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# **Developmental Trajectories of Autism**

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# Abstract

**Objective**—The goal of this study was to describe the typical, longitudinal, developmental trajectories of communication and social functioning in individuals with autism spectrum disorder (ASD) from childhood through adulthood and to determine the correlates of these trajectories.

**Methods**—Children with ASD who were born in California from 1992 through 2016 and enrolled with the California Department of Developmental Services were identified. Subjects with <4 evaluations in the database were excluded, resulting in a sample of 71,285 individuals. Score sequences were constructed based on evaluative items for communication and social functioning. Typical trajectories were identified using group-based latent trajectory modeling, and logistic regression was used to determine the odds of classification into a social adolescent decline trajectory by individual-, family-, and zip code-level factors.

**Results**—Six typical patterns of communication functioning and seven typical patterns of social functioning were identified. Whereas the majority of autistic individuals exhibit improved communication functioning as they age, the majority of individuals exhibit steady social functioning. A small group of individuals (5.0%) exhibits high social functioning in childhood that declines in adolescence. Membership in this adolescent decline group is associated with maternal non-Hispanic White race/ethnicity, female sex, moderate levels of maternal education, lower zip code-level median home values and population density, and higher zip code-level inequality.

Clinical Trial Registration (if any): Not Applicable

Address correspondence to: Christine Fountain, Department of Anthropology & Sociology, Fordham University, 113 West 60th St., Suite 916, New York, NY 10023, cfountain1@fordham.edu, 646-293-3959. Contributors' Statement

Christine Fountain contributed to the conception and design, acquisition of data, analysis and interpretation of data, drafted and revised the article, and had final approval.

Alix S. Winter contributed to the conception and design, acquisition and linkage of data, interpretation of data, drafting and revising the article, and approved the final version.

Keely Cheslack-Postava contributed to conception and design, interpretation of data, revising the article, and approved the final version.

Peter S. Bearman contributed to conception and design, acquisition and interpretation of data, revising the article, and approved the final version.

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**Conclusion**—Most autistic individuals show improved communication and social functioning as they age, but not all do. Trajectory group membership is correlated with socioeconomic status. Future research should investigate what drives these correlations.

#### Keywords

Autism Spectrum Disorder; Longitudinal Outcomes; Trajectory Models

#### Introduction

Autism spectrum disorder (ASD) is a lifelong condition. Although the traits of autistic individuals change – sometimes substantially<sup>1</sup> – over time, few lose their diagnosis.<sup>2–5</sup> Understanding "chronogeneity" – the heterogeneity over time -- in ASD traits, including identifying key moments of change and their causes, can aid clinicians in helping autistic people and their caregivers plan for the future.<sup>6</sup>

A number of studies have examined longitudinal ASD condition trajectories. However, research has been hampered by a paucity of large and diverse samples with frequent observations over long follow-up periods.<sup>6,7</sup> A typical trade-off in these studies is that, in order to utilize validated clinical assessments, they rely on small, unrepresentative clinical samples with short observational periods and infrequent follow-ups.<sup>8–12</sup> Results from studies using group-based longitudinal trajectory methods and clinical assessments generally find substantial heterogeneity in ASD trait trajectories and a group that improves significantly over time.<sup>9–15</sup> Typically, the number of trajectory groups identified decreases in smaller samples, with best-fitting models finding two to five groups.<sup>8–15</sup> Many models identify a group that becomes more severe over time but are based on young samples with short follow-up periods that do not allow examination of later potential inflection points.<sup>8–11,14,15</sup> In addition, the individual and community socioeconomic correlates of trajectories have been infrequently examined.

A unique study of chronogeneity in ASD traits had the advantage of a large, diverse sample, although it depended on administrative data rather than clinical assessments.<sup>16</sup> Using administrative data with annual follow-ups to age 14, this study found six distinct trajectories, including a group whose communication skills, measured by word usage and expressive and receptive language, improved dramatically over time.<sup>16</sup> Membership in the communication improvement group was associated with higher socioeconomic status (SES) as well as White race/ethnicity.<sup>16</sup> Unlike some other studies, this research did not find a trajectory with autism traits becoming stronger over time, but was unable to assess trajectories past early adolescence.

Addressing knowledge gaps about the longitudinal trajectories of autism traits through adolescence and early adulthood could help clinicians understand how resources and interventions shape the lives of autistic people and assist clinicians and caregivers in better targeting them. Further, research is needed to understand how documented socioeconomic and ethnic disparities in ASD diagnosis<sup>17,18</sup> might also be reflected in longitudinal trajectories of ASD traits.

In this study, we draw on a large database of autistic persons with annual evaluations from diagnosis through age 27 years. We use these evaluations to examine over 70,000 longitudinal trajectories and uncover patterns of development in two core domains of ASD. We then examine how these trajectories relate to one another and assess trajectory group associations with individual- and community-level sociodemographic characteristics.

### Methods

#### Population

The population of interest for this study is autistic persons who reside in California and were born in 1992-2016. The Lanterman Act requires the state to provide services for all residents with developmental disabilities, including autism. The California Department of Developmental Services (DDS) coordinates diagnoses and services and has kept digital records of its caseload since 1992; these records were acquired through a data use agreement.

Although DDS enrollment is voluntary and may not include all eligible persons with autism, eligibility is not means-tested, and most children with autistic disorder or ASD (hereafter referred to as ASD) in California are enrolled.<sup>19</sup> In 2014, the DDS adopted the DSM-5 diagnostic criteria for ASD, potentially expanding the eligible population.<sup>20</sup>

#### Dataset linkage and sample selection

We matched ASD caseload records from the DDS for 1992 through November 2019 to birth records from the California birth master files (BMF) for 1992-2016 on infant names, birthdate, sex, and race/ethnicity using Stata's user-written dtalink command.<sup>21</sup> Uncertain matches were manually reviewed; overall, 86.0% of DDS records were matched to a birth record, with match rates increasing over time.<sup>18</sup>

We then selected the 862,794 annual records of the 122,392 children born in 1992-2016 who ever appeared in the DDS caseload with an ASD diagnosis. We excluded evaluations for infants under one year of age, those missing evaluative items, duplicates, and individuals with fewer than four evaluations, resulting in 71,136 trajectories. Missing data on sociodemographic and community characteristics (see Supplementary Table A) further reduced the sample to 67,888 individuals for the regression analysis.

