

The Down Syndrome Program: Helping Nevada Reach For The Stars

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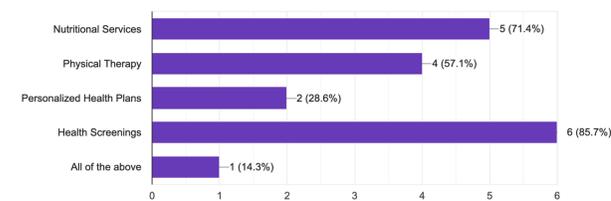
Abstract

The prevalence of Down syndrome in Nevada is 11.7 per 10,000 live births, yet prior to 2021 there were no statewide organizations to serve Nevadans with Down syndrome.¹ The Down Syndrome Program was established to meet community needs and ease the process of navigating the healthcare system for people with Ds in Nevada. The program is based within the Kirk Kerkorian School of Medicine at University of Nevada, Las Vegas and is the first of its kind in the state. The aim is to offer care coordination, clinical, and educational services. Despite being at a greater risk for chronic health conditions, people with disabilities receive lower rates of preventative health care services. Furthermore, many families are not aware of the many local organizations serving those with intellectual disabilities. Currently, the program connects individuals with local resources, provides care coordination, conducts research, and creates educational materials. Future directions include expanding current efforts to include outreach with healthcare professionals in the community. To address the needs of comprehensive healthcare for those with Ds, the program aims to bring greater value to the current clinical services being provided with the eventual addition of annual health screenings for adults with Ds.

Community Need

At the start of the DSP, we sent a survey to a small group of stakeholders, i.e. parent group of Down Syndrome Organization of Southern Nevada, Opportunity Village, Special Olympics, to assess the needs of the community. The results determine the resources we offer during workshops and will influence the clinical services once it's established.

Clinical Services: Please indicate which of the following services you are interested in.
7 responses



Educational Resources: Please indicate what topics you are interested in learning about.
7 responses

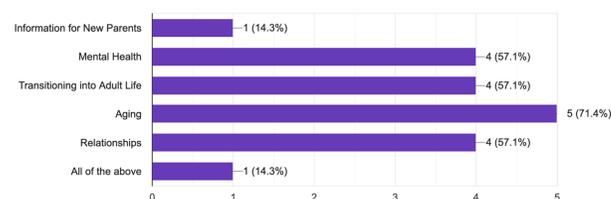


Figure 1: Initial survey results for clinical and educational resources that were requested

Services

Our services include:

- Connecting people with resources
 - Educational resources (aging, nutrition, etc.)
 - Local community resources (day programs, respite care, etc.)
 - Online resources (social activities, support groups, etc.)
 - Service offered in English and Spanish
- Care coordination
 - Finding specialists that are applicable to the individual
 - What we consider: insurance, language barriers, convenient locations/telehealth, experience with Ds
 - Service offered in English and Spanish
- Research
 - Informing families about open studies within the UNLV CARE Lab (physical therapy lab headed by Dr. Thessa Hilgenkamp that studies cardiovascular health and physical fitness in individuals with Ds)
 - Conducting in-house research: scoping review on care coordination
- Clinical services (in the future)
 - Annual health screenings for commonly occurring conditions in those with Ds
 - Offer telehealth appointments to reach rural Nevada
 - Service offered in English and Spanish

Table 1: Families' Reasons For Inquiry

Reason	Number of Individuals
Primary Care Provider	9
Speech, Occupational, and/or Physical Therapy	6
Life Skills Programs	4
Dentists	3
Educational Resources/Tutoring	3
Behavioral Therapists	3
Insurance Navigation	3
Community Resources	3
Respite Care	2
Nutritionist	2
Podiatrists	2
Support groups	2
Life Planning Resources/Aging	2
Endocrinologist	1
Optometrist/Ophthalmologist	1
Developmental Activities/Games	1

Demographic

The following figures were collected from a demographic survey that families completed and from the intake forms.

Annual household income

● \$50,000 to \$74,999 ● \$35,000 to \$49,999 ● Less than \$20,000

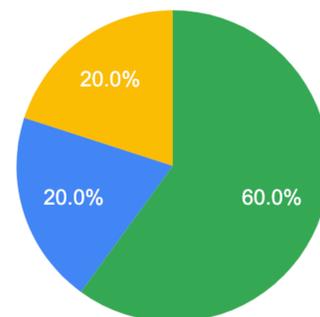


Figure 2: Annual household income of families that have participated in the program

Number of Patients by Age and Sex

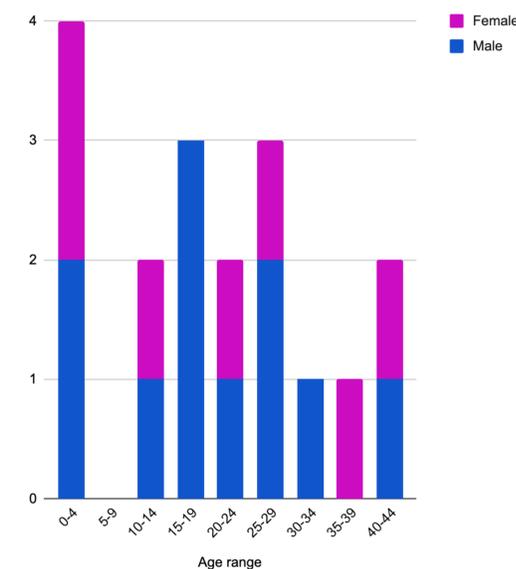


Figure 3: Patients' sex and age at the time of service

Future Aims

Clinical Services

- Clinical services provided by healthcare professionals with knowledge and experience serving individuals with Down syndrome
- Offer annual health screenings for mental health issues and other conditions related to Down syndrome
- Telehealth consultations would allow our clinical services to extend statewide and serve hard-to-reach populations such as those in rural areas

Educational Outreach

- Increase the knowledge, skills, and comfort level of medical students and resident physicians to care for individuals with intellectual disabilities
- Educate healthcare professionals in reducing disparities in healthcare for those with intellectual disabilities
 - Collaborate with Nevada Center for Excellence in Disabilities (NCED)

Research

- Enroll interested and eligible members of the community with Down syndrome and their families in innovative research studies aimed at advancing the understanding of this condition

Intended Outcomes

The main objectives of The Down Syndrome Program at the Kirk Kerkorian School of Medicine at UNLV are:

1. Improve health equity for individuals with Down syndrome in Nevada through:
 - Improved healthcare provider communication with people with intellectual disabilities
 - Ease of transition of care from childhood into adulthood
 - Ease attainment of referrals to specialists
1. Facilitate access, utilization, and satisfaction of healthcare services and community resources for people with Down syndrome and their families
2. Increase local access to cutting-edge research opportunities for people with Down syndrome and their families

References

1. Stallings, EB, Isenburg, JL, Short, TD, et al. Population-based birth defects data in the United States, 2012–2016: A focus on abdominal wall defects (Appendix S1). *Birth Defects Research*. 2019; 111: 1436–1447. <https://doi.org/10.1002/bdr2.1607>.

Contact Us!

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