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## **Connecting Members of the Treasure Valley Down Syndrome Association with Each Other**

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Abstract

Implementation of a physical membership directory for the Treasure Valley Down Syndrome Association to allow for a more effective means of exchanging contact information amongst its members during a time of no-contact.

*Keywords:* Down syndrome, Trisomy 21, Treasure Valley Down Syndrome Association, Membership, Directory

**Connecting Members of the Treasure Valley Down Syndrome Association with Each Other**

The Treasure Valley Down Syndrome Association (TVDSA) was founded over 40 years ago; throughout its existence there has not been a membership directory made available to its members. One of the largest complaints that TVDSA receives is the lack of peer interaction amongst members with Down syndrome. Currently, TVDSA members rely upon physical interaction with one another at various events to exchange contact information. Due to Covid 19, these in-person events have been on hold for the last two years and members have not had the opportunity to exchange their contact information. I created and implemented a membership directory as a better method for TVDSA members to connect with one another.

**Innovative Approach****My Problem**

How might I connect the members of TVDSA with one another? Either I allow members to connect with each other at TVDSA functions and exchange contact information amongst themselves or I provide TVDSA members with a membership directory.

**My Approach**

To complete my project, I worked directly with the non-profit organization, TVDSA, following a service-learning format. My interaction with the Board of Directors included the approval and distribution of opt-in waivers to allow each member's contact information to be included in the directory as well as funding approval for the printing and mailing of the directories.

The waivers were distributed to the TVDSA membership via email. Each member who chose to be included in the directory completed an opt-in form with the name(s) of the parents and/or guardians, the name of the individual with Down syndrome, their age, hobbies, address,

phone number, and email address. I collected the information and compiled the directory, arranged by age, which was printed and subsequently mailed to each member.

### **Emotional Intelligence**

D'Haem (2007) has reported on the challenges for many children with Down syndrome to develop close friendships, writing that, "Friends play a significant role in mental and physical health; however, individuals with Down syndrome ..., even those who are included in general education programs, have not developed friendships as hoped. After a decade of inclusion and structured school programs to facilitate friendships, many parents report that peer relationships end after school hours". As a parent, I want my children to build life-long friendships with their peers. As a mother to a child with Down syndrome, I notice that my son has more difficulty making friends than his typical brothers do; his typical peers are more advanced behaviorally and emotionally than him which makes it difficult to find hobbies in common.

I posed the question, "What do you, as a parent of a child with Down syndrome, want for your son or daughter?" to the members of TVDSA. The answer I received the most was, friendship and connection with peers. A membership directory will allow for the individuals with Down syndrome to connect with one another to forge friendships as well as for parents and guardians to connect with each other for fellowship.

### **Creative Thinking**

The creation of the *Treasure Valley Down Syndrome Association Member Directory* has allowed me to use my creative thinking skills. Using various computer software programs, I designed the directory, waiver, submission form, and follow-up survey.

The implementation of a membership directory is unique for TVDSA because for the 40+ years that TVDSA has been in existence, the nonprofit has relied solely on events for members to exchange contact information with one another. Due to Covid 19, these in-person events have been on hold for the last two years and members have not had the opportunity to exchange their contact information. As members of TVDSA have expressed an interest in connecting their children with other children with Down syndrome, as well as their own interest in connecting with fellow parents, the implementation of a directory provides a unique opportunity for members to connect with one another by having the contact information of fellow members compiled within a physical booklet which they each received in the mail.

### **My Innovative Solution**

At the commencement of my project, I set out to create a more effective method for members of TVDSA to be able to communicate with one another. My solution was to create a membership directory for the paid members of TVDSA. As TVDSA has a privacy policy in place, I found it necessary to create and provide an opt-in form, wherein each person/family that would like to be included in the directory submitted this form and its required information to have their information released within the directory, versus copying the information from the membership log. Only paid members received a copy of the directory which created an additional incentive to become a paid member of TVDSA.

### **Results**

#### **Stakeholder Benefits**

##### ***TVDSA Board***

The benefit of my project to the TVDSA Board of Directors is to provide an additional incentive of paid membership. TVDSA is a non-profit organization which welcomes any

individual or family who have a loved one with Down syndrome, whether that be a son, daughter, sister, brother, coworker, neighbor, or friend. Everyone is welcome to participate in any TVDSA event with or without a paid membership.

As a non-profit organization, TVDSA relies solely on donations and membership fees to fund events, programs, and scholarships. As there is no requirement to become a paid member, TVDSA has struggled to produce incentives for individuals or families to choose to become a paid member.

