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## *Introduction*

### **What is Transition?**

Transition happens every time a person undergoes a major life change – and if your son or daughter is an adolescent, an important life transition is approaching. This is the transition from adolescence to adulthood – from school into the world. The move to adulthood is an exciting time that will provide new opportunities for your son or daughter.

Transition also presents challenges. As the parent of a teenager with a developmental disability, you may be dealing with the usual challenges of adolescence as well as challenges related to your child's disability. The regional center is here to give you the help and support you need to effectively meet those challenges.

The transition to adulthood requires you and your child to make decisions about his future. We encourage you to start thinking about transition long before it is time for your child to leave school. Age 12 or 13 is not too early. To make good decisions, you and your family need to have enough information about all of your options. Gathering the information, thinking things through, and trying out options – all these take time.

### **What's in this guide?**

This guide is designed to help you plan for your adolescent's transition to adulthood. It contains answers to the questions most often asked by parents about this stage of their child's life. The guide also tells you where to get additional information of the type that adolescents and their families going through the transition process often request.

Of course, the guide is not your only resource for information about transition. As you and your child progress through this stage in his life, we expect that you will make liberal use of two other valuable resources of the regional center: your Service Coordinator (SC) and the Koch-Young Resource Center (KYRC).

### **How does the regional center help with the transition into adulthood?**

Your Service Coordinator's role will remain the same throughout your child's transition and for the rest of his life. The SC will continue to meet with you and your child to review and update his Individual Program Plan (IPP). He or she will help you locate and coordinate the support, information and service choices that you and your child need to feel secure in the decisions you make. (See Sections 4 and 5 of *Your Partners in Support: Guide to Lanterman Regional Center*, for a discussion of the IPP and your Service Coordinator's responsibilities.)

During the transition years, your Service Coordinator can help your child and your family focus on outcomes and objectives that will enable your child to reach his life goals. The Service Coordinator can also help by participating as a team member in the school's Individual Transition Plan (ITP) meetings. You may contact your SC directly to invite him or her to ITP meetings. Please give the Service Coordinator lots of notice prior to the meeting, so he or she can be available as well as prepared to give you support at the meeting and advocate with other agencies involved in the transition process.

### *How Does The School Help With The Transition Into Adulthood?*

#### **What is an Individualized Transition Plan (ITP)?**

Each year that he is in school, an Individualized Education Program (IEP) is developed for your child. As you probably know, the IEP is a legal contract between the school and your family containing educational goals and the services necessary for your child to meet those goals. It is required by a federal law called the Individuals with Disabilities Education Act, or IDEA.

IDEA also requires schools to provide transition planning for all students with disabilities to help prepare them for the movement to post-school activities. Transition goals, objectives, and activities should be included in your child's IEP, or in an attached document called an Individual Transition Plan (ITP). Transition planning generally begins when the child is 14 at a combined IEP/ITP meeting, and occurs annually after that, as long as the child remains in school.

Beginning when your child is 14, his IEP **should** include a statement of transition needs, focusing on the course of study that will best prepare him for transition. For example, your child's IEP/ITP team may consider goals related to vocational education, work experience or advanced-placement courses.

Beginning when your child is 16, his IEP **must** include a statement of needed transition services. (This may occur earlier if it is determined to be appropriate.) Needed transition services are coordinated activities based not only on the student's individual needs, but also on his preferences and interests. The services are designed to help the student achieve specific outcomes written into the IEP/ITP. The school will connect the student with a variety of agencies that can provide the services and supports necessary to help him make a successful transition from school.

### What types of services should we consider when planning for transition?

The focus of transition is on helping the student develop the skills or obtain the services and supports necessary for him to function adequately as an adult at home, in the community, and at work or in some other day activity. This requires the development of employment and other adult living objectives as a part of the IEP/ITP, and the provision of transition services to ensure the achievement of those objectives.

