

Using a Communication Passport within a Multidisciplinary Genetics Clinic

Stephanie L. Santoro, MD*†; Diana Brenner-Miller, SLP‡; Clorinda Cottrell, LICSW*; Joy Bress, PT§; Amy Torres, BS*; Brian G. Skotko, MD, MPP*†

Abstract

Introduction: Multiple clinic models for Down syndrome exist; one model is the multidisciplinary, specialty clinic, such as the Massachusetts General Hospital Down Syndrome Program (MGH DSP). **Methods:** Intra-team communication was identified as an area for improvement. Our team developed an intervention, the Passport, a paper-based communication tool passed by parents between clinical teams who evaluated the same patients in different locations. Metrics included an electronic survey of parents and clinicians and tracking the frequency of Passport use. The analysis included the use of Statistical Process Control charts and rules. **Results:** The parental suggestions for communication-based interactions improved from 54% (32/60) to 17% (3/18) ($P < 0.01$). Communication scores within the MGH DSP team and between the team and parents were high at 86% and 96%, respectively. Overall satisfaction with the MGH DSP remained consistently high during our project, with a mean score of 6.49 out of 7. The MGH DSP team members reported communication scores with a mean of 85 out of 100. **Conclusions:** Implementation of a paper Passport tool incorporated parents in the real-time, intraclinic communication between our MGH DSP teams, leading to improved communication suggestions and high marks on the other metrics followed. Such a tool could be useful for other multidisciplinary clinics where team members evaluate the same patients at different locations on the same day. (*Pediatr Qual Saf* 2021;6:e472; doi: 10.1097/pq9.000000000000472; Published online September 24, 2021.)

INTRODUCTION

Down syndrome (DS) is associated with medical and psychological comorbidities due to extra genetic material from chromosome 21, impacting over 200,000 people in the United States.^{1,2} Current models for health care of individuals with DS are varied and include (1) a primary care physician serving as the sole medical home; (2) a DS specialist in communication with a

primary care physician; or (3) a clinic consisting of a multidisciplinary team specific for DS. Studies of pediatricians have shown that each pediatrician cares for 1–2 patients with DS on average.³ The current standard of care may involve a primary care physician providing care informed by the American Academy of Pediatrics guidelines.⁴ However, these guidelines are often not followed.^{3,5,6} Moreover, as most patients with DS are siloed and distributed among many individual primary care physicians, it may be difficult and unrealistic for primary care physicians to remain up-to-date on changing guidelines. Guidelines specific for the growing population of adults with DS have recently been published.⁷

Specialty clinics for DS with varying schedules, volumes, and locations exist throughout the United States.⁸ The team members integrated into specialty clinics differ and may include a physician, social worker, nutritionist, therapists, and others. Prospective patients and families may connect with these specialty clinics through various methods, including parent resource groups, social media, and websites.⁹ Our subspecialty clinic for DS, the Massachusetts General Hospital Down Syndrome Program (MGH DSP), and such multidisciplinary clinics improve care.¹⁰

We initiated this study to view the MGH DSP from the lens of quality improvement, identify areas for improvement, and approach the clinic using quality improvement methodology to improve parent satisfaction, especially to identify areas for improvement and to implement interventions to improve those areas.



From the *Down Syndrome Program, Division of Medical Genetics and Metabolism, Department of Pediatrics, Massachusetts General Hospital, Boston, Mass.; †Department of Pediatrics, Harvard Medical School, Boston, Mass.; ‡Department of Speech, Language and Swallowing Disorders & Reading Disabilities, Massachusetts General Hospital, Boston, Mass.; and §Department of Physical Therapy and Occupational Therapy, Massachusetts General Hospital, Boston, Mass.

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*Corresponding author. Address: Stephanie L. Santoro, MD, Department of Pediatrics, Harvard Medical School, 125 Nashua St, Suite 821, Boston, MA 02114
Fax: 617 726-4148
Email: ssantoro3@mgh.harvard.edu

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METHODS

During participation in the Partners Clinical Process Improvement Leadership Program (CPIP), we selected this project. Partners CPIP is an intensive 6- to 8-session program to engage clinical teams in using process improvement tools to reduce variation in care and improve outcomes for patients.¹¹

Identifying the Problem

The MGH DSP obtains parent-based feedback through an electronic survey sent by email approximately 2 weeks after a visit. All English-speaking parents with an email address on file receive it. The survey consists of a general question: “Overall, how would you rate your experience?” with responses from 1 to 7 with “1” being “terrible,” “4” being “neutral,” and “7” being “wonderful.” There are also open-response questions to ask about what worked well and what the respondent would like to see improved. In planning this quality improvement project in January 2019, a review of previous responses to the survey in the 2018 calendar year identified the topic of communication as the area for improvement: 7 of 22 (32%) suggestions were related to communication, accounting for the most significant proportion of suggestions for improvement. Baseline data from January 2017 to March 2019 showed that 54% of improvement suggestions were related to communication. Additional areas for improvement suggested less often include scheduling, time, and facilities.

