

Network Measures of Collaborative Support for Young Adults With Autism

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abstract

OBJECTIVES: The treatment of autism requires complex, multimodal interventions, provided by parents and providers across settings. As young adults with autism spectrum disorder (ASD) transition into adulthood, new stakeholders are added to support planning for postsecondary employment. In this article, we investigate the use of dynamic social network measures that describe the resources of young adults throughout transition.

METHODS: A longitudinal, dynamic social network survey (Social Dynamics of Intervention [SoDI]) was conceptualized, designed, and conducted as a feasibility test, measuring changes in collaboration among parents and school staff members who provided interventions for children with ASD in 2 urban public schools. Using the SoDI, we tracked the following over time: the team who provided interventions, their locations, the interventions they provided, the autism trainings they attended, and the density of the team's problem-solving network for the child.

RESULTS: Using the SoDI, we successfully identified stakeholders across settings who provided interventions for each child. Results indicated variation in the density of problem-solving and trust related to ASD intervention across teams as well as variation in intervention and autism knowledge networks during the school year. Adaptations of the SoDI for mapping pre- and posttransition resources and social connectivity across stakeholders for young adults with ASD are proposed in the Discussion section.

CONCLUSIONS: Dynamic social network approaches can be used to capture changes in intervention, autism knowledge, and social connectivity, providing informative descriptive data about how vocational rehabilitation policies might increase employment supports during the transition process for young adults with ASD.



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Dr McGhee Hassrick conceptualized, designed, and was lead author of the Social Dynamics of Intervention (SoDI), trained researchers in SoDI data collection methods, analyzed and interpreted the SoDI data, and drafted the initial manuscript conceptualizing the use of the SoDI for young adults during transition from postsecondary school to employment; Dr Carley provided social network expertise, analytical support, and coauthored the SoDI; Dr Shattuck provided research expertise about young adults with autism spectrum disorder and employment dynamics related to the transition to adulthood and contributed to the writing of the manuscript; and all authors critically reviewed the manuscript and approved the final manuscript as submitted.

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People on the autism spectrum often need complex, multimodal interventions and services that are individualized for each person and provided by a “de facto” team of parents, teachers, and other providers. Parents must acquire specialized knowledge, skills, and information about autism and its treatment to select appropriate treatments; master specialized teaching skills¹⁻⁵; obtain information about where to find services; gain familiarity with relevant laws; and negotiate with others on the child’s team.^{6,7} Moreover, autism co-occurs over 60% of the time with other cognitive, behavioral, and health disorders, further complicating treatment.^{8,9} The complexity of finding and arranging interventions and coordinating them as needs shift across the life course in multiple, different settings with many different community and school partners presents challenges for people with autism, their parents, and providers.

Although collaboration among the de facto team is challenging throughout schooling years,¹⁰⁻¹⁴ it becomes especially important during the transition from school to work, as young adults with autism spectrum disorder (ASD) take on additional levels of responsibility for managing dramatic shifts in the architecture of services as they exit eligibility for special education. The coordination of interventions and services can be framed as a life course health development challenge,¹⁵ in which weak coordination efforts during childhood and young adulthood shape later adult outcomes, such as job attainment.¹⁶

As young adults on the spectrum transition into adulthood, new providers emerge to support their quest for positive outcomes in many realms, such as employment, health, postsecondary education, and community living. Most face a significant decrease in services after

high school, often referred to as the “service cliff.”⁹ Learning skills needed for postsecondary success will likely require synchronization of transition goals among youth, their parents, school staff, and community providers.¹⁷⁻¹⁹

However, measuring transition coordination and service provision is fraught with difficulties. Little is known about how school, clinic and community providers, youth, and parents work together across contexts to synchronize goals day to day, beyond the mandated annual individualized education program meeting.²⁰ There are no studies in which researchers have systematically tracked how transition supports and links to adult-serving providers are interwoven throughout the transition process for young adults with ASD.

