and offer to connect them with other families.
- We also offer family events, community groups, and mentorship opportunities for connection.



# FAMILY SUPPORT

- We also provide support to families throughout the lifespan, including:
  - Referrals, resources, and linkages to meet needs generally and specific to Ds as they arise;
  - Workshops and conferences to empower families to meet the needs of their loved one with Down syndrome; and
  - Caregiver support groups, which enable caregivers to connect and learn from one another.



# WHO WE SERVE

- Primary customer are caregivers of individuals with Down syndrome (typically parents, but also grandparents, adult siblings, and other invested parties). Secondary customer are individuals with Down syndrome.
- Down syndrome is the most commonly occurring genetic condition, affecting 1 in every 700 births. Experts estimate that Down syndrome is the leading cause of intellectual and developmental delay in the United States.




# WHEN AND WHY

- Services are provided most intensely during the first year of life and intermittently throughout the life span, with no set schedule, based on family need and interest. Typically, family needs increase around developmental milestones and transitional periods. Duration depends on family needs, but typically range from .25 - 1.5 hours per interaction.
- With the right supports, individuals with Down syndrome are capable of amazing things. Our services educate and empower families to meet the needs of their loved ones with Down syndrome so they can reach their full potential.

# GOALS OF SERVICES

- Families will have increased confidence in their ability to advocate for and/or seek out services and community support for their loved one with Down syndrome
- Families will have increased knowledge regarding Down syndrome, associated health concerns, adjusted developmental milestones, and available resources;



- Families will gain caregiving skills and feel better prepared to help their loved one with Down syndrome thrive and succeed;
  - Families will know where to turn for help when facing issues related to Down syndrome and they will be able to navigate formal support systems;
  - Families will feel connected to the wider Down syndrome community within the region.
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# FAMILY SUPPORT OUTCOMES

- Families who received family support services noted that:
  - Because of services provided, they know where to turn for help for a need related to Down syndrome (100%);
  - Services increased their knowledge about relevant community supports (100%)
  - Services increased their confidence in their ability to meet the needs of their loved one with Down syndrome (100%)
  - Services made them feel like they are part of a community (100%) and gave them a sense of belonging (100%)



# ORGANIZATION WIDE OUTCOMES


- Families who engaged in social and skill-building programming noted that
  - Programming made them feel like they are part of a community (96%) and that they had a support system (92%);
  - Programming helped improve their loved one with Down syndrome's communication skills (74%) and social skills (74%)
  - Programming helped improve their loved one with Down syndrome's self-confidence (92%);
  - Programming helped improve their loved one with Down syndrome's quality of life (74%)

# ORGANIZATION WIDE OUTCOMES


- Families who engaged in educational and outreach services noted that:
  - Because of services provided, they know where to turn for help for a need related to Down syndrome (100%)
  - Services increased their knowledge about relevant community resources and supports (100%);
  - Services increased their confidence about advocating for or seeking needed services for their loved one with Down syndrome (100%)
  - Services made them feel like they are part of a community (100%)




# DSAGSL AND THE PRODUCTIVE LIVING BOARD

- As of today, there are 795 households with a person with Ds in St. Louis County in our database.
  - Jan – June 2022 = 84 families directly served
  - July 2022 – July 2023 we proposed to directly serve 125 families in St. Louis County but will exceed this number in 2023 as we have already served 203 as of May 31<sup>st</sup>.
  - Indirect services are provided to all 795 families – resource emails, mailed newsletters with information, research and resources, Ages and Stages mailings, family connection events
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# OUTCOMES WE HAVE ACHIEVED (2021/22)

- 100% of participants report increased confidence in their ability to advocate for and/or seek out services
  - 100% of participants increase understanding of their or others' developmental disabilities
  - 100% of participants gain caregiving skills
  - 100% of individuals gain/maintain skills to navigate formal support systems
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# OUTCOMES WE HAVE ACHIEVED (2020/21)

- 100% of participants report increased confidence in their ability to advocate for and/or seek out services
  - 71% of participants increase understanding of their or others' developmental disabilities
  - 75% of participants gain caregiving skills
  - 100% of individuals gain/maintain skills to navigate formal support systems
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# LOOKING AHEAD

- Hired Director of Family Support in 2022
- New database that allows for better data collection and service tracking, with intent to continue targeted outreach to underserved families
- New ways for families to get support
- Reaching underserved communities



# MULTI-PURPOSE ROOM RENOVATION

- Funded the merging and remodel of two programs spaces in our office to create one big beautiful multi-purpose room.
- Hosts daily programs and events for the community
- Renovated ADA bathroom.
- Just as I am photography exhibit through June 30<sup>th</sup>.



# CONNECT WITH DSAGSL

[Facebook.com/DSAGSL](https://www.facebook.com/DSAGSL)

[Instagram.com/DSAGSL](https://www.instagram.com/DSAGSL)

[DSAGSL.org](https://www.DSAGSL.org)



# For more information



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