Prior to this project, the incentives to become a paid member were the use of the library, the opportunity to apply for scholarship funding, and the opportunity to run for election to the Board of Directors. My project created a new incentive to become a paid TVDSA member. Anyone who is or has a loved one with Down syndrome was able to submit their information to be included in the member directory, but only paid members received a copy of the directory.

### ***TVDSA Members with Down Syndrome***

The main benefit of my project to the TVDSA members with Down syndrome, especially the teens and adults, is the ability to connect, on their own, with other members with Down syndrome. Before this project, members relied solely on events to exchange contact information with one another and due to Covid 19, these in-person events have been on hold; members have not had the opportunity to exchange their contact information.

The membership directory is arranged by age of the individual with Down syndrome and includes a list of their hobbies. The directory allows a member with Down syndrome to find the contact information of another member with Down syndrome and connect with a potential friend who may share the same interest.

### ***Parents and Guardians of TVDSA Members with Down Syndrome***

Parents and guardians of TVDSA members with Down syndrome can find several benefits in this project. For one, they can connect their loved one with Down syndrome to their peers to forge friendships. They also have the added benefit of allowing parents and guardians the ability of fellowship with other parents. As a parent of a child with Down syndrome, I can attest that the diagnosis of Down syndrome is a scary and lonely one. Many new parents do not have experience with Down syndrome and feel isolated, confused, and helpless. Connecting with others who share in the same experience provides comfort, hope, and strength.

### *Myself*

I am a TVDSA member with a child with Down syndrome; as such, the benefits I see from this project are identical with other parents and guardians of TVDSA members with Down syndrome. As the leader on the project, I have the added benefit of the feeling of accomplishment. I saw a need and I completed a project to address and solve that need.

### **Impact on Stakeholders**

I believe that my project has had a positive impact on my stakeholders as determined by opt-in and follow-up survey responses. An email to opt-in to the directory was sent to 107 individuals and families, 33 of whom chose to be included in the directory. The age of the individuals with Down syndrome to be included in the directory ranged from two months of age to 57 years of age (Figure 1).

The follow-up survey was sent to 107 individuals and families, 35 of whom responded. Of those 35 respondents, 31 of them submitted their information to be included in the directory and four respondents did not (Figure 2). Of the four individuals who did not submit their information to the directory, 75% of them missed the deadline to be included (Figure 3).

Of the 35 respondents to the follow-up survey, 80% liked the idea of being able to connect their loved one with Down syndrome to other people with Down syndrome (Figure 4) and 77.1% liked the idea of being able to connect with other parents and guardians of loved ones with Down syndrome (Figure 5).

Of the 35 respondents to the follow-up survey, 88.6% consider the membership directory to be a good “perk” for paid membership (Figure 6) and 97.1% would like to see a new membership directory each year (Figure 7). Additionally, 8.6% of respondents would like to continue to receive a physical copy of the directory, 51.4% would like to receive a password protected link to an electronic copy of the directory, and 40% would like to receive both.

### **Different Approaches**

I chose to create a physical membership directory versus an electronic version primarily because of funding and time restraints. An electronic directory is a viable option for the future, and one the membership would like to see made available (Figure 8); however, time restraints did not allow for the research, voting, funding, and purchasing of an electronic directory platform at this time.

Ideally, I would have liked to have seen 100% participation from TVDSA members, however, a participation rate of 30.84% (33 of 107 members) exceeded my expectation of contact information submitted for inclusion in the membership directory.

### **Conclusion**

This project allowed me to enhance my communication skills, creative skills, and the virtues of patience and trust. To see this project to fruition, I worked alongside the TVDSA Board of Directors, which helped me to enhance my communication. I designed and created the opt-in waiver, follow-up survey, and membership directory; this allowed me to learn to use

various design software programs as well as the survey functionality of Google. My patience was tested as I waited for various responses and approvals from the members of the TVDSA Board as well as contact information from the membership itself. There were moments that I feared I would receive no response, but I learned to have faith in others and improved my ability to wait patiently and have trust in my peers.

The Treasure Valley Down Syndrome Association as well as its members, both with and without Down syndrome, benefited from my project. The introduction of a membership directory provides an additional “perk” to a paid membership which, subsequently, increases the funds which TVDSA will have available to fund programs and scholarships. The membership directory also allows members to connect with one another to forge friendships and fellowship.