Specific Aim

To improve intraclinic communication (between the medical team and PTT) in the MGH DSP, as perceived by parents and measured by the percentage of suggestions related to communication, from 54% to 25% by October 1, 2019, and sustained for 6 months.

METHODS

The Context

The MGH DSP includes multiple team members who provide medical care in 2 different locations. The medical team includes a physician, a social worker, a nutritionist, a self-advocate with DS, and a program coordinator. The medical team visits occur in an outpatient clinic building. The Pediatric Therapy Team (PTT) includes speech-language pathology, physical therapists, and occupational therapists; PTT visits occur in a separate building at MGH. All patients under age 6 have visits with both PTT and the medical team on the same day, often within 30 minutes of each other. In April 2020, the MGH DSP transitioned to a virtual visit model; in-state patients continued to see PTT through videoconferencing.¹²

Before the patients' arrival, a multidisciplinary team discussion occurs between the medical team and PTT members summarizing interval history and goals for a visit. Patient appointments can either begin with a medical visit

followed by the PTT visit or vice versa. The difference in geographic location—and the simultaneous evaluation of different patients—limits direct communication between the medical team and PTT in real-time.

The Team

To address intraclinic communication, a CPIP project team was created, including members of the medical team and PTT and parent(s) of 3 children with DS under age 6 years. Team interactions included email communication, in-clinic communication, and an in-person meeting. At the in-person meeting, parents and members of the medical team and PTT mapped the communication process in the MGH DSP. The medical team and PTT identified potential redundancy in the questions asked during a medical team visit and then repeated during a PTT visit, proposing this as an area for improved communication and efficiency. Parents reported a consistent message between PTT and the medical team but agreed that the re-asking of questions did occur. The medical team and PTT also noted that there was no consistent postvisit discussion for all patients. The medical team and PTT identified the opportunity for real-time communication between the 2 teams. Parents identified inconsistent concerns with communication (ie, feedback which was only noted by parent(s) of 1 child and was variable with no consistent theme), including receiving follow-up written reports and signage to the Audiology department.

Interventions

Building on discussion from the team meeting, the medical team and PTT brainstormed possible in-clinic communication methods. The intervention's goal was a simple, quick method of sharing short notes between the PTT and the medical team. Team members had limited access to pagers or computers during the clinic; therefore, an electronic option was not feasible or timely. A phone check-in during the clinic was also not an option. A paper-based form including a grid with each team members' role and a blank line, called a “Passport” (see **Supplemental Digital Content 1**, <http://links.lww.com/PQ9/A307>), was created. The first team who had a visit with the patient would complete the Passport during the visit with comments for the other team. Next, the team described the Passport concept to parents, and the team asked parents to carry the note to the second team visit. The Passport is on brightly colored paper to stand out from handouts and other papers given to the parent during a visit.

In September 2018, the PTT began joining the preclinic discussion telephonically. In April 2019, an audiologist began joining the preclinic discussion by phone.

Implementation

An email introduced the Passport to all team members by email. Teams began using the Passport on March 19, 2019.

