

# **Kabuki Syndrome**

## **Transition to Adulthood**



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*Note: Cathy & Larry Skerker are parents of a young adult daughter, Liz, who has Kabuki Syndrome.*

As parents, we all hope that our children lead happy and productive lives; we try to give them good values and a sense of self-esteem. We provide direction as they make plans for their future. We do things with them and for them so that they will be able to live as independently as possible. How well our children are equipped to meet the challenges of adult life depends largely upon the education they receive, the services available to them, and the support of family, friends and community.

In addition to a solid educational foundation, parents and children need to plan for the day the children leave public education and enter the adult world. Planning for this time needs to begin when our children reach high school. Because parents know their children better than anyone, their part in transition planning is extremely important.

The years of transition from school to adulthood are difficult for everyone, but especially for young people with Kabuki Syndrome. Our young adults leave the structured environment of school and go out into the community to face its maze of public and private agencies. These agencies often have long waiting lists for services with different eligibility criteria. The most effective transition planning involves our children and us as leaders in mapping the educational experience and the years after graduation. Parents and young adults contributing as equal partners in the Individual Educational Plan (IEP) process is paramount to successful transition outcomes.

Parents and students will probably want to begin making serious plans when the student is beginning high school or around age 14. At this time, your child's IEP planning meeting should include transition planning.

Prior to the IEP meeting, careful thought should be given to who is needed to determine transition services and develop a plan to address your child's needs:

- Student
- Family member
- Special Education teacher
- Vocational Education instructor
- General Education teacher
- Special Education administrator
- Community service representative (s) (e.g., community college, rehabilitation, mental health).
- Other school staff (e.g., transition specialist, guidance counselor, psychologist, social worker, therapists).
- Medicaid Service Coordinator (MSC)

These individuals will collaborate with you and your child to develop a well-thought-out plan. The IEP team will designate leadership, responsibility, targets and timelines for proposed transition activities.

A cooperative effort will be required by a variety of agencies and individuals if the IEP is to become a successful vehicle for preparing your son/daughter with Kabuki Syndrome for employment and independent living. The primary responsibility of the IEP team should be to develop, implement, and evaluate the IEP as well as to see that necessary resources and support services are provided so that transition activities will be successful.

Team members involved in developing and implementing the IEP could include the following:

1. *The Student.* The student assumes responsibility for identifying a career path, suggesting activities and services for his or her own transition plan, and providing feedback about the quality of experiences and services provided. The student states preferences and desires as well as committing to the plan.
2. *Parents and Family.* Family members participate in all phases of the IEP development, implementation and evaluation. They provide valuable feedback to other team members. They provide insight into the background and needs of the student. They also actively participate in and reinforce IEP activities as well as serving in an advocacy role.
3. *Special Education Personnel.* These educators assist in collecting information necessary to establish IEP goals and objectives for the student, coordinate services and resources, provide direct instruction, and reinforcement to the student, and help match student needs and interests with an appropriate career path. It is critical that they coordinate the activities in the IEP from one level to the next (e.g., facilitate the student's movement from middle school to high school) to provide a smooth, comprehensive transition within the school-based program and beyond.
4. *Administrators.* Administrators promote a positive attitude toward transition programming as it is developed through the IEP and provide the resources needed to implement IEP activities and services.
5. *Vocational Instructors.* Vocational personnel help provide the student with career development experiences and specific vocational instruction. They identify instructional and placement sites in the local community and recommend necessary supports.
6. *Academic Teachers.* Academic teachers teach and/or reinforce the generalized academic skills (e.g., math, communication, reading, critical thinking) identified as necessary to the career path chosen by the student.
7. *School Counselors.* Guidance personnel provide career and personal development information, conduct and interpret career assessment activities and help coordinate support services documented in the IEP. They monitor diploma and graduation requirements.
8. *School Support Personnel.* Support personnel represent a variety of diverse backgrounds and expertise that can be used to implement the activities documented in the IEP (e.g., remedial academic instructors, resource personnel,

psychologists, speech, occupational or physical therapists, personal aides, job coaches).