To improve the coordination of supports across the life course, new approaches are required that can track collaboration across settings and provide a baseline measurement of connectivity to enable team members to identify gaps and opportunities for collaboration to reach desired outcomes. In this article, a survey tool, designed by McGhee Hassrick and Carley, is introduced in which a social network approach is used to track care coordination among the parents, school staff, and community members who provide interventions for a child during 1 school year. The potential benefits for using a social network approach are exploited to track changes in the provision of social service resources for youth with ASD during their transition to adulthood.

METHODS

Subject Protection

This study was approved by the official institutional review boards at the University of Chicago, where these data were collected and

analyzed; the Weill Cornell Medical College, where these data were analyzed and deidentified; and Drexel University, where the deidentified data were analyzed and published.

Study Design

To test feasibility, a social network survey was conceptualized, designed, and conducted in the fall and spring to measure changes in collaboration among parents and school staff members who provided interventions for children with ASD in 2 public elementary schools in a large, Midwestern urban school district. All parents of children with a district diagnosis of autism and all school staff who provided services for children on the autism spectrum at each school were sought out for recruitment in the study. In total, 32 children with an ASD diagnosis, their primary parents, and 49 school staff members participated in the pilot study, which represented 82% of the total number of possible participants from the 2 schools. Of the 32 children in the study, 23 (58%) had “complete teams,” in which the primary parent and 70% or more of the child’s school providers completed the social network survey 2 times during the school year. All study participants reported interventions implemented per child. Parents and teachers reported communication per child, and other school staff reported communication per children with ASD in the school. All study participants voluntarily consented to participate in each wave of the study.

Social Network Survey Tool

The social network survey, called the Social Dynamics of Intervention (SoDI), was conducted at 2 time points during the school year to capture activities, communication, and problem-solving activities among parents and school providers per child for fall and spring of the school year. At each time point, face-to-face interviews were conducted with

participants that lasted between 30 and 45 minutes. Five types of data are reported in this article. In each survey, parents and school staff members at each school were asked to (1) identify if they provided interventions for each child in fall and spring. Each child's team (team size), defined as participants who were actively providing interventions for the child, was derived from these data.

Participants were also asked (2) where they provided interventions (location), and they were asked to (3) report and rate the effectiveness of the interventions they provided as "working" or "not working" for the child (interventions that work). In addition, participants were asked to (4) identify the autism trainings (autism training) they participated in that informed the interventions they were providing for children on the spectrum. Finally, participants were asked to (5) identify who they sought out to solve problems that the child was experiencing during intervention (problem-solving). Participants were shown a photo deck with the pictures and names of parents and school staff who provided interventions for children with ASD at the school to facilitate recall. In addition, parents were asked to identify any community or health care providers and their associated organizations who were providing interventions for the child and added them to the identified teams.

School Characteristics

Two schools (referred to as School A and School B) participated in the pilot study. They were selected from a large, Midwestern US school district and had students who were majority low-income (86.8% and 78.6%, respectively) and serviced children with disabilities (16% and 23.7%, respectively). In this article, findings from the pilot data are reported for 23 children and their teams of parents and providers.

TABLE 1 Descriptive Statistics for the 23 Complete Teams for Fall and Spring

	Minimum	Maximum	Mean	SD
Size of team				
No. team members (fall)	5	20	14.6	4.8
No. team members (spring)	5	22	15.5	5.0
Difference (spring to fall)	0	2	0.9	0.3
No. locations for interventions				
Fall	2	5	2.6	0.8
Spring	2	5	2.5	0.8
Difference (spring to fall)	0	0	-0.1	-0.1
No. effective interventions provided by team				
Fall	11	61	36.9	14.7
Spring	13	59	36.3	13.5
Difference (spring to fall)	2	-2	-0.6	-1.3
No. autism trainings attended by team				
Fall	5	33	20.2	7.6
Spring	6	41	27.1	11.2
Difference (spring to fall)	1	8	6.9	3.5
Density of team's problem-solving network				
Fall	0.2	0.5	0.3	0.1
Spring	0.2	0.7	0.5	0.1
Difference (spring to fall)	0	0.3	0.1	0

Potential applications for young adults with ASD in the home, school, and community settings are explored in the Discussion section.