#### **Dependent Variables: Communication and Social Functioning Measures**

DDS clients are evaluated annually using the Client Development Evaluation Report (CDER) to determine service needs. The CDER was revised in 2008,<sup>22</sup> so we created a crosswalk between comparable pre- and post-revision items (see Supplementary Figure A).<sup>16</sup> Communication scores evaluating language usage range from one (does not use words to communicate) to five (uses complete sentences and has a vocabulary of >30 words). Social scores assessing clients' abilities to engage in and maintain social interactions with others range from one (does not engage in two-way interaction) to four (initiates and maintains interaction with others in familiar and unfamiliar settings). Sequences of scores

vary in length from 4-26 years depending on birth cohort, age at ASD diagnosis, time on the DDS caseload, and frequency of evaluation.

#### Covariates

**Individual characteristics:** From the BMF we extracted: birth year; maternal education level, race/ethnicity, and birthplace; infant sex; and whether the birth was paid for by Medi-Cal (California's Medicaid program) as a proxy for socioeconomic status. Race/ethnicity is a social construct included due to its potential impact on children's treatment, evaluation, and service receipt. Year of DDS entry is the year of the first CDER (with any diagnosis). Age of ASD diagnosis is calculated as the difference between the first date on the DDS ASD caseload and BMF birth date, re-coded into five ordinal categories. A co-occurring Intellectual Disability (ID) diagnosis is coded as present if an ID diagnosis ever appeared in an individual's record.

**Community characteristics:** We included three characteristics of the five-digit zip codes in which individuals lived at entry into the DDS: high inequality (zip code with a Gini coefficient for household income in the top quintile of CA zip codes), low population density (persons per square mile in the bottom quintile); and median home value (in 2000 dollars). We derived these measures from the 1990 and 2000 decennial censuses, the 2008-2012 5-Year American Community Survey (ACS), and the 2014-2018 5-Year ACS and linearly interpolated rates for the intervening years.

#### Analyses

To identify and describe subgroups with similar developmental trajectories, we used groupbased latent trajectory modeling implemented with the *lcmm* package for R.<sup>23,24</sup> This approach assumes the population is composed of a number of subgroups with similar longitudinal trajectories and uses a polynomial equation to capture the relationship between age and the outcome, which, in our case, are latent variables characterizing individuals' communication or social functioning. Model selection was based on goodness-of-fit statistics and posterior probability classification tables to confirm group discrimination. We then allocated individuals to their most likely trajectory (Supplementary Table B).<sup>23</sup>

To examine the relationship between trajectory groups, we cross-tabulated group membership and compared each observed cell count to its expected value under an assumption of independence. To understand the sociodemographic compositions of each group, we calculated means and proportions by sociodemographic characteristics and conducted two-tailed tests for differences from the grand mean and  $\chi^2$  tests of independence for continuous and categorical variables, respectively. Finally, to examine correlates of membership in a social trajectory group characterized by declining functioning in adolescence, we used the GLM function in R to fit a logistic model with standard errors clustered on individuals' zip codes at entry into the DDS and calculated odds ratios with 95% confidence intervals.<sup>25</sup> This study was approved by the Columbia University and California Committee for the Protection of Human Subjects institutional review boards.

# Results

Table 1 shows the sample characteristics. Eighty-two percent of the sample is male, almost 23% have an ID diagnosis, and the modal child is diagnosed at age three years. Hispanic individuals comprise the largest racial/ethnic group (44%), and 43% of mothers are foreignborn, closely resembling the demographics of California's general population. Nearly 40% of births are paid for by Medi-Cal, and 27% of mothers have at least a 4-year college degree.

#### **Communication Trajectories**

The six communication trajectories with 95% confidence intervals are displayed in Figure 1. In five of six trajectories, there is improvement in evaluated communication skills and little change after about age 15 years. Among these trajectories, groups we label Early Growth and Moderate enter the DDS with moderate communication scores, whereas Mid Growth, Late Growth, and Limited Growth groups enter the DDS with low scores at first evaluation. Whereas members of the Early Growth, Mid Growth, and Late Growth groups – comprising the majority of our sample – reach the score ceiling at varying paces, members of the Moderate and Limited Growth groups improve less and plateau. Finally, the sixth group – labeled "Low Flat" – includes 8.6% of the sample and is comprised of individuals who never communicate with words at any age.

#### **Social Trajectories**

The seven social interaction trajectories with 95% confidence intervals are shown in Figure 2. These are markedly more varied than the communication trajectories. Three of the trajectories (High Growth, Medium-High Growth, and Moderate Growth) exhibit improvement, albeit to different levels; three (Medium-High Flat, Medium Flat, and Low Flat) show little change over time and jointly comprise the majority of our sample; and one (Adolescent Decline [AD]) has the highest evaluated social skills at entry to the DDS but exhibits substantial decline in adolescence.

#### Associations Between Communication and Social Trajectory Group Memberships

Figure 3 shows the joint distribution of membership in the two sets of trajectory groups, with larger circles signifying higher relative frequencies. In general, flat social trajectories tend to be associated with flat or limited improvement communication trajectories, and improving social trajectories tend to be associated with improving communication trajectories. The strongest association is between each dimension's Low Flat trajectories, reflecting a subgroup of severely affected individuals whose autism trait levels change little from childhood through adulthood. Meanwhile, the largest cells in Figure 3, each comprising 11% of the sample, are the co-occurrences of the Medium-High Flat social trajectory, characterized by fairly high, stable social skills, and the Early Growth or Mid Growth communication trajectories, which exhibit improved communication during childhood. Notably, more than half of the individuals in the AD group come from the Early Growth communication group.