The school district is responsible for ensuring that all needed transition services are provided. If the school is unable to provide a needed service, the school must call another IEP/ITP meeting to develop an alternative strategy to achieve the related transition goal. If the school fails to do this, you have the right to file a complaint with the California State Department of Education. Your Service Coordinator can provide you with information about this complaint process.

IDEA defines "related services" as those needed by the student to make progress toward his IEP/ITP goals, including those in the transition component. Your child has probably been receiving related services as part of his IEP. (In California, these services are referred to as Designated Instruction and Services, or DIS.) If a child needs any of these services in order to make progress toward an IEP/ITP goal, the school district must provide them.

The related services that are most relevant to the transition process are:

- Orientation and mobility instruction
- Physical and occupational therapy
- Specialized driver training instruction
- Counseling and guidance

- Psychological services
- Parent counseling and training
- Specially designed vocational education and career development
- Recreation services

### **Who should attend an IEP/ITP meeting?**

The usual participants in an IEP/ITP meeting include:

- Your child
- You
- Your child's general education teacher
- Your child's special education teacher
- A school administrator

The school must also invite a representative of any agency that is likely to provide the student with transition services to the IEP/ITP meeting. This may include your child's regional center Service Coordinator as well as representatives from other agencies such as the Department of Rehabilitation or the Department of Mental Health. The school will notify your family of any agencies that have been invited. If a representative from an involved agency does not attend, the school is required to take other steps to ensure that agency's participation in the transition planning process.

You can help ensure success of the planning process by inviting these agencies yourself. As in any IEP meeting, you may invite people of your choosing. To create an IEP/ITP team that can best meet your child's needs, you may decide to invite people in addition to the typical transition agencies – for example, people who have special knowledge of your child or whose expertise may benefit your child. This may include the director of a local recreation program, a nurse or therapist who has worked with your child, or a religious leader who has a relationship with your family. As a courtesy, you should let the school district know whom you plan to invite.

### **When do IEP/ITP meetings occur?**

The IEP/ITP meeting should occur at least once a year, beginning when the child is 14, although you may ask for a meeting at any time by sending a written request to the school. Students are entitled to transition services coordinated by the school district until they receive a diploma or certificate of completion from the school or reach age 22 and are no longer eligible for special education services. (The latter case is sometimes referred to as "aging out.")

An exit IEP meeting must be arranged before the student can leave the school district. The plan document developed at this meeting is essentially a “discharge plan” that describes the services and supports required by the student after he leaves school and specifies who will provide those services.

Schools must give parents written notice before they graduate or give a certificate of completion to a person who is not yet 22. Parents have a right to challenge this decision. If you find yourself in this situation, speak to your Service Coordinator about your options and about getting assistance, if needed.

### **How can we advocate for the best transition planning for our child?**

The following guidelines may help you be a more effective advocate for your child:

- Participate actively in all IEP/ITP and regional center IPP meetings. Be prepared to discuss your child’s strengths, weaknesses, interests and goals as well as your expectations for his future.
- Help your child learn to speak up and to advocate for his own needs.
- Invite your Service Coordinator or an advocate to the IEP/ITP meetings if you feel as though you need some help or support.
- Learn about community resources that can help in transition.
- Ensure that invitations to the IEP/ITP meetings are provided to agencies that provide services you believe could benefit your child.
- Learn about assistive technology if you believe your child may benefit from its use.
- Keep detailed records.
- Become personally involved in teaching your child work skills, independent living skills, communication skills, social skills, recreation skills, self-advocacy and self-determination skills.
- Learn about your rights in the IEP/ITP process.

### **What are my family’s rights and responsibilities in the IEP/ITP process?**

- You have the *right* to information about your child and your child’s program.
- You have the *responsibility* for seeking and maintaining this information.
- You have the *right* to review your child’s records.
- You have the *responsibility* to ask questions when you don’t understand terms or reports.
- You have the *right* to be full partners in your child’s program.
- You have the *responsibility* for becoming and remaining active members of the team.

