

## OUR MISSION

Our mission at DSNetwork is to educate, support and advocate for those in our community touched by Down syndrome.

DSNetwork achieves this goal through an open, supportive and collaborative network that connects individuals and families with needed resources and information.

## OUR VISION

A community that embraces, supports and inspires individuals with Down syndrome to live healthy, self-determined and fulfilling lives.

*What vision do you hold for your loved one with Down syndrome?*



# 2023 STRATEGIC INITIATIVES

## Caregivers

Parents, guardians, family members, respite & home care providers

1

## Health Care Professionals

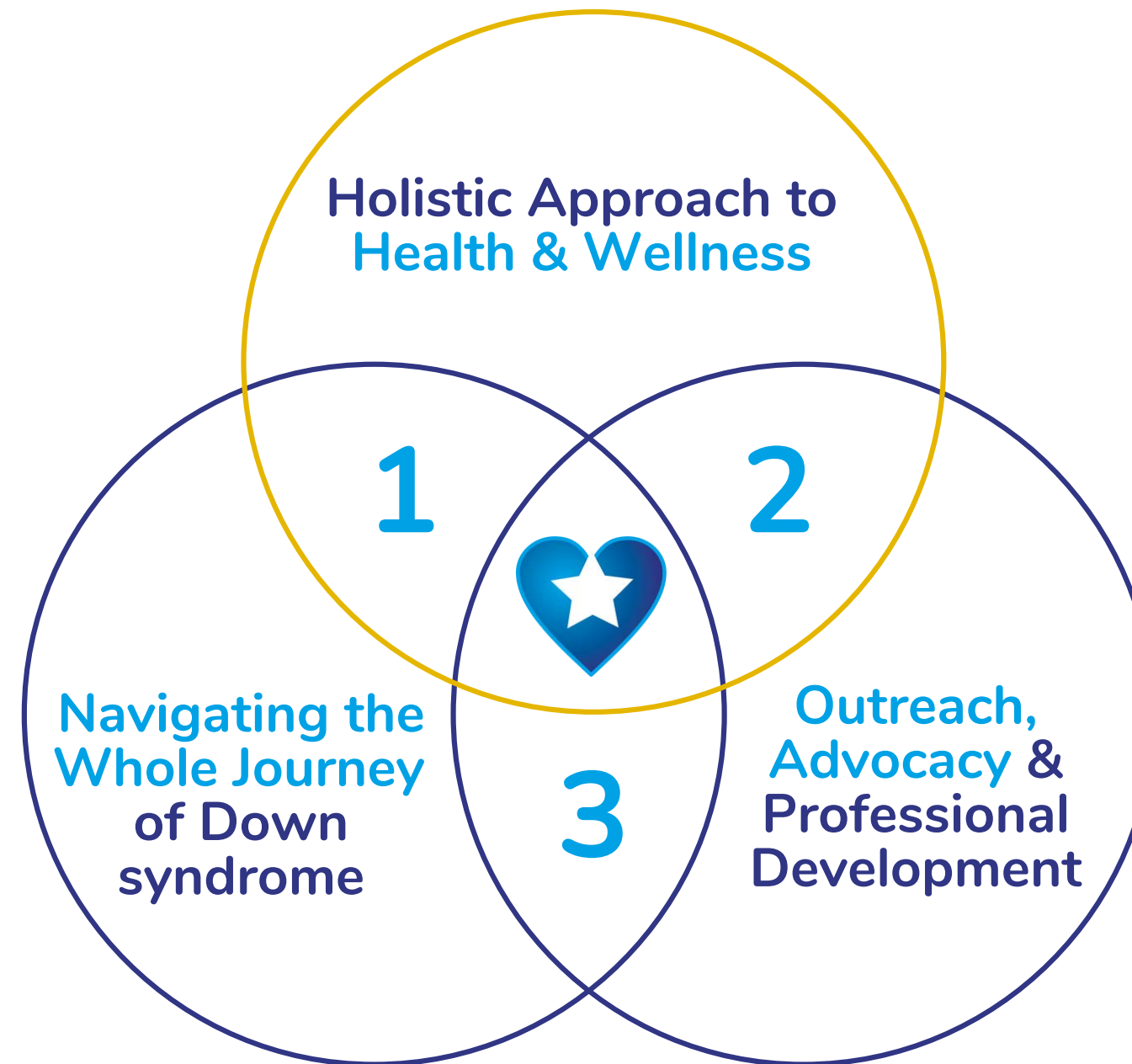
OB, pediatricians, primary care doctors, specialists, therapists, counselors & social workers

2

## Community

Friends, neighbors, employers, schools, other Down syndrome service agencies & community members

3



## Loved ones with Down syndrome

Serving people with Down syndrome from birth to adulthood across the state of Arizona



EDUCATE. ADVOCATE. SUPPORT.