Data Analysis

All data were double entered, and intervention and training data were double coded by research assistants with an interrater reliability of 0.80 or better on at least 2 coding tests. The data were analyzed and visualized by using the Organization Risk Analyzer, a social network analysis software developed by Carley.²¹ Network density for each child's problem-solving networks was calculated. Network density is the ratio of the number of actual connections that people on the team make with one another to solve problems versus the maximum possible connections people on the team could make with each other to solve problems.

A regression-based test was used for significance of the mean change in problem-solving within child teams over the course of the school year.²² The authors fit a linear model of the difference between the spring density of team problem-solving and the fall density of team

problem-solving ($y-x$), regressed on the mean-centered fall density of team problem-solving (I (fall density of team problem-solving, mean (fall density of team problem-solving)) and the mean-centered dummy variable for School B (I (dummy variable for School B, mean (dummy variable for School B))). The intercept of the regression model, and its SE, provide the regression-based test of significance in change in team problem-solving. Descriptive and regression statistics were calculated by using SPSS (IBM SPSS Statistics, IBM Corporation, Armonk, NY).

RESULTS

With the descriptive data that we report in Table 1, we illustrate changes in the 5 identified dimensions of team activity for all 23 children and their associated teams, including an increase in mean team size, a slight decrease in mean treatment location, stability in the number of effective interventions, and an increase in mean density of problem-solving within teams.

The results from the linear regression are reported in Table 2. The intercept, which is the mean difference (0.123), was statistically

TABLE 2 Testing the Significance of Change in the Density of Team Problem-solving

Model	Unstandardized Coefficients		Standardized Coefficients	P
	B	SE	β	
Constant	0.123	0.017	—	.00
Team problem-solving network density (fall)	0.184	0.211	.194	.39
School B	-0.010	0.037	-.062	.78

—, not applicable.

significant ($P < .001$) by using the regression-based test.

Although an increase in engagement among team members in problem-solving interactions is suggested in the overall finding across the 23 children, in further analysis of the configuration of interactions for each child, variation in who played a central role in problem-solving at each time point is suggested. In the sociograms in Fig 1, we demonstrate how problem-solving interactions vary across time for a particular child (referred to in Fig 1 as Child 1). The sociograms reveal an increased intensity of problem-solving interaction in the spring. Instead of 1-way exchanges that characterize the fall, most team members were participating in 2-way exchanges in the spring. Also, certain people were more active in the problem-solving network. In the spring, problem-solving became more intense in Child 1's team between the parent and

the special education teacher, but the speech therapist discontinued problem-solving with the parent in the spring.

DISCUSSION

In the descriptive statistics, we provide an overview of the number of people, locations, effective interventions, and autism trainings that were present in each child's team during the school year; in the regression-based test results, it is suggested that mean team problem-solving for children increased from fall to spring during the school year. Further variation at the child level revealed who was engaged in problem-solving for the child and how connections changed over time. In the pilot study results, it is suggested that the SoDI could be used to create a set of indicators, including summary statistics that compare children over

time, as well as sociograms to help teams better identify where and how engagement breaks down for each child's team. Such indicators can allow team members easier access to potentially useful information about who provides which treatments and where and identify opportunities missed or exploited for increasing engagement among parents and providers. In the next section, SoDI measures are suggested for use in tracking the service cliff that each young adult faces during their transition to work.