#### Sociodemographic Correlates of Trajectory Group Membership

Tables 2 and 3 show sociodemographic characteristics stratified by trajectory group. Children with co-occurring ID are more likely to be in the Low Flat communication and social trajectory groups. Children of White mothers are overrepresented among the Early Growth communication group, whereas children of Hispanic and Black mothers are underrepresented among this group. Children of Asian mothers are overrepresented among both the Low Flat communication and social groups. Children of foreign-born mothers are less likely to show early communication growth and more likely to exhibit a flat trajectory. Children of mothers of higher SES (as measured by maternal education or Medi-Cal status) are overrepresented among the Early Growth and underrepresented among the Low Flat, Limited Growth, and Late Growth communication groups. Social trajectory group membership is less clearly patterned with respect to maternal SES than communication, but children of higher SES mothers are less likely to be in the Low Flat and Moderate Growth groups.

Finally, children in the Early Growth communication and Medium-High Flat social groups tend to live in communities with, on average, high median home values and low population densities. In contrast, children in the Late Growth, Limited Growth, and Low Flat communication groups live in communities with lower home values. Children in the AD social trajectory group live in communities with both lower median home values and low population densities.

#### Understanding the Adolescent Decline Trajectory

Table 4 displays the results of a multivariable logistic regression model predicting assignment to the AD trajectory relative to all other social trajectories. The results reveal that AD is positively associated with female sex (OR = 1.21, 95% CI = 1.10, 1.32). AD children are less likely to be diagnosed either younger or older than age three. Children of White mothers are more likely to be in the AD group relative to children of Hispanic mothers (OR = 1.13, 95% CI = 1.03, 1.25), whereas children of Asian mothers are less likely (OR = 0.73, 95% CI = 0.63, 0.85). Those with foreign-born mothers have a slightly lower odds ratio relative to those with US-born mothers (OR = 0.88, 95% CI = 0.81, 0.97). Both low and high levels of maternal education are negatively associated with AD relative to HS graduates. Relative to Early Growth communication group membership, membership in any other communication trajectory group is negatively associated with an AD social trajectory.

Regarding community-level characteristics, living in a high-inequality zip code is associated with AD (OR = 1.14, 95% CI = 1.04, 1.27). Each standard deviation increase in median home value is associated with a decreased odds of AD by about 11% (OR = 0.89, 95% CI = 0.84, 0.93), while living in a low-density zip code is associated with a 16% increase in odds (OR = 1.16, 95% CI = 1.04, 1.29).

### Discussion

Using the largest available database with the longest follow-up of autistic persons, we uncover several typical patterns of ASD chronogeneity and their associations with

individual- and community-level demographic characteristics. Whereas most autistic persons exhibit improved communication as they age, their social functioning tends to remain steadier. Unlike previous studies, we also find a small group whose initially high social evaluations decline rapidly in adolescence.

#### Socioeconomic and Racial/Ethnic Disparities

Like a previous study of this population,<sup>16</sup> we find that children from families with more socioeconomic resources, as indicated by maternal education and private health insurance coverage, tend to exhibit more improvement. This is also true for neighborhood resources, where improvement is more common in zip codes with higher median home values.

We also find disparities by race and ethnicity; children of White mothers are overrepresented among the Early Growth communication trajectory, whereas children of Hispanic, Black, and Asian and foreign-born mothers are overrepresented among the communication and social trajectories displaying less growth. This analysis does not reveal the source of these disparities, which may be due to some combination of differential ascertainment,<sup>17,18,26</sup> racial bias in evaluations,<sup>27</sup> and unequal access to services and support,<sup>28</sup> among other potential explanations that require further research. However, these patterns align with broader socioeconomic and racial disparities in health<sup>29,30</sup> and may signify inequities in access to the resources that autistic people need to reach their full potentials.<sup>31,32</sup> Children of foreign-born mothers, meanwhile, may experience challenges arising from language access.

#### Adolescent decline in social skills

Prior research identified distinct trajectory groups that show significant improvement or decline through childhood,<sup>9,11,14–16,33</sup> and a few small studies describe children who "regress" into disruptive or aggressive behavior at puberty.<sup>34,35</sup> This study is unique in identifying a sub-group of autistic children whose social trajectory declines in adolescence in a large, diverse cohort.

In the US, roughly 50,000 autistic adolescents transition to young adulthood each year.<sup>36</sup> This transition is accompanied by changes in the healthcare support systems available to autistic persons, including changes in providers and insurance, and loss of educational services, creating obstacles to resource access at a critical time.<sup>36,37</sup> It is important to understand how these changes might co-occur with changes in autistic persons' trait trajectories.

A typical member of the AD group displays early, rapid improvement in their evaluated communication skills combined with early high social skills. It is possible that, given their high functioning at younger ages, these individuals are exposed to situations and environments, such as mainstream classes, that tax their abilities as they encounter the more complex social interactions of adolescence, resulting in a real or perceived decline in their social functioning. At the same time, the stresses of adolescence or the onset of psychiatric conditions,<sup>38,39</sup> such as depression or anxiety, may trigger a decline in these individuals' social skills. Adolescence has been found to be a difficult period for autistic

Those in the AD group are more likely to be female, diagnosed at age three, and have White mothers with a high school diploma. Although Medi-Cal receipt (an indicator of low household income) is not associated with AD, greater community-level resources as measured by median home values are protective, whereas living in a high-inequality or low-density community are risk factors.