- You have the *right* to stand up for your child to make sure he or she gets the services needed.
- You have the *responsibility* to base your actions on accurate information.
- You have the *right* to make suggestions and recommendations about your child's program or services.
- You have the *responsibility* for doing so.
- You have the *right* to a vision for your child's future.
- You have the *responsibility* for helping your child achieve it.

### **What agencies and organizations provide transition services?**

In addition to regional centers, a number of agencies provide transition services. These include:

- California Department of Education
- Department of Rehabilitation
- Social Security
- Department of Mental Health
- Employment Development Department
- Private Industry Councils
- Regional Occupational Programs
- Community Colleges
- State Universities

We describe the roles of these agencies below. This list is not exhaustive and not all agencies may be available in your area or to your child.

Many of these agencies will continue to provide services to your child after he completes the transition process.

### **The role of the Regional Center**

Your regional center Service Coordinator can help you identify or obtain services that your child will need to facilitate transition. These services include:

- Independent living skills training
- Safety and mobility training
- Housing
- Day activities
- Transportation

- Supported employment
- Medical care
- Respite
- Advocacy services
- Other family support services

Your Service Coordinator should be invited to IEP/ITP meetings, but he or she may also assist transition planning through the IPP process. The Koch-Young Resource Center can also connect your family to information and support throughout the transition.

### **The role of the California Department of Education**

The California Department of Education oversees the public schools in California. Each school district (sometimes referred to as local education agency, or LEA) offers different types of transition services. Among these services are general education and skill training, health screenings, and a variety of vocational development programs such as Transition Partnership Programs (in collaboration with the Department of Rehabilitation) and Regional Occupational Centers/Programs (ROC/Ps).

To learn about the types of services that your child's school district offers, contact the district's Special Education Division and ask to speak with someone who can help you with transition services. In some schools, the Vocational Education Division may also be involved in transition. The phone numbers for the Divisions of Special Education and Vocational Education are located in the white pages of your phone book, listed alphabetically under the name of the school district.

### **The role of the Department of Rehabilitation**

The Department of Rehabilitation (DR) provides employment support to people with disabilities. To be eligible for these services, a person must have a physical or mental impairment that makes it difficult for the person to get or keep a job, and must be expected to benefit from DR services.

DR services are time-limited, ending when support is no longer needed and when the individual is transitioning to ongoing support through the regional center. Some school districts offer joint vocational training programs with DR during students' last one or two years of high school. They are called Transition Partnership Programs (TPP).

DR also offers transition services after high school through joint programs with adult schools, colleges, and universities (e.g., WorkAbility programs), but these programs serve only a small number of regional center clients.

For adults, DR offers Vocational Rehabilitation Services and supported employment. If your child is enrolled in a joint program while in school, DR will help him transition into adult services, if necessary. A representative of this department should be invited to your child's IEP/ITP meeting in the year or two before your child exits the school system. At the final IEP/ITP meeting, the DR representative can help your child transition into a post-school work program such as supported employment or a sheltered workshop.

You should keep in mind that DR may have a waiting list for adult services, so it is helpful to get the process going early. If your child is not enrolled in a joint program, you may contact the DR local office directly to apply for adult services. The local office is listed in the white pages of the telephone book, under State Government Offices (Rehabilitation, Department of). You may also go to the DR Web site, at <http://www.dor.ca.gov>

### **The role of Social Security**

Social Security provides financial assistance to people with disabilities through two programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). The Social Security office can also help to connect your son or daughter with public medical insurance programs like Medi-Cal and Medicare.

To qualify for SSI benefits, a person must be blind or disabled, have limited income and resources, and meet citizenship and residency requirements. The disability must make the person unable to work, and be expected to last at least 12 months or result in death. To qualify for SSDI benefits, a person must be disabled or blind, and have paid into Social Security through his employment. A person with a disability may also qualify for SSDI through a parent who has received this benefit.