% Communication Suggestions in the MGH Down Syndrome Program, p Chart

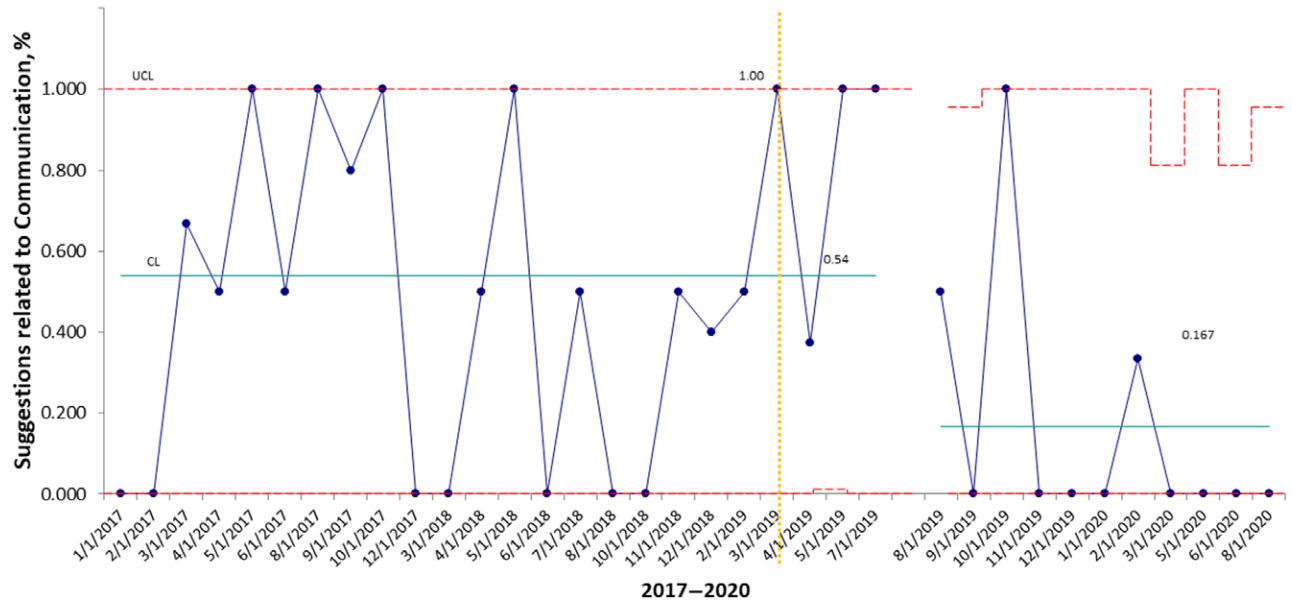


Fig. 1. Monthly percentage of parent suggestions related to improving communication in the MGH DSP Program, p Chart, from 2017 to 2020. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; SPC rules indicate 2 stable process stages. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month). The dotted yellow line indicates the Passport communication tool intervention in March 2019.