9. *Service Agencies and Adult Service Providers.* Your MSC (Medicaid Service Coordinator), representatives of agencies and adult service providers present specific information to the team regarding the type and kind of services available through the agency; requirements to qualify for services; availability of services at the local level; procedures for applications; and contact person, location, and telephone numbers. Examples of agencies and adult service providers include the following:
  - Vocational and Educational Services for Individuals with Disabilities (VESID)
  - Office of Mental Health (OMH)
  - Commission for the Blind and Visually Handicapped (CBVH)
  - State Employment Services
  - Office of Mental Retardation and Developmental Disabilities (OMRDD)
  - Dept. of Social Services (DSS)
  - Local rehabilitation agencies and community services
  - Local adult service providers
10. *Post Secondary Education Personnel.* Postsecondary education representatives provide information about available instructional programs, admission requirements and procedures, supports services provided to students with disabilities, and articulate strategies that have been coordinated with secondary programs.
11. *Employers and Members of the Business Community.* These individuals provide valuable information concerning the labor needs of business and industry, changes in technology, the impact of instructional programs and curricula, and current and future job prospects. They can also provide instructional sites and participate in transition activities (e.g., job shadowing, guest speakers, job fairs).
12. *Work Experience Coordinators.* These individuals are school-based educators whose primary responsibilities include developing job sites, setting up supports, placing students at work sites, supervising student progress, and acting as liaisons between school programs and employers.
13. *Transition Specialists.* These individuals provide the liaison between school, the home, and various adult service agencies assisting the student in the transition process. Their roles and responsibilities are as diverse as the student they serve.

While all of these transition team members may not be involved at the same time, teachers, other professionals and families should look to every source available for assistance. It is important to remember that transition planning is not an exact science but an art. Every transition plan will be designed to meet each individual student's needs.

The essential ingredients in a successful transition to adult life are:

- Sound preparation in secondary school, including work and learning experiences in the local community.
- Adequate support for students before and after school, including both generic services (YM CA, available to all), and special services (VESID, available to those who meet eligibility requirements).
- Secure adult opportunities and services that include follow-up and advocacy.
- Cooperation between students, their parents, teachers and adult service providers.

So, how do we begin to plan for the transition to adult life outside of school?

The resources and values of your family as well as you adolescent's strengths, weaknesses and preferences will be important factors when making decisions about transition issues. Your feeling and answers to these questions should also be explored:

- What do you *not* want to have happen?
- What concerns you most about your child's future?
- What barriers do you face in making your dreams possible?
- What would improve your child's life?
- What steps can you take to make changes in your life?
- What can others do to support you in meeting your needs?

These are some of the issues you will want to consider when planning your child's future.

<b>Income:</b>	How will he/she support himself/herself?
<b>Employment:</b>	What will he/she do for work?
<b>Adult Services:</b>	Is he/she linked to an adult service agency? What day programs, recreational programs, housing opportunities and respite services can he/she access through this agency?
<b>Living Arrangements:</b>	How and where can he/she live as independently as possible?
<b>Recreation/Leisure:</b>	What will he/she do for fun?
<b>Transportation:</b>	How will he/she travel to and from work, day programs, social opportunities, and medical appointments?
<b>Medical Needs:</b>	What do we need to do to be sure he/she can get medical and dental health care when necessary? Has he/she found a primary physician to whom he/she will transition after the pediatrician? Will his/her medical specialists (ENT, Ortho, Cardio, etc.) continue to follow him/her as an adult?

- Advocacy:** Will he/she be able to self-advocate and make choices?
- Case Management:** Do we have a Medicaid Service Coordinator (MSC) working with us?
- Long Term Planning:** Have we met our child's future needs through wills, trusts and guardianship?