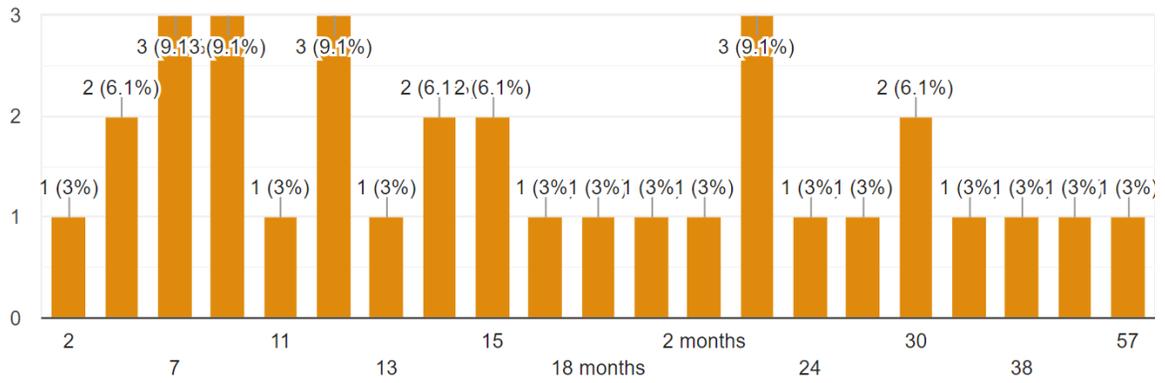
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Figures

**Figure 1**

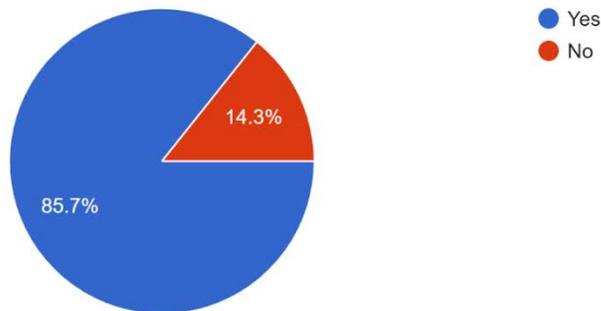
*Age of Individual with Down Syndrome*



*Note.* 33 responses

**Figure 2**

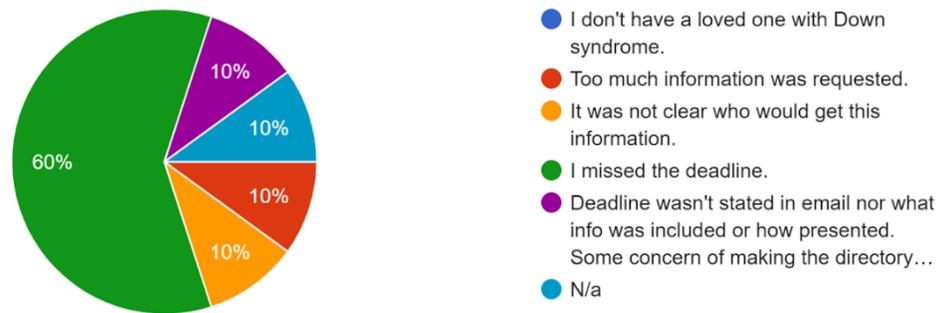
*Information Was Submitted to be Included in the TVDSA Member Directory*



*Note.* 35 responses

**Figure 3**

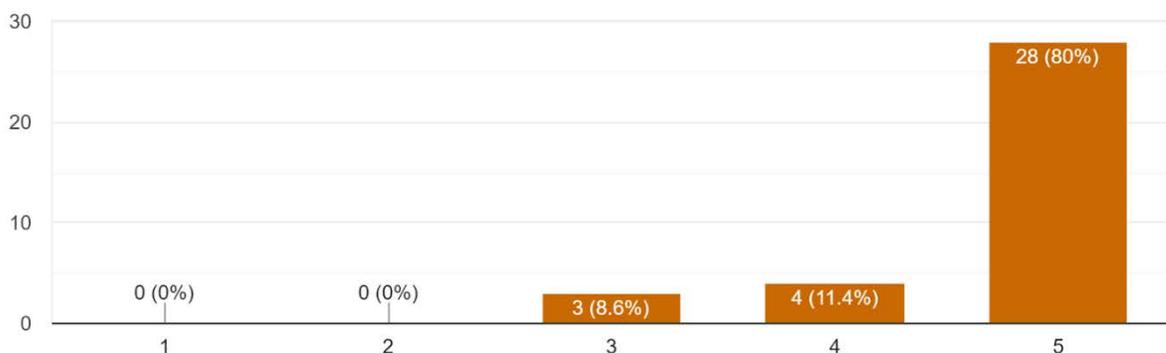
*Factors Affecting Willingness to Not be Included in the Member Directory*



*Note.* 10 responses. This question was only to be responded to if the individual did not submit their information to be included in the directory; however, six individuals who chose to opt-in to the directory answered this question. Of the four individuals who answered this question and did not submit their information to be included in the directory, one did not have a loved one with Down syndrome and three missed the deadline.