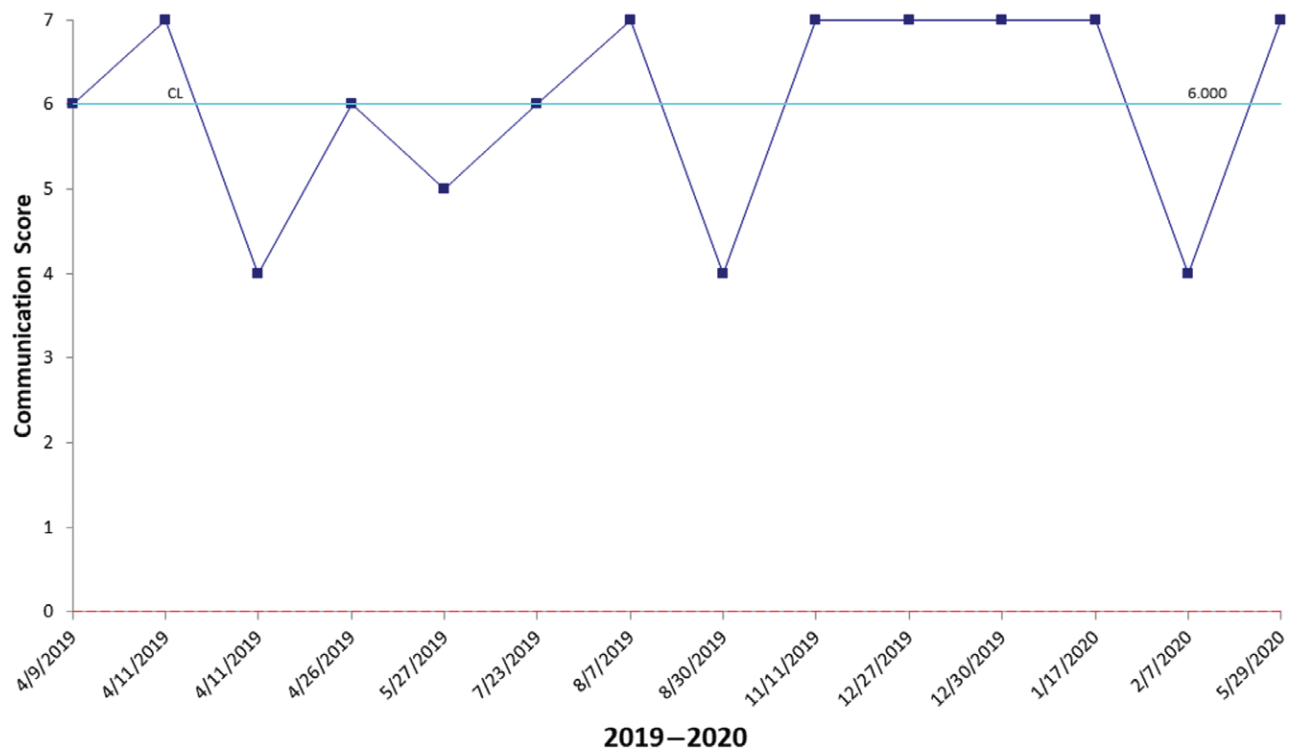


Fig. 2. Parent ratings of the communication between the PTT and the medical team: with “1” being “terrible,” “4” being “neutral” and “7” being “wonderful,” in the MGH DSP from 2019 to 2020, c chart. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage.

Measures

Data sources included: (1) electronic survey of parents of children seen by both medical team and PTT; (2) the Passport; and (3) electronic survey of team members. Our primary outcome was the percentage of suggestions related to communication, captured through a REDCap survey, which was calculated as the number of suggestions related to communication divided by the total number of suggestions.¹³ We tracked 6 additional measures: scores on the parent REDCap survey calculated as a raw score on a scale of 1–7 with responses from 1 to 7 with “1” being “terrible,” “4” being “neutral,” and “7” being “wonderful” regarding (1) communication between the PTT and the medical team; (2) communication between the PTT and you; and (3) global outcome, defined as the overall satisfaction score on REDCap survey calculated as score divided by the total possible score. In addition to the parent REDCap survey, a REDCap survey of MGH DSP team members served to capture balancing measures: (1) the team evaluation of communication during a clinic day and (2) team feedback on the Passport to identify any negative comments regarding passport use. We also collected Passports after the clinic to capture a process measure: the percentage of Passport use calculated by the number of Passports used divided by the number of PTT patients with a complete visit.

Analysis

We plotted raw scores in c-charts and monthly percentages (of communication suggestions and overall satisfaction) in p-charts. We tracked the impact of this clinical change for more than 12 months. Centerline shifts were determined using standard statistical process control (SPC) chart rules.^{14,15} We used the group of rules published by the American Society for Quality to detect special cause variation on control charts.¹⁶

The Partners Institutional Review Board approved this study.

RESULTS

Beginning this project in January 2019, we identified communication as the most often suggested area for improvement. We developed an intervention to improve intrateam communication: the paper Passport implemented in March 2019.

Parent Feedback in REDCap

Tracking the percentage of suggestions of improvement related to communication on REDCap survey showed a baseline of 54%, with a shift in data, and data after intervention in March 2019, show a post-intervention rate of 17% ($P < 0.01$; Fig. 1).