In the month before your child turns 18, he should apply (or re-apply) for the appropriate Social Security benefits. To learn more about Social Security, call their toll free telephone number, 1-800-772-1213, or look in the white pages of the telephone book under United States Government Offices (Health and Human Services, Department of). You can also obtain information about Social Security benefit programs on the Web, at <http://www.ssa.gov/about.htm>

### **The role of the Department of Mental Health**

The Department of Mental Health provides services to people with mental and emotional disabilities. Services may include assessment and diagnosis, inpatient and outpatient care, 24-hour crisis counseling, youth and children services, medication, and mental health rehabilitation services.



Your local Mental Health agency is listed in the white pages of your telephone book under County Government Offices (Mental Health Services). You can also get information about mental health services in Los Angeles County at <http://www.dmh.co.la.ca.us>

### **The role of the Employment Development Department (EDD)**

This department works with job-ready persons, ages 16 and older (or between 12-16 for students with special work permits from their school). Services include:

- Counseling, testing, and job development
- Internet job search
- Job training
- Job referrals
- Labor market information
- Unemployment benefits

To contact your local Employment Development Department, look in the white pages of the telephone book under State Government Offices (Employment Development Department). You can also find information about this department at <http://www.edd.ca.gov>

### **The role of Private Industry Councils**

Private Industry Councils (recently renamed Workforce Investment Boards) are funded by federal dollars to serve people with characteristics associated with long-term welfare dependency. At least 25% of people served by this program must have disabilities. These Councils contract with private, local community agencies to provide services. The services may include vocational assessment, paid work experience, vocational training and education, on the job training, job placement, and post-employment services and support.

One-Stop Career Centers are examples of local agencies that contract with Private Industry Councils to provide job services. To contact a One-Stop Career Center, look in the blue pages of your yellow pages telephone book (Community Services Section) under Employment. You can also find a list of local centers on the Web at <http://www.sjtcc.ca.gov/SJTCCWEB/ONE-STOP/pic.htm>

## **The role of Regional Occupational Programs (ROCP)**

ROCPs are publicly-funded programs operated in cooperation with local school districts. They offer cost-effective job training for high school students and adults. These low-cost programs offer a combination of classroom and hands-on experience focused on development of specific job skills such as child care and veterinarian assistant. ROCPs do not offer student support, so people wishing to take advantage of these programs must have a level of skill that allows them to function independently. More information about these programs can be found on the Web, at <http://lacorop.org>

## **The role of the Community Colleges**

Students with a developmental disability who are interested in pursuing post-high school educational opportunities at community colleges may access a variety of services through the Disabled Students Programs and Services (DSPS) at the college. Students with disabilities are not required to participate in DSPS, and may choose to attend without using these services. Disabled Students Programs and Services may include:

- Job Placement through a joint program with the Department of Rehabilitation
- General Education
- Certified Vocational Education Programs
- Assistive Technology
- Accommodations for classes
- Learning Disability Programs

To contact your local community college, look under Schools – Academic Colleges and Universities in your yellow pages telephone book, or go to <http://www.cccco.edu> on the Web.

## **The role of the State Universities**

Some students with a developmental disability continue on to a state university, either California State University (CSU) or the University of California (UC). A student with a developmental disability may decide to seek assistance through the Office of Disabled Students (ODS) at their institution. ODS may be able to connect students with services such as accommodations for classes and job placement.

To contact a state university in your area, look under Schools – Academic Colleges and Universities in the yellow pages of your telephone book.

## *What Options Does The Future Hold?*

As your child approaches adulthood, you are probably asking yourself many questions about his future.

- What will happen after high school?
- Will he get a job? If not, what will he do during the day?
- Where will he live?
- Will he have friends, get married, or have a family?
- Who will look out for him when we, his parents, are no longer able?

People with developmental disabilities, now more than ever, can look forward to rich and meaningful lives that, increasingly, are similar to the lives of their non-disabled peers. This progress is due in large part to societal changes occurring over the past several decades.