**Figure 4**

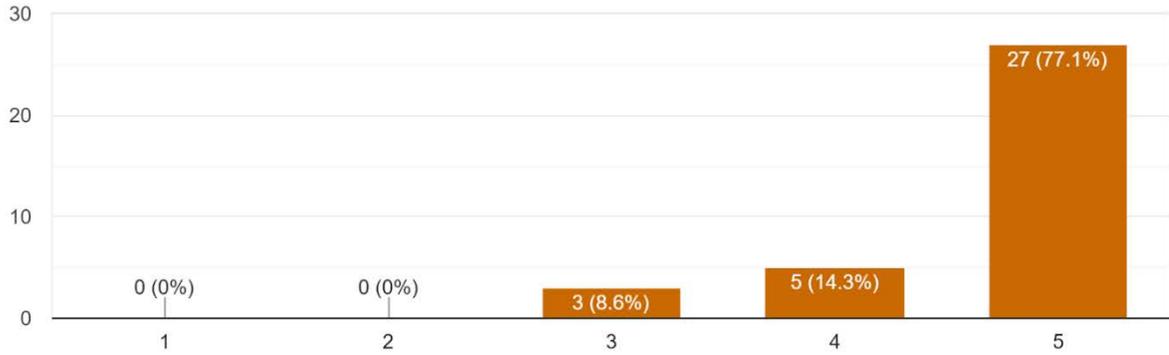
*I Like the Idea of Being Able to Connect My Loved One(s) With Down Syndrome to Other People with Down Syndrome*



*Note.* 35 responses. On a scale from one to five where one is “I do not like this idea at all” and five is “I like this idea a lot”.

**Figure 5**

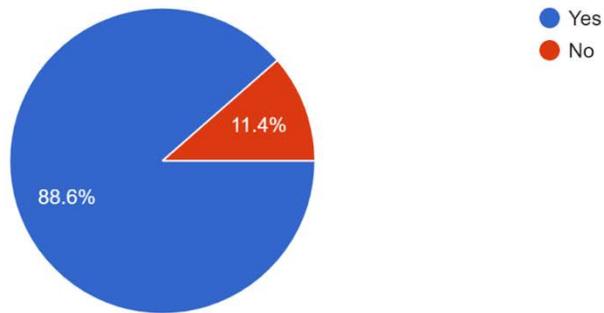
*I Like the Idea of Being Able to Connect with Other Parents and Guardians of Loved Ones with Down Syndrome*



*Note.* 35 responses. On a scale from one to five where one is “I do not like this idea at all” and five is “I like this idea a lot”.

**Figure 6**

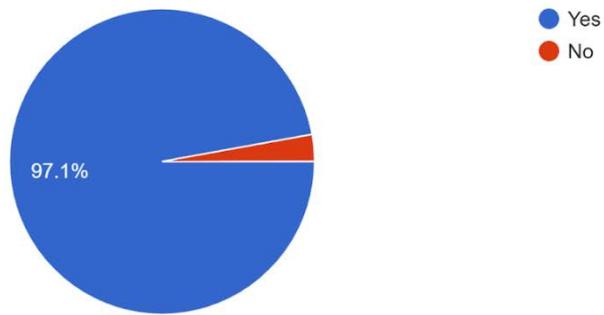
*I Consider the Member Directory to be a Good “Perk” for my Paid Membership*



*Note.* 35 responses

**Figure 7**

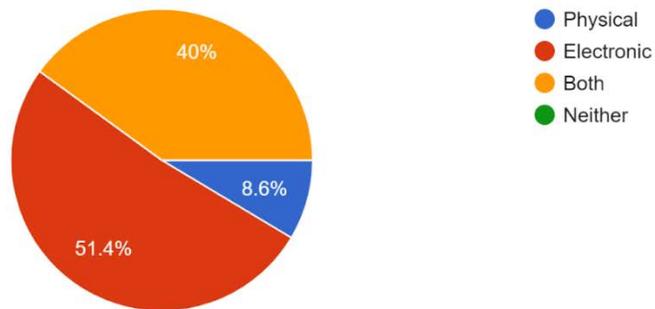
*I Would Like a New Member Directory Each Year*



*Note.* 35 responses

**Figure 8**

*Preference of a Physical Directory or an Electronic Directory*



*Note.* 35 responses