#### Neurodiversity

Challenges to the medical model of ASD by the neurodiversity movement have pointed out that ASD traits, including differences in social and communication functioning, are not necessarily skill deficits, but reflect the range of variation in human interaction.<sup>42,43</sup> Through this lens, we acknowledge that, although it is unclear how the trajectories revealed in our study population might differ from those in the neurotypical population, it is likely that the latter also display significant chronogeneity and socioeconomic disparities. Further, the associations between trajectory groups and community-level variables remind us that evaluations of traits signify not just characteristics of individuals, but interactions between individuals and their environments.

#### Limitations

First, both the DDS' definition of ASD and the items used to evaluate social and communication functioning changed during our study period. To the extent we can investigate given younger cohorts' shorter observation windows, we do not find evidence of discontinuities in the trajectory groups identified coinciding with these changes. Second, the evaluative items are not clinical assessments and may omit relevant dimensions. In addition, potential ranges of behavior may be truncated by the low levels of interaction represented by the highest scores, especially for older individuals. Finally, the sample is 82% male. While this is consistent with the gender composition found in most studies of community-identified ASD, it is possible that girls are disproportionately under-identified, and it is unclear how this might affect our results.<sup>41,44</sup>

#### **Future Research Directions**

Areas for future research include: investigating the mechanisms behind racial/ethnic and SES disparities in trajectories and the social decline experienced by the AD group; reproducing these findings using clinically validated measures of social communication; and translating these findings into specific recommendations for clinicians, caregivers, policymakers, and autistic people themselves. In addition, in light of the finding that female sex is associated with the AD group and the under-representation of girls in this dataset, more research is needed on ASD in girls, particularly in adolescence. Finally, many autistic persons do not receive a diagnosis until later in childhood or adulthood,<sup>45</sup> and research is needed to understand how their trajectories might differ.

## Conclusion

Although most individuals diagnosed with ASD show improved communication and social interaction functioning as they age, albeit at varying rates and to varying levels, not all do. Improvement is more common in relation to communication than social functioning, and we uncover a small group that exhibits a decline in their social functioning in adolescence. Trajectory group membership is correlated with SES and race/ethnicity, indicating that unequal access to resources contributes to disparities in individuals' experiences of ASD's chronogeneity.

Clinicians can aid in the provision of effective and inclusive services for autistic persons throughout the life course. Clinicians can ensure that all children are screened according to the American Academy of Pediatrics' recommendations and assist in accessing appropriate resources and support.<sup>46,47</sup> Clinicians should also remain aware that autism traits, social expectations, and needs change as children age. Adolescence can be a time during which autistic children experience stress and may benefit from additional support. Further, the stigma and discrimination faced by autistic children can intersect with that arising from other characteristics, such as race and economic status.<sup>40</sup> Physicians can provide more effective care to diverse populations by developing cultural competence and awareness of systemic racism and advocating for policies that alleviate disparities.

## **Supplementary Material**

Refer to Web version on PubMed Central for supplementary material.

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#### Abbreviations:

AD	Adolescent Decline
ACS	American Community Survey
ASD	Autism Spectrum Disorder
BMF	Birth Master Files
CDER	Client Development Evaluation Report
DDS	(California) Department of Developmental Services
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
нѕ	High school

ID	Intellectual Disability
OR	Odds Ratio
SES	Socioeconomic status
ZCTA	Zip Code Tabulation Area

#### References

- Waizbard-Bartov E, Ferrer E, Young GS, et al. Trajectories of Autism Symptom Severity Change During Early Childhood. J Autism Dev Disord. Published online May 14, 2020. doi:10.1007/ s10803-020-04526-z
- Billstedt E, Gillberg C, Gillberg C. Autism after Adolescence: Population-based 13- to 22-year Follow-up Study of 120 Individuals with Autism Diagnosed in Childhood. J Autism Dev Disord. 2005;35(3):351–360. doi:10.1007/s10803-005-3302-5 [PubMed: 16119476]
- McGovern CW, Sigman M. Continuity and change from early childhood to adolescence in autism. J Child Psychol Psychiatry. 2005:46(4):401–408. doi:10.1111/j.1469-7610.2004.00361.x [PubMed: 15819649]
- 4. Robinson EB, Munir K, Munafò MR, Hughes M, McCormick MC, Koenen KC. Stability of Autistic Traits in the General Population: Further Evidence for a Continuum of Impairment. J Am Acad Child Adolesc Psychiatry. 2011;50(4):376–384. doi:10.1016/j.jaac.2011.01.005 [PubMed: 21421177]
- Seltzer MM, Shattuck P, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. Ment Retard Dev Disabil Res Rev. 2004;10(4):234–247. doi:10.1002/ mrdd.20038 [PubMed: 15666341]
- Georgiades S, Bishop SL, Frazier T. Editorial Perspective: Longitudinal research in autism