- **Promotion of Equal Access:** Laws such as the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) have promoted the right of people with developmental disabilities to equal access in education, employment, use of public facilities, transportation and communication.
- **Community Integration:** People with developmental disabilities are increasingly participating in mainstream society in integrated environments, rather than living and working in segregated environments.
- **Supported Employment:** More and more individuals with developmental disabilities are working in real jobs in regular work settings, with assistance from a job coach who helps the worker be as independent as possible in the workplace.
- **Self-Determination:** Individuals with developmental disabilities are increasingly exercising their right to decide for themselves how they want to live their lives.
- **Self-Advocacy:** People with developmental disabilities are learning how to speak up for themselves and protect their rights.

As people with developmental disabilities gain more control over their lives, the challenge for families is how to support them in ways that balance their desire for independence and self-determination with their families' need to ensure their health and welfare. Parents ask themselves: How can we teach our son or daughter to dream, yet provide him or her with realistic building blocks for the future? How can we overcome our own fears of letting go?

By starting to plan early, both the adolescent and the family will be better prepared for the future. The following pages provide an overview of the options available to people with developmental disabilities and what steps may be needed to achieve them.

## Work, Education, and Training Opportunities

- What options are available for work, education, or training?
- How can we prepare our son or daughter for employment?

### What options are available for work, education, or training?

Post-high school options for people with developmental disabilities include:

**Competitive Employment:** Consumers have regular jobs in the community, which they maintain on their own without any type of assistance or support. An outside agency, such as the Department of Rehabilitation, may help the consumer prepare for and find competitive jobs, but that agency only provides temporary support.

**Supported Employment:** Consumers work in regular jobs in the community with ongoing assistance from a job coach. Job settings include individual placements, work crews, and enclaves (a group of employees being supported in a single work site).

**Sheltered Workshops:** Sheltered Workshops and Work Activity Centers provide vocational training in a protected environment. The emphasis in these programs is on helping clients gain skills necessary for competitive or supported employment. These services are funded by the Department of Rehabilitation.

**Regional Center Funded Day Programs:** For consumers who do not qualify for competitive or supported employment or a sheltered workshop, the regional center coordinates programs offering consumers daytime activities that are purposeful or meaningful. Day programs include Activity Centers, Adult Development Centers, and Behavior Management Day Programs that offer different types of services, activities, and levels of supervision, depending on consumers' needs.

**College and University, Trade Training and Adult Education Options:** More and more consumers are enrolling in community colleges and other post-high school education and training programs. A few attend four-year colleges and universities.

### How can we prepare our son or daughter for employment?

Most adults with developmental disabilities want to engage in meaningful work, and to have the responsibilities and gain the independence that come from having a real job. With support, even adults with significant disabilities have succeeded in obtaining and holding jobs in the community. They hold jobs in settings such as food service, building maintenance, gardening and landscaping, retail, car detailing, hospitality, and health care.

In helping your adolescent choose the type of work he would like to do after high school, it is important to keep in mind that the job should match the young adult's interests as well as his abilities. We know that different types of people are attracted to different types of jobs. In this regard, your son or daughter is just like everyone else.

The acquisition of skills necessary to become a successful worker takes place over many years. Parents should start as early as elementary school to foster skills that will increase their child's future options. Parents can:

- Encourage your child to take on tasks at home (household chores, meal preparation, or taking care of a pet). This will help to build a sense of competence and responsibility.
- Involve him in community activities such as scouting, sports, or arts clubs. This will help him develop his own interests and build social skills.
- Let him make choices. For example, let him choose his own clothes, select items in the grocery store, or decide on a weekend activity for the family.
- Teach him how to communicate his wants and needs.

Perhaps most important of all, talk to your child's teacher and SC about your expectation that he will go to work after high school. Ensure that employment objectives are included in his IEP/ITP. In the earlier transition years, IEP objectives should promote basic skills such as grooming, physical fitness, mobility, communication, and social skills. These skills are the building blocks for future employment success.