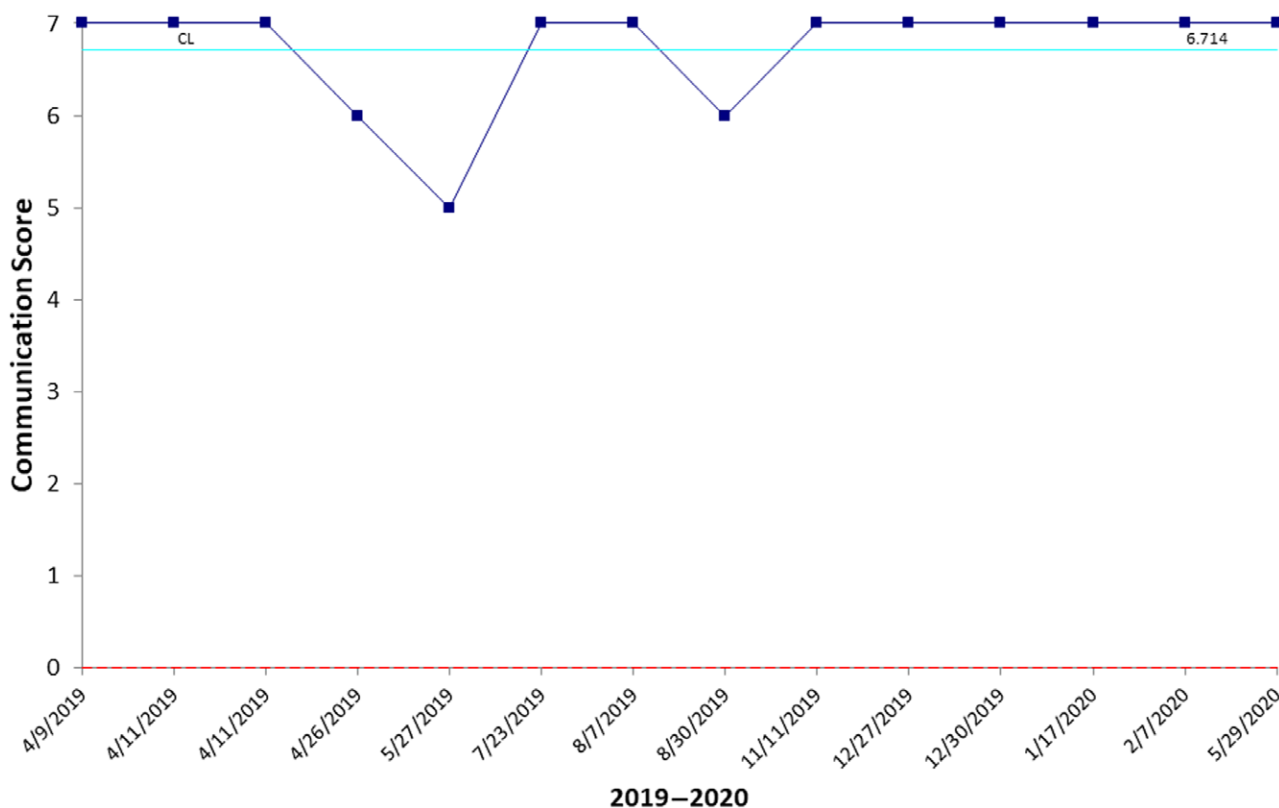


Fig. 3. Parent ratings of the communication between the PTT and them: with “1” being “terrible,” “4” being “neutral” and “7” being “wonderful,” in the MGH DSP from 2019 to 2020, c chart. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage.

After implementing the intervention, raw scores about communication reported by parents on the REDCap survey showed high scores without special cause variation. Parents rated the communication between the PTT and the medical team a mean of 6.0 out of 7 (86%; Fig. 2). Parents rated the communication between the PTT and them at a mean of 6.71 out of 7 (96%; Fig. 3). Tracking the impact on our global outcome, we found that parents’ overall satisfaction score with the MGH DSP on the REDCap survey remained consistently high during our project, with a mean score of 6.49 out of 7 (92.7%; Fig. 4).

Team Metrics

After implementing the intervention, responses from MGH DSP team members on a REDCap survey showed communication scores with a mean of 85 out of 100 (Fig. 5). Of note, a few days met special cause variation. When reviewing the open-response comments associated with these outlier scores, this was often due to instances

when parents did not pass the Passport from one MGH team to another. Comments from team members giving feedback on the Passport use were generally positive but identified the need to incorporate this into the clinic routine (Table 1, Supplemental Digital Content 2, <http://links.lww.com/PQ9/A308>). As we collected Passports after the clinic, we found that the % Passport Use was 41% (Fig. 6).

DISCUSSION

The multidisciplinary specialty clinic is one model for care delivery that can improve care for individuals with DS. To continue to maximize the care we provide and to continue to better our clinic at the MGH DSP, we initiated a quality improvement project in 2019 to focus on intrateam communication with attention to parent feedback and team input. Implementing a simple paper-based Passport for communication between the medical team and PTT showed