   introducing the concept of chronogeneity.' J Child Psychol Psychiatry. 2017;58(5):634–636.
   doi:10.1111/jcpp.12690 [PubMed: 28414862]
- Lombardo MV, Lai MC, Baron-Cohen S. Big data approaches to decomposing heterogeneity across the autism spectrum. Mol Psychiatry. 2019;24(10):1435–1450. doi:10.1038/s41380-018-0321-0 [PubMed: 30617272]
- Farmer C, Swineford L, Swedo SE, Thurm A. Classifying and characterizing the development of adaptive behavior in a naturalistic longitudinal study of young children with autism. J Neurodev Disord. 2018;10(1):1. doi:10.1186/s11689-017-9222-9 [PubMed: 29329511]
- Gotham K, Pickles A, Lord C. Trajectories of autism severity in children using standardized ADOS scores .Pediatrics. 2012;130(5):e1278–1284. doi:10.1542/peds.2011-3668 [PubMed: 23090336]
- Solomon M, Iosif AM, Reinhardt VP, et al. What will my child's future hold? phenotypes of intellectual development in 2–8-year-olds with autism spectrum disorder. Autism Res. 2018;11(1):121–132. doi:10.1002/aur.1884 [PubMed: 29076255]
- Szatmari P, Georgiades S, Duku E, et al. Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. JAMA Psychiatry. 2015;72(3):276–283. doi:10.1001/jamapsychiatry.2014.2463 [PubMed: 25629657]
- Visser JC, Rommelse NNJ, Lappenschaar M, Servatius-Oosterling IJ, Greven CU, Buitelaar JK. Variation in the Early Trajectories of Autism Symptoms Is Related to the Development of Language, Cognition, and Behavior Problems. J Am Acad Child Adolesc Psychiatry. 2017;56(8):659–668. doi:10.1016/j.jaac.2017.05.022 [PubMed: 28735695]
- Baghdadli A, Michelon C, Pernon E, et al. Adaptive trajectories and early risk factors in the autism spectrum: A 15-year prospective study. Autism Res. 2018;11(11):1455–1467. doi:10.1002/ aur.2022 [PubMed: 30270526]
- Kim SH, Bal VH, Benrey N, et al. Variability in Autism Symptom Trajectories Using Repeated Observations From 14 to 36 Months of Age. J Am Acad Child Adolesc Psychiatry. 2018;57(11):837–848.e2. doi:10.1016/j.jaac.2018.05.026 [PubMed: 30392625]

- Venker CE, Ray-Subramanian CE, Bolt DM, Ellis Weismer S. Trajectories of autism severity in early childhood. J Autism Dev Disord. 2014;44(3):546–563. doi:10.1007/s10803-013-1903-y [PubMed: 23907710]
- Fountain C, Winter AS, Bearman PS. Six developmental trajectories characterize children with autism. Pediatrics. 2012;129(5):e1112. [PubMed: 22473372]
- Wiggins LD, Durkin M, Esler A, et al. Disparities in Documented Diagnoses of Autism Spectrum Disorder Based on Demographic, Individual, and Service Factors. Autism Res Off J Int Soc Autism Res. 2020;13(3):464–473. doi:10.1002/aur.2255
- Winter AS, Fountain C, Cheslack-Postava K, Bearman PS. The social patterning of autism diagnoses reversed in California between 1992 and 2018. Proc Natl Acad Sci. 2020;117(48):30295–30302. doi:10.1073/pnas.2015762117 [PubMed: 33199592]
- Croen LA, Grether JK, Hoogstrate J, Selvin S. The changing prevalence of autism in California. J Autism Dev Disord. 2002;32(3):207–215. [PubMed: 12108622]
- American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. 5th Edition. American Psychiatric Association; 2013.
- 21. Kranker K Dtalink: Faster Probabilistic Record Linking and Deduplication Methods in Stata for Large Data Files. Stata Users Group; 2018. Accessed September 23, 2021. https:// ideas.repec.org/p/boc/scon18/31.html
- 22. Client Development Evaluation Report CA Department of Developmental Services. Published February 8, 2019. Accessed September 20, 2021. https://www.dds.ca.gov/transparency/cder/
- 23. Nagin D. Group-Based Modeling of Development. Harvard University Press; 2005.
- 24. Proust-Lima C, Philipps V, Liquet B. Estimation of extended mixed models using latent classes and latent processes: the R package lcmm. J Stat Softw. 2017;78(2). doi:10.18637/jss.v078.i02
- 25. R Core Team. R: A language and environment for statistical computing. Published online 2022. https://www.R-project.org/
- 26. King MD, Bearman PS. Socioeconomic Status and the Increased Prevalence of Autism in California. Am Sociol Rev. 2011;76(2):320–346. doi:10.1177/0003122411399389 [PubMed: 21547238]
- Harrison AJ, Long KA, Tommet DC, Jones RN. Examining the Role of Race, Ethnicity, and Gender on Social and Behavioral Ratings Within the Autism Diagnostic Observation Schedule. J Autism Dev Disord. 2017;47(9):2770–2782. doi:10.1007/s10803-017-3176-3 [PubMed: 28597187]
- 28. Eilenberg JS, Paff M, Harrison AJ, Long KA. Disparities Based on Race, Ethnicity, and Socioeconomic Status Over the Transition to Adulthood Among Adolescents and Young Adults on the Autism Spectrum: a Systematic Review. Curr Psychiatry Rep. 2019;21(5):32. doi:10.1007/ s11920-019-1016-1 [PubMed: 30903399]
- 29. Marmot MG. The Status Syndrome: How Social Standing Affects Our Health and Longevity. Macmillan; 2004.
- 30. Link BG, Phelan JC. Social conditions as fundamental causes of disease. J Health Soc Behav. 1995;35:80–94.
- Smith KA, Gehricke JG, Iadarola S, Wolfe A, Kuhlthau KA. Disparities in Service Use Among Children With Autism: A Systematic Review. Pediatrics. 2020;145(Supplement\_1):S35–S46. doi:10.1542/peds.2019-1895G [PubMed: 32238530]
- Liptak GS, Benzoni LB, Mruzek DW, et al. Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. J Dev Behav Pediatr JDBP. 2008;29(3):152–160. doi:10.1097/DBP.0b013e318165c7a0 [PubMed: 18349708]
- 33. Georgiades S, Tait PA, McNicholas PD, et al. Trajectories of Symptom Severity in Children with Autism: Variability and Turning Points through the Transition to School. J Autism Dev Disord. 2022;52(1):392–401. doi:10.1007/s10803-021-04949-2 [PubMed: 33704613]
- Périsse D, Amiet C, Consoli A, et al. Risk Factors of Acute Behavioral Regression in Psychiatrically Hospitalized Adolescents with Autism. J Can Acad Child Adolesc Psychiatry. 2010;19(2):100–108. [PubMed: 20467546]

