

**DOCUMENT SUMMARY** This 2012 longitudinal study is powerful evidence against the concept of a fixed, stable diagnosis of autism in early childhood. By tracking toddlers from 18 to 36 months, the research identified four distinct developmental trajectories—"severe persistent," "worsening," "improving," and "nonspectrum"—proving that a child's diagnostic presentation can change dramatically over time. This paper directly challenges the validity of a single-point-in-time assessment and shows that minimal, "treatment as usual" early intervention has no measurable effect on these developmental paths.

**FILENAME**

Lord\_2012\_RESEARCH\_research\_article\_ASD\_Developmental\_Trajectories\_diagnostic\_instability.md

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**Core Update Frequency:** Static **Tags:** #diagnostic\_instability, #autism, #toddlers, #longitudinal\_study, #developmental\_trajectories, #assessment, #ADOS, #early\_intervention, #regression, #no\_normal\_brain **Related Docs:**

Lane\_2019\_RESEARCH\_research\_article\_Silver-

Russell\_Syndrome\_autism\_IQ.md,

Kuijper\_2017\_RESEARCH\_research\_article\_Narrative\_Production\_ASD\_ADHD.md

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## Patterns of Developmental Trajectories in Toddlers With Autism Spectrum Disorder

### Why This Matters to Enliten

This paper is a foundational piece of evidence for our entire model. It scientifically validates the concept of **diagnostic instability** in young children, which is a core reason why we reject the traditional, high-stakes, single-point assessment system. The central finding of four distinct developmental trajectories provides concrete proof that an autism diagnosis at age two is not a fixed, lifelong prophecy but a snapshot of a dynamic process. We can use this research to explain to parents and professionals that a child's path is not set in stone and that ongoing, collaborative monitoring is far more valuable than a one-time label.

Furthermore, the study's findings on the ineffectiveness of "treatment as usual" and the limitations of both clinical judgment and single-point standardized testing reinforce our mission. It shows that generic services don't work and that a more nuanced, longitudinal approach is required to truly understand a child. This paper gives us the scientific backing to advocate for a system that embraces developmental fluidity and prioritizes understanding an individual's unique journey over assigning a static category.

### Critical Findings: Evidence Against Diagnostic Stability

The study followed toddlers referred for possible autism from approximately 18 to 36 months, using frequent ADOS assessments to plot their development. The analysis revealed four distinct

developmental trajectory classes, demonstrating that there is no single path for young children with autistic traits.

- **Four Trajectory Classes:** The analysis identified four groups of children who changed in similar ways over time.
  - **Severe Persistent (21% of sample):** This group showed consistently high scores on the ADOS over time, with no significant evidence of change in either social-affective (SA) or restricted/repetitive behavior (RRB) symptoms.
  - **Worsening (21% of sample):** This group started with lower (less abnormal) scores than the severe persistent group but showed a clear pattern of worsening symptoms over time, with scores for both SA and RRB symptoms increasing.
  - **Improving (19% of sample):** This group showed steady improvements, with their social-affect (SA) scores decreasing significantly over time. They also showed more rapid gains in verbal and nonverbal skills compared to the severe persistent group.
  - **Nonspectrum (40% of sample):** This group consistently scored low on the ADOS and included all but one of the children who never received an ASD diagnosis at any point.

## The Failure of the Current Assessment Model

The study highlights the inadequacy of relying on a single assessment or a single type of measure.

- **Single Assessments Are Insufficient:** The existence of "worsening" and "improving" trajectories proves that a single assessment at one point in time can be misleading. A child's presentation can change significantly over the course of their early development.
- **Two Assessments are Better Than One:** For predicting a final diagnosis, using an ADOS score from a single assessment was significantly less accurate than using the sum from two assessments taken within 3 months of each other.
- **Clinician Judgment Can Miss Gradual Change:** Clinicians' own diagnostic certainty ratings were less sensitive to the trajectories of improvement or worsening compared to the standardized ADOS scores collected over time. Clinicians were most certain about the children who *did not change* (the severe persistent and nonspectrum groups) but had more trouble tracking the children who were actively changing in either direction.

## Rethinking "Regression" and "Early Intervention"

- **Gradual Worsening, Not Dramatic Regression:** The "worsening" group showed a gradual increase in symptoms over time, not a sudden loss of skills. These children were no more likely to be described by parents as having a "regression" than children in the other groups. This challenges the common narrative of dramatic regression and reframes it as a potential "slowing of development and gradual social withdrawal".
- **"Treatment as Usual" is Ineffective:** The study found **no evidence of an association between treatment and trajectory** within the groups of children ever diagnosed with ASD. The minimal, non-specific early intervention that was available to these children (e.g., non-categorical preschool, some speech therapy) had "relatively little measurable effect on core symptoms or cognitive measures". This is not evidence that intervention

cannot work, but that the generic "treatment as usual" provided was not effective in altering these developmental paths.

## Quotes We Might Use

- **On the different paths:** "The best trajectory typology, using Autism Diagnostic Observation Schedule (ADOS) scores, revealed 4 trajectory classes... severe persistent (21%), worsening (21%), improving (19%), and nonspectrum (40%)".
- **On the need for ongoing monitoring:** "The finding that one third of the children with an ever ASD diagnosis showed worsening between 12 and 36 months further supports the need for careful follow up that continues beyond 12- and 18-month screens".
- **On the improving group:** "The finding that nearly one third of the children who had at least one diagnosis of ASD showed steady improvements in social-affect and increases in the slope of acquisition of verbal skills between 12 and 36 months is extremely encouraging".
- **On the limits of clinical judgment:** "Clinicians diagnostic judgments were not as sensitive to trajectories of improvement or worsening as the standardized instruments".
- **On the ineffectiveness of generic treatment:** "There was no evidence of an association between treatment and trajectory within the ever ASD groups". This is "evidence that minimal, nonspecific early treatment as usual of toddlers with ASD had relatively little measurable effect on core symptoms or cognitive measures".