## OUR BELIEFS

- Quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to lead fulfilling and productive lives
- All individuals are worthy and deserving of comprehensive and compassionate care and services
- Health is a state of complete physical, mental and social well-being and not merely the absence of sickness
- People with Down syndrome can and should be active participants in their health and wellness
- Education, and the dissemination of information are essential to improving and enhancing the health and well-being of people with Down syndrome



## CELEBRATION

People with Down syndrome are living longer lives! Due to better medical understanding and increased consideration for treatable chronic health conditions, life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 years in 1983 to 60 years today.

## OPPORTUNITIES

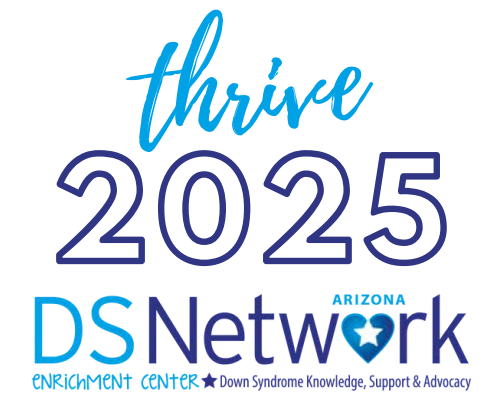
There is a great opportunity for big strides toward improving overall quality of life.

Physical activity and quality nutrition are vital for people with Down syndrome to improve physical, mental, and social health and overall functional ability.

**DAILY MOVEMENT AND  
GOOD FOOD START AT HOME  
AND BENEFIT THE ENTIRE FAMILY!**

# *How we can support, educate & advocate*

## **PROMOTE LIFELONG HEALTH AND IMPROVE QUALITY OF LIFE FOR PEOPLE WITH DOWN SYNDROME**



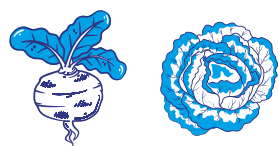
1. Connections to help navigate and access quality health care and services
2. Health education to individuals with Down syndrome and their caregivers
3. Movement, nutrition and outdoor curriculum and modeling throughout all programming, activities and events
4. Opportunities to collaborate with health care professionals and other agencies that serve people with Down syndrome
5. Platforms to share experiences and success stories





Quarterly interactive online education of current topics to support caregivers, professionals, and community members touched by Down syndrome

*Down to Earth*  
COMMUNITY & THERAPEUTIC  
GARDENING PROGRAM



Community garden program for teens and adults to be outdoors, learn about food, nutrition and gardening

**BUDDY UP FOR LIFE™**  
**BUDDY UP TENNIS**



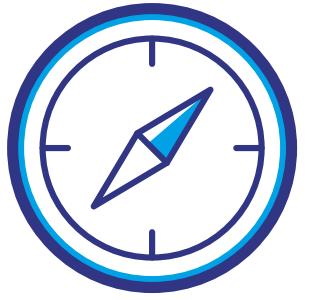
Developing brave athletes on the court with the self-worth and confidence to conquer their challenges and achieve their fullest potential off the court in collaboration with Buddy Up for Life

*Fitness & Exercise*  
PROGRAMS OF  
DOWN SYNDROME NETWORK



Variety of movement opportunities for all ages thanks to partnerships with KinectAbility Athletics, National Down Syndrome Society 321Go! Wellness program and ASU Adaptive Exercise Program

## NEW POSITION: COMMUNITY HEALTH NAVIGATOR (CHN)



Families and providers across the state of Arizona with loved ones with Down syndrome from birth to aging adults are in need of support to navigate the sometimes overwhelming and complex services (DDD, AHCCCS, ALTCS, SSI), health care and service providers dedicated to the Down syndrome community.

People with Down syndrome may have various health and development concerns throughout their lives and sometimes experience complex medical needs. The CHN will help individuals caring for their loved ones with Down syndrome overcome barriers to quality care and therapies.

- offer referrals and recommendations to providers
- address barriers including access to care and services
- help educate caregivers and individuals with DS to be self advocates

Research indicates that navigation reduces health disparities, improves engagement, enables people to get the care they need, improves health outcomes and reduces health care costs.

Navigation support facilitates integrated continuity of care, ensuring referrals to appropriate levels of care, services, and resources, including warm hand-off and confirmation of referral follow-ups.

# 2023 STRATEGIC INITIATIVES

## Caregivers

Parents, guardians, family members, respite & home care providers

1

## Health Care Professionals

OB, pediatricians, primary care doctors, specialists, therapists, counselors & social workers

2

## Community

Friends, neighbors, employers, schools, other Down syndrome service agencies & community members

3



## Loved ones with Down syndrome

Serving people with Down syndrome from birth to adulthood across the state of Arizona



# *How we can support*

**HELP CAREGIVERS NAVIGATE THE WHOLE JOURNEY OF RAISING AND CARING FOR A PERSON WITH DOWN SYNDROME FROM BEFORE BIRTH THROUGHOUT THE AGING PROCESS**

1. Guidance and support in the areas of education and adult transitions
2. Access to lifespan boot camps or "playbooks" (early years, school years, adolescence, entering adulthood and aging)
3. Connections to other parent mentors
4. Interactive webinar series recorded and archived
5. Directory of providers and services available
6. New caregiver support group - Dual Diagnosis (DS-ASD)