- 35. Kobayashi R, Murata T, Yoshinaga K. A follow-up study of 201 children with autism in Kyushu and Yamaguchi areas, Japan. J Autism Dev Disord. 1992;22(3):395–411. doi:10.1007/ BF01048242 [PubMed: 1383189]
- 36. Malik-Soni N, Shaker A, Luck H, et al. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatr Res. 2022;91(5):1028–1035. doi:10.1038/ s41390-021-01465-y [PubMed: 33767375]
- 37. Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF. Services for Adults with an Autism Spectrum Disorder. Can J Psychiatry. 2012;57(5):284–291. doi:10.1177/070674371205700503 [PubMed: 22546060]
- Paus T, Keshavan M, Giedd JN. Why do many psychiatric disorders emerge during adolescence? Nat Rev Neurosci. 2008;9(12):947–957. doi:10.1038/nrn2513 [PubMed: 19002191]
- Yeh TC, Chen MH, Bai YM, et al. Longitudinal follow-up of subsequent psychiatric comorbidities among children and adolescents with autism spectrum disorder. J Affect Disord. 2023;331:245– 250. doi:10.1016/j.jad.2023.03.042 [PubMed: 36965622]
- 40. Botha M, Frost DM. Extending the minority stress model to understand mental health problems experienced by the autistic population. Soc Ment Health. 2020;10(1):20–34.
- 41. Calderoni S Sex/gender differences in children with autism spectrum disorder: A brief overview on epidemiology, symptom profile, and neuroanatomy. J Neurosci Res. 2022;n/a(n/a). doi:10.1002/jnr.25000
- Pellicano E, den Houting J. Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. J Child Psychol Psychiatry. 2022;63(4):381–396. doi:10.1111/ jcpp.13534 [PubMed: 34730840]
- Baron-Cohen S Editorial Perspective: Neurodiversity a revolutionary concept for autism and psychiatry. J Child Psychol Psychiatry. 2017;58(6):744–747. doi:10.1111/jcpp.12703 [PubMed: 28524462]
- 44. Maenner MJ. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ. 2023;72. doi:10.15585/mmwr.ss7202a1
- 45. Davidovitch M, Levit-Binnun N, Golan D, Manning-Courtney P. Late Diagnosis of Autism Spectrum Disorder After Initial Negative Assessment by a Multidisciplinary Team. J Dev Behav Pediatr. 2015;36(4):227. doi:10.1097/DBP.000000000000133 [PubMed: 25651066]
- 46. Hyman SL, Levy SE, Myers SM, et al. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. 2020;145(1):e20193447. doi:10.1542/peds.2019-3447 [PubMed: 31843864]
- 47. Lipkin PH, Macias MM, COUNCIL ON CHILDREN WITH DISABILITIES SODABP, et al. Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening. Pediatrics. 2020;145(1):e20193449. doi:10.1542/peds.2019-3449 [PubMed: 31843861]

#### **Article Summary**

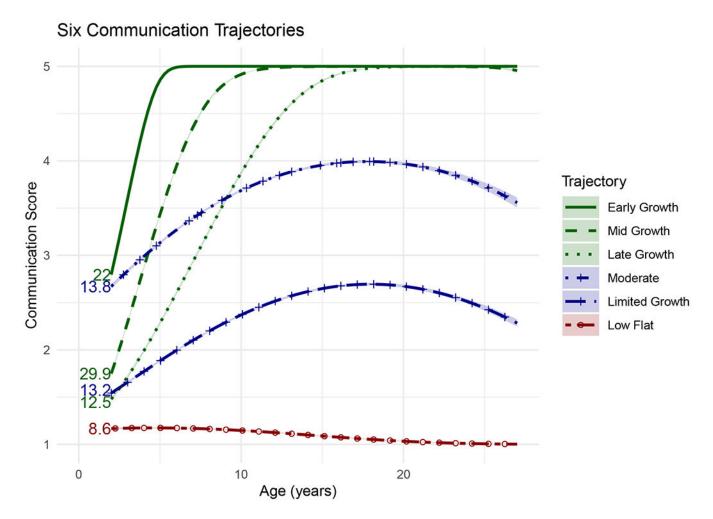
We describe variation in longitudinal autism characteristics in a large group of autistic persons and assess family and community characteristics associated with these patterns.

#### What's Known on This Subject

Autism's core indicators, communication and social interaction deficits, can change through the life course. Longitudinal autism trajectories are known to vary, but the sources of heterogeneity are poorly understood, and studies on longer trajectories spanning diagnosis to adulthood are lacking.

#### What This Study Adds

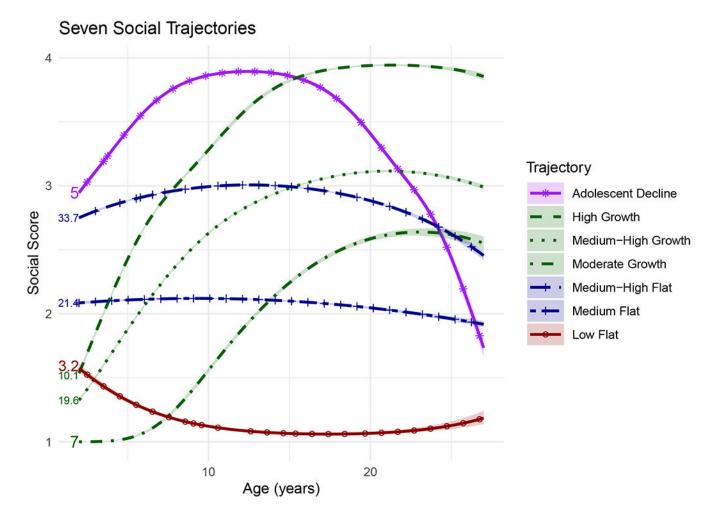
We describe variation in communication and social trajectories from diagnosis through age 27 in a large, diverse autism population. We observe a group whose social skills decline at puberty and identify individual and community characteristics associated with trajectory patterns.