Team Maps for Transition-Aged Youth

Although stability in intervention delivery during the school year and an increase in efforts made by team members to engage one another in solving problems for younger children on the spectrum is suggested in our findings, many young adults experience serious disconnection across multiple domains of adult life posttransition from secondary school, with 66% not transitioning into employment or education in the first 2 years after leaving high school.⁹ Mapping how the structure of disconnection occurs during transition can help determine

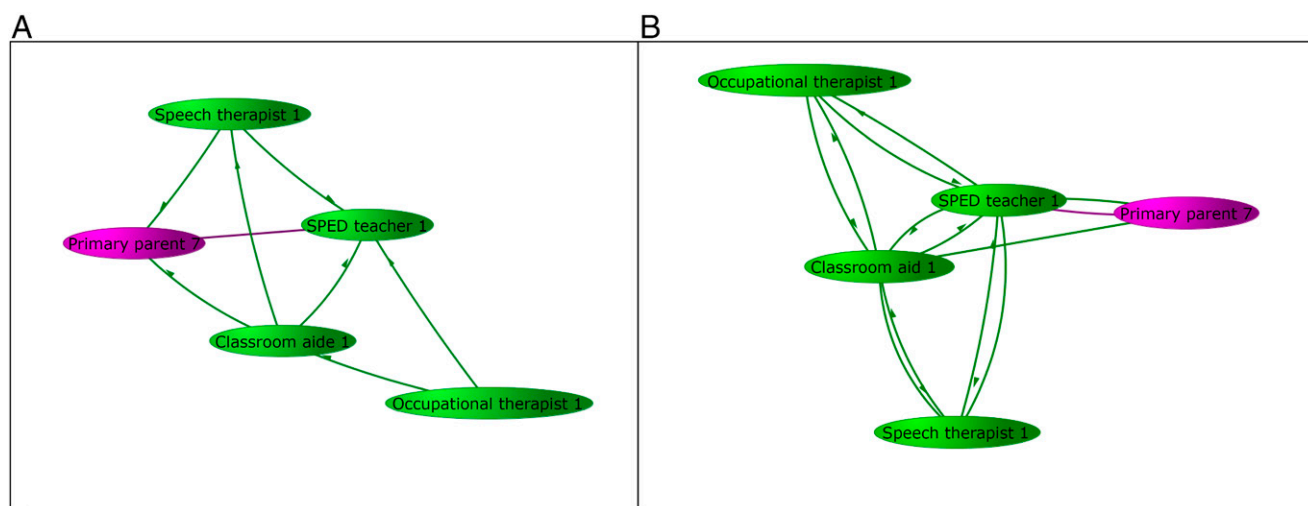


FIGURE 1

Changes in team problem-solving network for Child 1. A, Fall. B, Spring. SPED, special education.

the best ways to reconnect young adults with ASD during this turbulent time.

Sociograms for transitioning youth could be used to illustrate the details of the service cliff, as it was experienced by each person. A successful school to work transition indicator would identify overlap across the transition, with employment or community living service providers in the pretransition and posttransition team map for the young adult. The SoDI would allow teams to track the level of engagement by adult-serving providers at each time point, helping the young adult's team identify services gaps and seek solutions. By using the domain of employment as an illustrative example, work-related interventions and services priorities pre- and posttransition would indicate a successful support network. A successful posttransition network could measure the degree to which the young adult received integrated supports from family and community providers.

Such a tracking system would also provide information about which services were dropped or sustained when the young adult transitions off the services cliff. It is suggested

in recent findings that every type of service that young adults received posttransition from high school decreased in frequency, with less than one-third of young adults receiving the same services they had pretransition.⁹ Tracking the disconnect could potentially help young adults, their parents, and providers figure out which gaps emerge pre- and posttransition and how to fill them.

Team Problem-solving Networks for Transition-Aged Youth

Although the SoDI was originally designed to measure problem-solving among team members, it could be redesigned to include each youth as part of their own team. The network maps could reveal who the young person turns to for help to solve everyday problems and who the young adult trusts among parents and providers. Determining preferred interaction partners for the young adult would provide useful information for the young adult and their team.

CONCLUSIONS

Dynamic social network approaches can capture changes in intervention, autism knowledge, and social connectivity, providing information that could inform the pre- and

posttransition process for young adults with ASD. Such tracking systems are in the early stages of development. Much more research is needed to determine how to link network configurations with ideal outcomes for children on the spectrum.

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ABBREVIATIONS

ASD: autism spectrum disorder
SoDI: Social Dynamics of Intervention

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