0 - 7 YEARS

Parent mentor support, resources, encouragement and navigating the care for a child with Down syndrome

Children play and interact with other children, parents connect, share their knowledge and experiences, and support each other



8 - 17 YEARS

Community-based opportunities and activities to socialize and meet friends in a supportive atmosphere



18+ YEARS

Helping individuals and families navigate each stage of adulthood from high school to older age



Parent mentor support, resources, encouragement and navigating the care for a child with Down syndrome

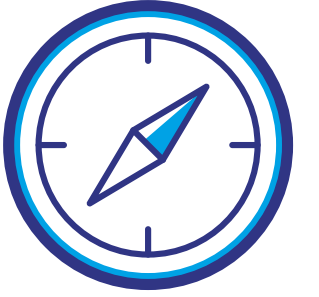


Children play and interact with other children, parents connect, share their knowledge and experiences, and support each other



Community-based opportunities and activities to socialize and meet friends in a supportive atmosphere

## NEW POSITION: EDUCATION GUIDE & ADVOCATE

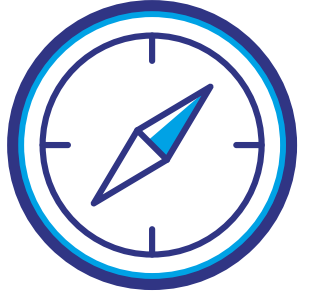


A complex system of federal, state, and local laws, plus policies and regulations, oversees special education. A special education advocate takes on many responsibilities to empower families by:

- Advising parents about services, programs, and accommodations that meet their children's individual needs (ie. school options, ESA, etc.)
- Helping parents interpret reports and evaluations
- Assisting parents with drafting requests and responses
- Preparing parents for school meetings that outline the services and accommodations
- Offering referrals to special education attorneys when appropriate
- Helping to develop transition plans from preschool, grade school, middle school, high school and beyond



## NEW POSITION: ADULT TRANSITION SUPPORT PERSON CENTERED PLANNING GUIDE



Person-centered planning (PCP) is a process for selecting and organizing the services and supports that an adolescent or adult with Down syndrome needs to thrive and achieve a fulfilling and high quality life. It is a process that is centered and directed with a teen and/or adult with Down syndrome. The coach helps the individual and family consider various paths, engage in decision-making and problem solving, monitor progress, and make needed adjustments to their plan. Each plan is tailored to the individual's dreams and needs, making things understandable for the individual, supporting self advocacy and helping the individual gain control of their life.

Families often find that their whole village/support system changes as their youth reaches the age of 14 at the time when transition planning with the school IEP team begins. This adult transition time can be extremely overwhelming since there are many new players to work with and agencies with formal processes to navigate. The coach offers detailed ideas on how to build and strengthen their community to support their youth or adult family member in designing the life they want. Effective person-centered planning can be helpful whether the person is preparing to leave high school or whether an adult who needs a better situation and long-term support.

The person-centered planning approach identifies the person's strengths, goals, needs and desired outcomes. The approach also identifies the person's preferences in areas such as guardianship, recreation, transportation, friendships, therapies and treatments, housing, financial planning, vocational training and employment, family relationships, and social activities. Unique factors such as culture and language also are addressed.

# 2023 STRATEGIC INITIATIVES

## Caregivers

Parents, guardians, family members, respite & home care providers

1

## Health Care Professionals

OB, pediatricians, primary care doctors, specialists, therapists, counselors & social workers

2

## Community

Friends, neighbors, employers, schools, other Down syndrome service agencies & community members

3



## Loved ones with Down syndrome

Serving people with Down syndrome from birth to adulthood across the state of Arizona



# *How we can advocate*

**HELP GROW AWARENESS OF DOWN SYNDROME IN THE ARIZONA COMMUNITIES, EDUCATE PROFESSIONALS & ADVOCATE FOR PEOPLE WITH DOWN SYNDROME.**

1. Focus on a legislative/public policy issues via ad-hoc advocacy committee
2. Education and outreach to additional medical students, health care providers, social workers, care providers, educators, therapists, businesses
3. Serve and be known as the statewide resource
4. Expand services into Northern Arizona
5. Collaborate with other cognitive disability organizations
6. Continue to explore Adult Clinic and partnerships



# 2023 Events

## SIGNATURE FUNDRAISING EVENTS

- Lights, Camera Auction Gala (Apr 29)
- 321 Swing (Sep)
- Down Syndrome Walk Arizona & 2024 Calendar (Nov)

## COLLOBORATE WITH OTHER ORGANIZATIONS

- Super Fest
- World Down Syndrome Day
- Spring Dance Formal
- Spring Family Picnic
- Fall Costume Ball
- Fall Pumpkin Patch
- Holiday Party

## Goals

1. Increase event volunteerism
2. Form solid event planning & sponsorship committees
3. Colloborate with other Down syndrome agencies on community gatherings

**DSNetwork**  
ARIZONA  
ENRICHMENT CENTER ★ Down Syndrome Knowledge, Support & Advocacy