#### Figure 1.

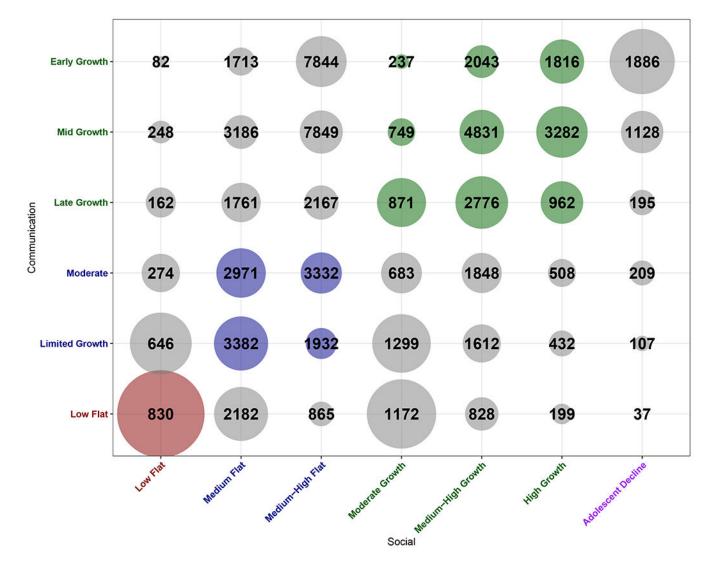
Communication Trajectories: Means and 95% Confidence Intervals for Predicted Scores by Age and Trajectory Group Assignment

Fountain et al.





Social Trajectories: Means and 95% Confidence Intervals for Predicted Scores by Age and Trajectory Group Assignment



#### Figure 3.

Crosstabulation of Social and Communication Trajectory Assignments (N, with circles scaled by ratio of observed joint frequency to the expected number under assumed independence)

#### Table 1.

# Descriptive Statistics for Sample

Variable	N Non-Missing	% (n); Mean (SD)
Sex	71,284	
Male		82.2 (58,604)
Female		17.8 (12,680)
Ever Diagnosed with Intellectual Disability	71,285	22.6 (16,096)
Age of Diagnosis with Autism	71,285	
2 or younger		13.6 (9,677)
3		37.3 (26,554)
4		13.9 (9,917)
5		8.6 (6,165)
6 or older		26.6 (18,972)
Maternal Race/Ethnicity	70,463	
Hispanic White		43.6 (30,712)
Non-Hispanic White		32.1 (22,609)
Black		7.5 (5,276)
Asian		14.8 (10,408)
Other		2.1 (1,458)
Mother born outside US	71,219	43.1 (30,674)
Delivery Paid by Medi-Cal	71,141	39.4 (28,033)
Maternal Education	69,754	
< HS		19.7 (13,740)
HS/Some College		53.2 (37,120)
>= College		27.1 (18,894)
Gini for ZCTA	69,835	0.4 (0.0)
Median Home Value (in 2000 \$s)	70,174	288,317.7 (150,472.9
Population Density per Square Mile	69,895	6,892.3 (6,783.9)

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# Table 2.

Summary Statistics by Communication Trajectory Assignment (% for categorical variables and mean (sd) for continuous variables)

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			Increasing		<u>Flat</u>	It	Floor
Variable	Overall	Early Growth	Mid Growth	Late Growth	Moderate	Limited Growth	Low Flat
N	71,222	15,638	21,298	8,897	9,841	9,431	6,117
Sex							
Male	82.2	82.8	82.6	83.5	81.9	81.4	79.3
Female	17.8	17.2	17.4	16.5	18.1	18.6	20.7
Ever Diagnosed with Intellectual Disability	22.6	8.7	16.3	27.9	24.6	37.7	45.4
Age of Diagnosis with Autism							
2 or younger	13.6	13.0	11.0	13.7	13.1	15.5	21.8
0	37.3	34.1	34.4	37.5	35.9	44.7	45.9
4	13.9	13.9	13.3	14.2	16.7	14.0	11.2
ŷ	8.6	10.0	7.9	8.8	1.11	7.2	5.8
6 or older	26.6	29.1	33.5	25.8	23.3	18.7	15.3
Maternal Race/Ethnicity							
Hispanic White	43.6	37.1	43.0	48.5	47.1	46.9	44.2
Non-Hispanic White	32.1	42.2	35.1	25.6	26.2	24.6	26.1
Black	7.5	5.8	7.0	8.4	8.2	8.8	8.9
Asian	14.8	13.0	12.9	15.4	16.2	17.4	18.5
Other	2.1	1.8	2.0	2.0	2.2	2.3	2.2
Mother born outside US	43.1	34.9	40.8	47.8	48.7	48.9	46.9
Delivery Paid by Medi-Cal	39.4	30.8	37.9	45.7	41.0	46.1	44.3
Maternal Education							
< HS	19.7	13.0	18.8	24.1	21.6	24.3	23.4
HS/Some College	53.2	50.1	54.4	54.1	52.7	53.7	55.8
>= College	27.1	36.9	26.8	21.8	25.7	22.0	20.9
Gini for ZCTA	0.4~(0.0)	0.4 (0.0)	0.4 (0.0)	0.4~(0.0)	0.4 (0.0)	0.4~(0.0)	0.4 (0.0)
Median Home Value for ZCTA (2000 \$)	288,265.6 (150,407.0)	314,553.0 (160,209.9)	290,033.2 (151,747.6)	267,356.4 (138,275.6)	288,036.0 (146,354.8)	271,773.1 (141,927.0)	271,302.0 (145,641.2)
Population Density per Square Mile	6.892.2 (6.783.8)	6,154.6 (6.102.1)	6,783.4 (6.571.0)	7,467.3 (7.269.8)	7,478.4 (7.295.4)	7,236.3 (7.118.5)	6.843.6 (6.856.9)

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Note: All variables have a significant (<.001) association with trajectory group assignment based on  $\chi^2$  test of independence (for categorical variables) or Kruskal-Wallis rank sum test (for continuous variables). Author Manuscript

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# Table 3.