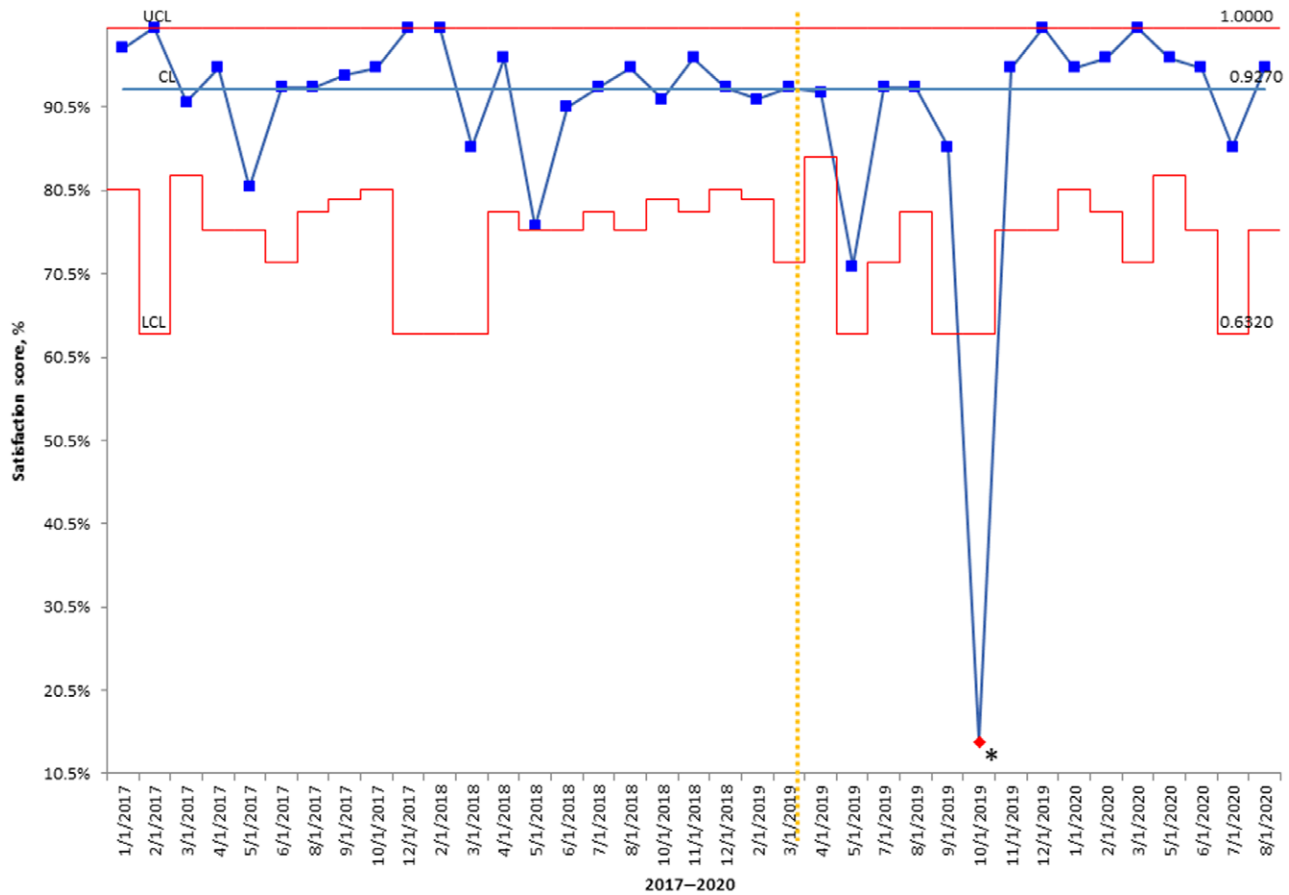


Fig. 4. Monthly mean overall satisfaction score percentage in the MGH DSP, p chart, from 2017 to 2020. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate one stable process stage. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month). The dotted yellow line indicates the Passport communication tool intervention. *The positive comments with this response did not seem to match the rating of “1” given.

