



# Developing a Model for the Transition from Pediatric to Adult Care

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## Adult Specialty Clinics for Sex Chromosome Aneuploidy WITH Grant Progress Report

### Introduction

Adults with X and Y variations **experience difficulty in finding adult specialists familiar with the range of medical issues** that affect them into adulthood.

A range of endocrine disorders, neurological complications, and autoimmune disorders affect the health of these adults. Many have continuing problems with psychiatric complications, autism spectrum disorders, and learning disabilities.

Nearly 20% of the 500 annual requests to the AXYS Help Line request assistance finding medical professionals who can provide specialty consultation and treatment for adults with an X or Y variation.

Some adults with an X or Y variation may not be completely independent of their parents, and therefore **the approach must be family centered**.

**Pediatric programs have experience with providing multi-disciplinary care; adult clinics find more difficulty in coordinating care.** Multi-specialty evaluations can document medical and neuro-developmental barriers to successful employment, enabling workplace accommodations and supports. In addition, the evaluations allow this population to access public programs that promote their ability to live independently.

### Plans

Thanks to the generous support of the **WITH Foundation**, AXYS has partnered with the **eXtraordinary Kids Clinic at Children's Hospital Colorado** and the **eXtraordinaryY Clinic at Emory University** in Atlanta to pilot two efforts to better serve individuals with an X or Y variation transition from pediatric care to adult care.



- **AXYS executed cooperative research agreements with our partnering clinics.**
- **Leads from each clinic identified potential leads for an adult clinic at their institution or an affiliated institution serving adults.**
- **Pilot programs for adult clinics are being formed using the protocols developed by the multidisciplinary clinics for children**
- **Additional services protocols will be developed for services needed by adults such as vocational services and assistance with public support programs.**



### Challenges

Because adult medical services are often provided by different departments, in separate clinical buildings, initiating a program successfully requires a clinic coordinator who can devote dedicated time to evaluating the needs of each patient, coordinating appointments for them, particularly if the patient is traveling from a distance, and compiling visit and lab records into a report for the patient's primary care physician.

Providing clinic coordinator startup costs will allow these specialty clinics to begin operating at least one day per month, with the goal of five adult patients per month per clinic during the initial year of operation.

Ideally, AXYS will extend its project to two years, with a goal to expand the number of adults in interdisciplinary care to 150 patients annually.

### Conclusion

Creating pilot adult clinics can pave the way for interdisciplinary care for adults with X and Y variations.