### **Service Coordinators**

Like typical teenagers, young adults with Kabuki Syndrome vary greatly in their abilities and interests. In helping you plan your future transition needs, it is most helpful to link with a Medicaid service coordinator (MSC). These individuals often have a social work background and work for an agency. It is important to use an agency whose beliefs about people with disabilities are similar to yours. You can find out by talking to people in the agency's Intake Department, or by talking to friends or other people who have used their services. When talking to an agency, it is also important to use one that has a reputation for pleasing the people they work for and working hard to get services for them.

A Medicaid service coordinator (MSC) is paid to work for you to help you decide:

- What you want or need
- Where to find the help
- If the service you receive is what you want/need

During this transition time, you should use an MSC to help find services and to plan for the future. In many cases, you have been doing some of what a service coordinator does. You most likely will want to continue assisting your son/daughter, but getting services can be difficult. There are many rules to follow and much paperwork to complete. A good MSC will make sure you are getting all the benefits to which you are entitled, will know what services are available in your community and will assist you with the paperwork necessary to gain these services

As our Kabuki children become young adults we need to think about and explore each facet of their lives to adequately plan for their future. Your child's strengths and weaknesses in following areas should be considered when planning the best future possible. Your MSC can help you assess your needs related to the skills listed below and assist you in looking at how you can best support your son's or daughter's needs.

### **Independent Living Skills**

- Banking skills
- Money management
- Consumer skills
- Time management
- Mobility skills
- Apartment seeking skills

- Household management
- Meal planning & preparation
- Telephone skills
- Self-Advocacy skills
- Social skills
- Living situation options
  - Independently in an apartment
  - Apartment with support
  - Live in his/her own home
  - At home with family (one Kabuki family provided a mobile home on their premises for their young adult! Remember...think outside the box!).
  - Community residence (group home)
  - Foster home

### **Community Participation**

- Accessing recreational activities available in the community
- Leisure time activities
- Special interest areas
- Religious group activities
- Volunteer opportunities
- Level of community access
  - Independently
  - With agency support
  - With Family support

### **Employment**

- VESID assistance
- Vocational assessment
- Job seeking skills
- Job coach assistance
- Work behavior training
- Interview skills training
- Resume writing
- “On the Job” training
- Application assistance
- Vocational training programs
- Self advocacy skills
- Employment options
  - Full time competitive
  - Part time competitive
  - Supported employment
  - Sheltered workshop setting
  - Day habilitation program
  - Military service
  - Adult/community ed

## **Financial**

- Financial support
- Earned income
- Unearned income
- Medicaid
- Health/Life insurance
- General public assistance
- Food stamps
- Supplemental Security Income (SSI)
- Social Security Disability (SSD)
- Medicare
- Guardianship/Supplemental Needs Trust/Will
- Money management
- Budgeting
- Banking skills

## **College Selection**

- Trade Schools
- Business School
- Apprenticeship
- Community College – 2 year
- 4 year college/university
- Contact and coordinate with disabled student services
  - Application assistance
  - Financial aid assistance
  - Educational accommodations

## **Personal Care & Hygiene**

- Clothing care
- Dressing
- Grooming
- Personal hygiene
- Safety issues
- First Aid training
- Sex education
- Meal Prep and nutrition
- Transportation and mobility skills
- Telephone Skills
- Shopping Skills
- Voter Registration
- Driver/Non-Driver ID

## **Medical**

- Medication
- Insurance (dental & medical)
- Need for ongoing medical care
- Disability/Medicaid/Medicare
- Managing medical care

## **Transportation**

- Use of public transportation
- Transportation to & from work/day hab
- Transportation to & from community activities
- Transportation to & from medical appointments/therapies
- Mobility issues

## **Post Secondary/Continuing Ed**

- Application assistance
- Transportation
- Financial aid
- Contact & coordinate with campus student services
- Study skills programs
- College/program selection
- Transfer of evaluation information
- Parent training
- Orientation programs
- College fairs
- On campus support
  - Reader
  - Note taker
  - Sign interpreter
  - Tutor
  - Personal care attendant
  - Others – check individual programs

## **Guardianship**

As our children reach the age of 18, it is important to have guardianship established if your child requires this level of support. At the same time, it is advisable that you have up to date wills and if possible establish a supplemental needs trust. It is highly recommended that you seek the services of a lawyer with a background in disability law to assist you with preparing these documents.