Summary Statistics by Social Trajectory Assignment (% for categorical variables and mean (sd) for continuous variables

		<u>Decline</u>		Increasing		Flat		Floor
Variable	Overall	Adolescent Decline	High Growth	Medium-High Growth	Moderate Growth	Medium-High Flat	Medium Flat	Low Flat
Ν	71,184	3,563	7,202	13,945	5,014	23,999	15,214	2,247
Sex								
Male	82.2	79.9	81.3	83.4	82.6	82.0	82.5	81.4
Female	17.8	20.1	18.7	16.6	17.4	18.0	17.5	18.6
Ever Diagnosed with Intellectual Disability	22.6	15.9	16.6	24.6	30.9	18.2	26.6	40.5
Age of Diagnosis with Autism								
2 or younger	13.6	14.0	15.7	10.4	14.6	13.8	14.7	14.1
3	37.3	41.6	44.5	34.8	37.9	35.5	37.9	35.5
4	13.9	13.7	13.6	15.8	14.2	13.6	13.0	12.6
5	8.6	8.7	6.4	10.7	8.8	9.0	7.5	6.9
6 or older	26.6	22.1	19.8	28.2	24.5	28.1	27.0	30.9
Maternal Race/Ethnicity								
Hispanic White	43.6	41.6	43.5	42.7	47.2	42.7	44.5	47.9
Non-Hispanic White	32.1	40.4	34.8	32.4	23.7	35.3	27.9	20.6
Black	7.5	7.7	7.6	7.5	7.4	7.5	7.5	6.1
Asian	14.8	8.5	11.8	15.5	19.3	12.5	17.8	23.2
Other	2.1	1.8	2.3	1.9	2.3	2.0	2.2	2.2
Mother born outside US	43.1	32.2	38.4	44.5	53.5	38.1	48.4	60.7
Delivery Paid by Medi-Cal	39.4	37.9	39.4	37.2	45.0	38.1	41.3	44.7
Maternal Education								
HS/Some College	53.2	58.3	55.1	52.0	51.8	53.8	52.4	49.8
< HS	19.7	15.5	17.7	20.0	25.3	17.6	21.4	28.8
>= College	27.1	26.1	27.1	28.0	23.0	28.6	26.2	21.4
Gini for ZCTA	0.4 (0.0)	0.4 (0.0)	0.4~(0.0)	0.4~(0.0)	0.4 (0.0)	0.4 (0.0)	0.4 (0.0)	0.4 (0.0)
Median Home Value for ZCTA (2000 \$)	288,246.4 (150,445.1)	270,235.7 (140,456.1)	284,420.0 (148,982.0)	281,414.6 (143,311.7)	280,159.4 (151,737.4)	297,076.2 (157,272.5)	290,944.0 (148,972.5)	277,793.9 (139,967.5)

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		Decline		Increasing		Flat	It	Floor
Variable	Overall	Adolescent Decline	High Growth	Medium-High Growth	Moderate Growth	Medium-High Flat	Medium Flat	Low Flat
Population Density per Square Mile	6,890.7 (6,781.4)	5,988.6 (6,233.3)	5,988.6 (6,233.3) 6,520.2 (6,541.0)	6,979.6 (6,744.3)	6,979.6 (6,744.3) 7,703.6 (7,561.0) 6,517.4 (6,450.1) 7,375.5 (7,113.3)	6,517.4 (6,450.1)	7,375.5 (7,113.3)	7,870.8 (7,375.5)

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Note: All variables have a significant (<.001) association with trajectory group assignment based on  $\chi^2$  test of independence (for categorical variables) or Kruskal-Wallis rank sum test (for continuous variables).

#### Table 4.

Logistic regression results assessing correlates of Adolescent Decline trajectory group assignment (N = 67,888)

	Estimate	(95% CI)
Female	1.21	(1.10 - 1.32)
Intellectual Disability Diagnosis	1.09	(0.99 - 1.22)
Age at Diagnosis (ref = age 3)		
2 or younger	0.89	(0.79 - 1.00)
4	0.78	(0.70 - 0.87)
5	0.72	(0.63 - 0.82)
6 or older	0.59	(0.53 - 0.65)
Race/Ethnicity (ref = Hispanic White)		
NH White	1.13	(1.03 - 1.25)
Black	1.07	(0.92 - 1.24)
Asian	0.73	(0.63 - 0.85)
Other	0.92	(0.69 - 1.21)
Mother born outside US	0.88	(0.81 - 0.97)
Maternal Education Level (ref = HS or S	ome Colleg	e)
<high school<="" td=""><td>0.90</td><td>(0.81 - 1.00)</td></high>	0.90	(0.81 - 1.00)
Bachelors or Higher	0.85	(0.77 - 0.93)
Medi-Cal Delivery	1.08	(0.98 - 1.18)
Communication Class (ref = Early Grown	th)	
Mid Growth	0.38	(0.36 - 0.42)
Late Growth	0.15	(0.12 - 0.17)
Moderate	0.15	(0.12 - 0.17)
Limited Growth	0.07	(0.06 - 0.09)
Low Flat	0.04	(0.03 - 0.05)
ZCTA level Variables		
High Inequality (Gini 5Q)	1.14	(1.04 - 1.27)
Median Home Value	0.89	(0.84 - 0.93)
Low Population Density (1Q)	1.16	(1.04 - 1.29)

Notes: Models are calculated with robust standard errors clustered by 5-digit ZCTA. Model is adjusted for Regional Center of first entry into DDS and year of entry into DDS.