

# Barriers to optimal psychiatric care for adolescents with co-occurring developmental disability and severe mental illness in New York State



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CONFLICT OF INTEREST  
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## 1: INTRODUCTION

Severe mental illness among adolescents with existing intellectual or developmental disability is common[1] and persists into adulthood[2]. In New York State, this “dually diagnosed” population’s access to psychiatric care is managed by two separate agencies, which requires either the mental illness or the developmental disability to be considered the “primary” diagnosis for youth and their families to be connected to services. This structure complicates access to care and may also be problematic on ontological grounds, as advances in knowledge increasingly call into question the existence of a clear dividing line between mental illness and developmental disability.

## 2: HISTORICAL CONTEXT

Historically, the New York State Office of Mental Health (OMH) was responsible for the care of individuals with intellectual and developmental disabilities, in large part through the provision of state hospital placement. A strong movement towards deinstitutionalization in the 1970s led to a need for community services for the developmentally disabled. In 1978, the Office of Mental Retardation and Developmental Disabilities (now the Office for People with Developmental Disabilities, or OPWDD) was created in response to that need, as an agency separate from OMH[3].

## 3: TODAY

Two systems exist: one for developmental disability, and one for mental illness. The family of an adolescent who has both must navigate this schism:



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## AN INITIATIVE TO BRIDGE THE GAP

Adolescents with developmental disabilities often present to ERs and inpatient units for behavioral problems[4]. Repeated ER visits can be frustrating for patients and families.

NYSTART (Systemic, Therapeutic, Assessment, Resources and Treatment) is an OPWDD initiative that strengthens support for these youth by providing intensive mental health care in the form of in-home crisis intervention and short-term therapeutic support[5].

## OBSTACLES IN CROSSING THE GAP

A representative case: “Alex,” a 22-year-old male, had a longstanding history of problems with language/social communication and restrictive/repetitive behavior; he was not initially recognized as having autism. He entered the mental health system, with multiple psychiatric inpatient hospitalizations for aggression throughout his teenage years that didn’t acknowledge his underlying problem. When, at 22, he received an autism diagnosis, redirecting his treatment away from OMH services and into an OPWDD-run group home proved difficult: the process took many weeks and required a psychological report, adaptive skills testing, cognitive testing, a psychosocial summary, a physical exam, an authorization to release school records, a description of his autism symptoms, an attestation from his psychiatrist, and a letter of support from an OPWDD administrator[6].

## 4. TOMORROW

Clinicians and researchers have, in recent years, moved towards considering child and adolescent mental illness in a neurodevelopmental context[7]. Commensurate with this shift, mounting evidence has suggested that mental illnesses per se and neurodevelopmental disorders such as autism overlap significantly at a genetic level[8], and symptom patterns that cut across disorders have increasingly become a focus of attention[9,10]. Given these circumstances, New York State’s schism in care between OPWDD and OMH can be a source of confusion to families and providers.

## 5. CONCLUSIONS

New York State’s split-agency approach to services for developmental disability and for mental illness complicates access to care for youth with complex symptoms that cut across diagnoses in both categories, and may be increasingly problematic as the field continues to shift away from categorical diagnosis. Fortunately, initiatives such as NYSTART are helping to bridge the artificial gap between agencies.

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OPWDD  
Office for People with Developmental Disabilities

OMH  
Office of Mental Health

Existing intellectual/developmental disability  
and  
Emerging severe mental illness