Down Syndrome Clinic to You (DSC2U)
An online personal care plan for caregivers and primary care physicians wherever they are

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Friday, September 6, 2019
Sandra Baker

• Has nothing to disclose.

Jeanhee Chung, M.D., M.S.

• Has nothing to disclose.
Brian Skotko, MD (in absentia)

Principal investigator, DSC2U
Emma Campbell Endowed Chair in Down Syndrome
Director, Down Syndrome Program & Down Syndrome Research Program
Massachusetts General Hospital
He has a sister with Down syndrome.
"In an era when the offer of prenatal testing is universal and termination of pregnancies involving Down syndrome is commonplace, families of people with Down syndrome often say they worry that the medical establishment has passed them by. They feel marginalized, unseen, and unserved. Families of people with Down syndrome don't want admiration, and they don't want pity. They feel a critical and urgent need for adequate health care for their loved ones, which is the right of every American."

—Patricia Bauer, caregiver
Having Down syndrome creates a health disparity

Only 9.8% of patients* presenting for the first time at a Down syndrome specialty clinic were up-to-date on 5 of the basic healthcare screens recommended by the American Academy of Pediatrics.

About 71 Down syndrome clinics in the U.S.

At best, all of these clinics serve fewer than 5% of the population with Down syndrome.

How can we leverage technology to help the >95% patients with Down syndrome in the U.S. who are not able to make it to a specialty clinic?

dsc2u.org
DSC2U returns customized info for caregivers and PCPs.

1. Caregiver Checklist for You

2. Primary Care Provider Plan to Share

Thyroid function tests (blood work). Molly is due for her thyroid check. Further testing is needed. Treatment options are available for those with a confirmed diagnosis [video]. More information on thyroid conditions in Down syndrome.

You indicated that within the past 12 months, Molly has not had her thyroid levels drawn. Individuals with Down syndrome have a significant risk of developing thyroid problems, which are important to treat. Experts recommend that everyone with Down syndrome have thyroid levels checked annually.

We know Molly’s health and wellness are very important to you, and we hope these resources will be helpful as you oversee her care. At the same time, a long list can sometimes feel a bit overwhelming. We encourage you to talk through the contents of this checklist with Molly’s primary care provider and other trusted caregivers or family members who may help you with Molly’s care.

The suggestions in this checklist were generated by a computer, based on your answers to the DSC2U intake form. The checklist was not prepared or reviewed by a clinician specifically for Molly but was assembled from information that was carefully chosen by a team of medical experts. Whenever possible, the information in this document was drawn from national healthcare guidelines for people with Down syndrome. The information has been reviewed to make sure it is consistent with current best practices.
Goal
Does the Caregiver Plan and PCP Letter increase appropriate screening compared to usual care?

Vision care, audiology testing, and screening for thyroid disease, celiac disease and obstructive sleep apnea

Target enrollment
• 200 caregivers
• No more than 144 whites
• No fewer than 25 Hispanics (Latinos/Latinas)
• No fewer than 20 Blacks/African Americans
• No more than 120 participants of either sex
What was our key result?

Goal
Does the Caregiver Plan and PCP Letter increase appropriate screening compared to usual care?

Vision care, audiology testing, and screening for thyroid disease, celiac disease and obstructive sleep apnea

Primary outcome

<table>
<thead>
<tr>
<th>Number of tests indicated &amp; completed/recommended</th>
<th>Control</th>
<th>DSC2U</th>
<th>Overall p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>134 (62.0%)</td>
<td>77 (69.4%)</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>67 (31.0%)</td>
<td>31 (27.9%)</td>
<td>0.004*</td>
</tr>
<tr>
<td>2</td>
<td>13 (6.0%)</td>
<td>3 (2.7%)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>2 (0.9%)</td>
<td>0 (0.0%)</td>
<td></td>
</tr>
</tbody>
</table>

* Statistically significant
How successful was our outreach?

230 caregivers randomized

<table>
<thead>
<tr>
<th></th>
<th>Reached</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>White or Caucasian</td>
<td>201</td>
<td>≤ 144</td>
</tr>
<tr>
<td></td>
<td>(88.5%)</td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>28</td>
<td>≥ 25</td>
</tr>
<tr>
<td></td>
<td>(12.3%)</td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>12</td>
<td>≥ 20</td>
</tr>
<tr>
<td></td>
<td>(5.3%)</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(6.1%)</td>
<td></td>
</tr>
</tbody>
</table>

Insurance
- 61 (27%) Public
- 167 (73%) Private

Education
- 13 (6%) High school graduate or GED
- 50 (22%) Some college or 2 year
- 166 (73%) 4+ year college

Health literacy
- 25 (11%) Poor health literacy

Numeracy
- 57 (25%) Poor numeracy
How did we reach out to caregivers?

- Study announcement posted on Facebook and Twitter on October 3, 2017

Accounts belonging to Dr. Brian Skotko & the MGH Down Syndrome Program

<table>
<thead>
<tr>
<th>One week later...</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interested</td>
<td>366</td>
</tr>
<tr>
<td>Contacted for consent</td>
<td>183</td>
</tr>
<tr>
<td>Hispanic</td>
<td>&gt; 25</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>&lt; 144</td>
</tr>
<tr>
<td>Black or African American</td>
<td>&gt; 20</td>
</tr>
</tbody>
</table>
How did we reach out to caregivers?

• **Targeted emails** through NIH DS-Connect® Down syndrome registry

• **E-mail requests** to more than 300 local parent organizations through DSAIA (Down Syndrome Affiliates in Action)

• **Follow up calls** by DSC2U caregiver advisors to 60 organizations in targeted regions of the country

• **Direct e-mail and social media posts** (e.g., FB event) to personal network of African-American families by caregiver advisors
What was critical for effective outreach?

• Down syndrome patient advocacy well-established at the national and local levels and already trusted by family members
• Committed group of caregiver advisors
  • Recruitment was driven by our closely allied caregiver advisors with information- and resource-sharing networks of their own
• Invested PI who identifies closely with the Down syndrome community and who actively cultivates his own network
  • Also provided name recognition which was valuable in initiating conversations with local groups
What were some barriers we faced?

• National organization membership predominantly Caucasian and English-speaking
  • Membership often reflects demographics of leadership
• Impact of gentrification has created pockets of communities that are more spread out and difficult to find and reach.
• Challenging to connect with individuals with rare conditions who identify with or find their community in non-health organizations (e.g., churches)
• Not always clear whether outreach to local organizations was successful
What should we consider for next time

• Identify and engage meaningfully with smaller organizations in the community and leverage their social media networks and mechanisms of engagement (e.g., newsletters), and get/give feedback

• Reach out to broadly-based “special needs networks” which may have greater African-American representation, but still are likely to have a greater concentration of affected families

• Consider alternative approaches to dissemination, e.g.:
  • Presentations/outreach/meetings at people’s homes
  • Outreach to media that serve different groups
What are opportunities for future research?

• To study if DSC2U can result in greater reduction in disparities when adapted to specific cultures and/or languages

• To learn how we can extend the DSC2U support model to address issues that disproportionately affect individuals with Down syndrome, e.g., dementia.

• To explore if this model can be applied in other health conditions, particularly those that are rare for which specialists are few and far between
Learn More

• www.pcori.org
• info@pcori.org
• #PCORI2019
• www.dsc2u.org
Thank You!

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www.massgeneral.org/downsyndromeresearch

Band of Angels Foundation