- Guardianship is designed to protect and promote the well being of those whose functional limitations prevent them from making their own decisions.
- Guardianship is a legal relationship between a competent adult and a person over the age of 18, whose disability causes incompetence (a ward). The disability may be caused by mental illness, developmental disability, age, accident or other

- causes. A developmental disability or mental illness is not, by itself sufficient reason to declare someone incompetence. Competency has to do with a person's ability to make an "informed decision," or, with the risk of harm that they may experience due to their inability to provide for themselves or manage their affairs.
- The guardian is given the right to make decisions on behalf of the person with a disability. When a guardian is appointed, the Court gives the guardian the authority to exercise certain legal rights in the best interest of the ward. The Court when giving rights to a guardian takes them away from the ward. Because guardianship involves such a serious deprivation of liberty and dignity, the law requires that guardianship be imposed only when other less restrictive alternatives have proven to be ineffective.
  - In making the selection of an individual to serve as guardian, first consideration is usually given to those who play a significant role in the person's life. The guardian should be someone who is both aware and sensitive to the disabled person's needs and preferences. It is very important to remember that guardianship is a relationship in which one person places trust and confidence in the capability, integrity and fidelity of another. It is within the power of the Court to name two co-guardians if two individuals wish to share the duties.

### **Supplemental Needs Trusts**

- A Supplemental Needs Trusts (SNT's) is a legal document that provides a supplemental source of income for people with disabilities. Because of certain legal limitations on these trusts, individuals can remain eligible for means-based government benefits that are based on need, such as Supplemental Security Income (SSI), Medicaid and Food Stamps. An SNT is not counted as a beneficiary's resource for SSI purposes. For purposes of SSI and Medicaid, the trust is not "actually available" to the beneficiary because he or she has no legal right to say how the money is spent, nor do they have direct access to the funds.
- The purpose of an SNT is to enhance the quality of the life of the person with the disability (who is referred to as the "beneficiary" because the trust is set up for his/her benefit). The trust can purchase additional support services, therapy and care that is not covered (or not covered adequately) by the Medicaid program, but that are important to your child's well being.
- SSI & Medicaid provide the basic level of support for food, clothing, shelter and medical care. The SNT fills in the gaps. Based on the beneficiary's particular needs, the trust can pay for the following to the extent they are not covered by Medicaid:
  - Additional medical treatment or insurance
  - Individualized therapy
  - Special medical equipment
  - Case management
  - Recreational activities
  - Other goods, services and activities

You know your young adult the best. Talk together. Find out his/her feelings about working, living independently and becoming an adult. Steps along the way to adulthood

might include going to summer camp, holding a summer job, belonging to community or school organizations, and having responsibilities in your home. Include all members of your family in planning for the transition from school to adult life. Don't forget your own network of family, friends and acquaintances. They may be able to help your son/daughter find a job, a place to live, new friends, and other support systems, which may be key in their success.

While many of the terms used and programs written about here are specific to the United States, they can be used as guidelines to navigating educational programs and government benefit programs in other countries. Because there are so many things to consider when planning the future, it is easy to become stressed and overwhelmed. Don't give up!! Planning the future will assure that you and your son/daughter will be able to make the decisions that will affect the quality of your child's life as an adult. This is a time when other parents and friends can be of help. This Kabuki group is a wonderful resource for other parents, family members and professionals. Remember to always think outside the box and never be afraid to try something new and creative!