MGH Down Syndrome Program Team member Communication Scores, c Chart

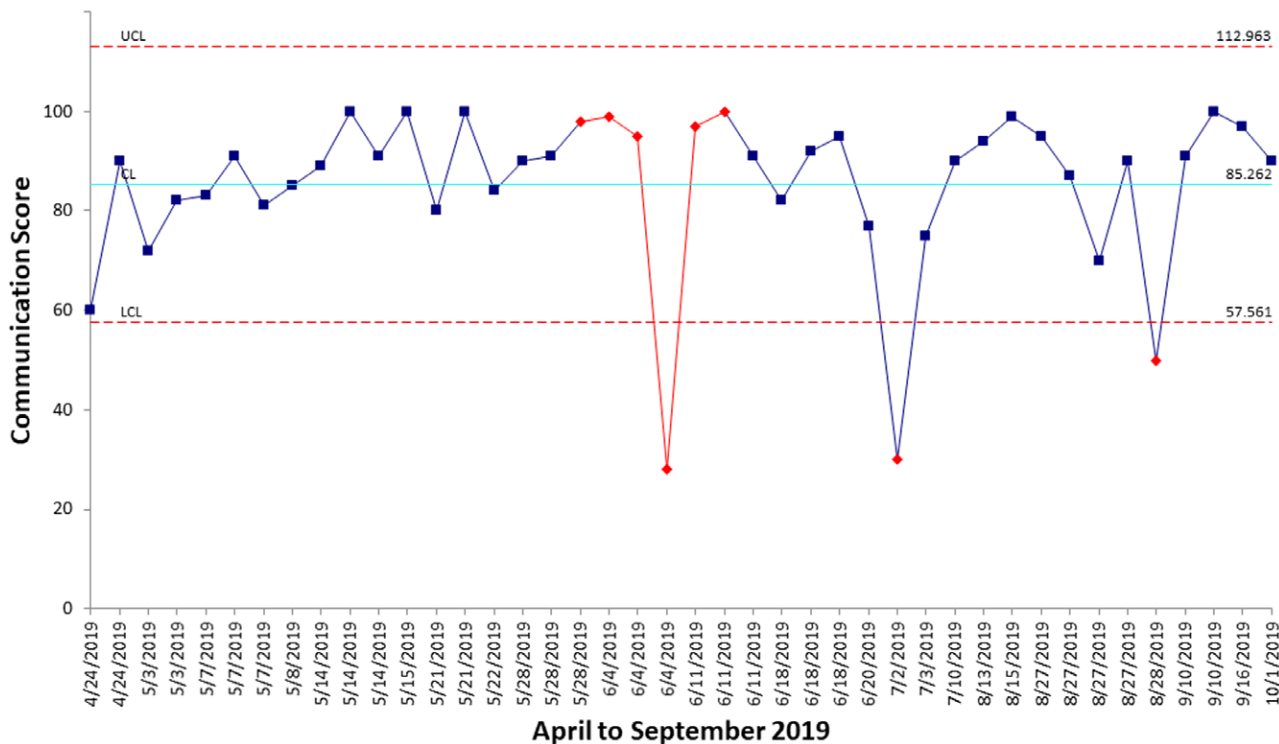


Fig. 5. MGH DSP team member ratings of the communication from 0 to 100, from April to September 2019, c chart. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage. Red lines indicate the control limits (± 3 SDs).

1. decrease in the number of parental concerns related to intrateam communication;
2. high scores on communication as perceived by parents and team members; and
3. positive feedback from team members regarding the use of the Passport.

We were pleased to see that a relatively simple, no-cost intervention led to improvement in the rate of parental feedback about our communication skills. This intervention was able to improve communication in our team across disciplines and locations in our hospital. Our project may provide an idea for real-time intrateam communication in other multidisciplinary, specialty clinics.

Similarly, team feedback regarding the Passport was generally positive, but opportunities for continued improvement were noted. Team members rated communication within the DSP as generally good and did not report difficulty using the Passport. We were pleased that our Passport intervention did not have a negative impact on the team’s work. Intrateam communication is an essential area for quality improvement work, given the importance of communication in delivering medical care.¹⁶⁻¹⁸ Team dynamics are important, as teamwork climate impacts patient safety and quality.^{19,20} Other interventions

to improve team communication, such as integrating the paper-based Passport into electronic health records, identifying other techniques for communication after a visit, and creating a dashboard of metrics to create a culture of quality and safety, may be useful next steps for future study.

Our study has additional limitations. Our clinic may not represent other DS specialty clinics, and our patient population may not generalize to all individuals with DS. We only had an English survey, but we would like to expand our survey to include non-English speakers in the future to ensure that we are capturing the views of our entire clinic sample. We want to increase this rate to ensure that our survey responses represent all the patients who receive care in our clinic and their families. The final months of our study were impacted by the COVID-19 pandemic as our clinic quickly transitioned to a virtual model. At that time, we ceased using the paper Passport and added a team after-visit email for communication. We acknowledge that the COVID-19 pandemic may have impacted our quality improvement project by drawing attention to other pressing issues. However, in our data, we did see an improvement up to the COVID-19 pandemic, after which our clinic transitioned to a virtual model in April 2020. We did not see changes in our other

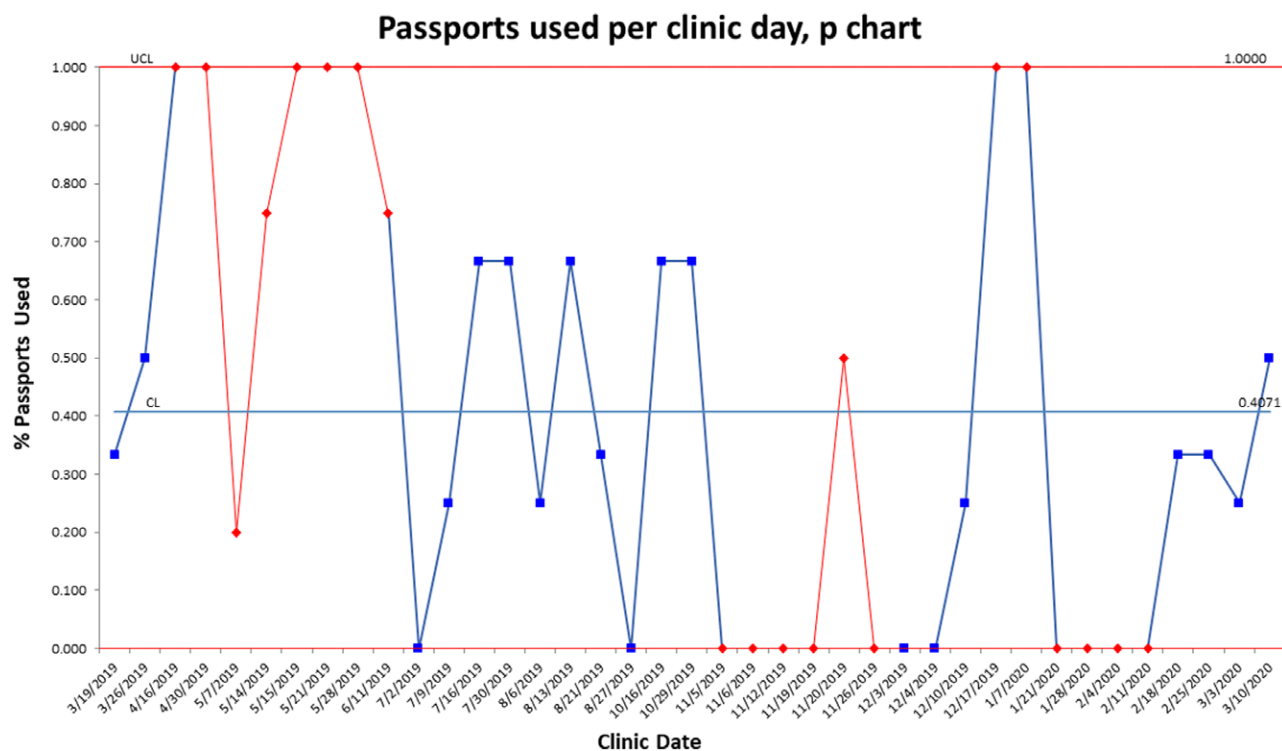


Fig. 6. Percentage of patient visits in which the Passport communication tool was used in the MGH DSP, p Chart, from March 2019 to March 2020. A solid blue line indicates the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate one stable process stage. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that clinic day).

clinic metrics in studying our transition to the virtual clinic from April 2020. We generally saw a consistent response rate on our REDCap parent survey.¹¹ We feel that we have demonstrated improvement by implementing an innovative but simple tool to improve communication.

CONCLUDING SUMMARY

Intrateam communication was identified as an area for improvement. Implementation of a paper-based Passport tool incorporated parents in the real-time, intraclinic communication between our MGH DSP teams, leading to improvement in communication suggestions and high marks on the other metrics followed.

DISCLOSURE

Dr. Skotko occasionally consults on the topic of DS through the Gerson Lehrman Group. He received remuneration from DS nonprofit organizations for speaking engagements and associated travel expenses. Dr. Skotko received annual royalties from Woodbine House, Inc. for the publication of his book, *Fasten Your Seatbelt: A Crash Course on DS for Brothers and Sisters*. Within the past 2 years, he had received research funding from F. Hoffmann-La Roche, Inc., and LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS. Dr. Skotko was an expert witness for legal

cases. Dr. Skotko served in a nonpaid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. Dr. Skotko had a sister with Down syndrome. Dr. Santoro served on the Professional Advisory Board for the Massachusetts Down Syndrome Congress. The other authors have no financial interest to declare in relation to the content of this article.

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