Some specific steps that you and your child should take during the transition years include:

- Participate in vocational assessments to learn about your child's interests, skills, and potential.
- Learn about your child's personal learning style and any accommodations he will need to become a successful student or employee.
- Investigate assistive technology options.
- Develop mobility and safety skills.
- Participate in vocational education programs through the school.
- Obtain a Social Security card.
- Become involved in different types of work experiences in different settings. This may be done through temporary positions arranged by the school, through summer employment, or through volunteer positions.
- Contact providers of adult services (Department of Rehabilitation, Employment Development Department, etc.) to access job support.

For many young people, the job development process continues after high school. They need additional support after high school to develop job skills, to find a job, or to keep the job. Some adults will also want to change jobs at some time in their lives. Your Service Coordinator can help your son or daughter coordinate services from adult agencies after he or she has left high school.

## Living Arrangements

- Where will our child live as an adult?
- How can we prepare for this change in living arrangement?

### Where will our child live as an adult?

Many young adults, with or without disabilities, live with their families (mom, dad, siblings) in the years just after high school. Indeed, many continue living with families well into middle age. There is great acceptance today of diversity in how people live. At the same time, many young adults choose to live independently from their families. For them, the options generally include:

- **An independent living arrangement**, with some training and support, fading to little or no paid support after a specified period of time.
- **A supported living arrangement**, alone or with one or two other people, with as much ongoing support as needed to live successfully in a house, condo, or apartment in the community.
- **A licensed community-care facility**, or staffed group home, often serving six residents with roughly comparable support needs.
- **A licensed health-care facility**, typically serving 4 to 15 people who need extra nursing support because of self-care deficits, behavior challenges, or medical needs
- **A certified family home** for one or two adults living with individuals or families who provide support.

### How can we prepare for this change in living arrangement?

Families need to talk with their sons and daughters about where and how they might like to live. Since your child (and you) may not be aware of all of the options, you should seek out information about the alternatives. The Koch-Young Resource Center has books and videotapes to help you and your child learn about different living options, and skill-building materials to help foster increased independence for your child. You may also ask your Service Coordinator to arrange observations of different types of living arrangements so you can see for yourself what the options are like.

You will no doubt want your child to be as independent as possible in his living arrangement, no matter where it is. Helping him build independent living skills, such as cooking, cleaning, shopping, and money management, is a good way to help ensure this.

It is important to involve your Service Coordinator early in the planning for a change in living arrangement. The SC can help you identify appropriate options and help prepare for a move. Many residential support programs have waiting lists, so you need to start planning at least a year before your son or daughter expects to move.

You may also need to prepare yourself emotionally for your child's move out of the family home. When a child leaves home, families may worry about his safety or welfare, and whether he will be happy in his new setting. Parents who have devoted time and attention to child-rearing may be at loose ends regarding what they want to do once they no longer have this person to care for. If this is the case for you, you may find it helpful to talk to other regional center families who have gone through this transition. Call the Koch-Young Resource Center and ask them about peer support or an appropriate support group. You should also ask your SC for a copy of the Guide to the Regional Center insert dealing with Community Living Options.

## Health Care

- Why focus on health in transition planning?
- What are some skills that our child should learn to promote a healthy lifestyle?
- What about our child's special health care needs?
- How can I help our child learn to speak up with health care providers?
- What types of preventive health care services should our son/daughter receive?
- Does our daughter need to have gynecological exams?
- How can we help our child find an adult primary care physician?
- Will our child's medical insurance change?

### Why focus on health in transition planning?

Managing one's own health care is one of the most important responsibilities of adulthood. You can help your adolescent prepare to take on this responsibility by giving him opportunities to learn the skills he will need to maintain a healthy lifestyle. These include skills needed to access preventive health services that will help him stay healthy, as well as skills to manage any special health care needs that he may have. He will not only need to know what to do, he will also need to be able to communicate with his health care providers and advocate for necessary services.

Families can work with the IEP/ITP team to develop appropriate health maintenance goals for their son or daughter. Health care professionals, such as a school or regional center nurse, can be invited to IEP/ITP meetings to provide advice on health-related transition issues.

### **What are some skills that our child should learn to promote a healthy lifestyle?**

Just like all young adults, people with developmental disabilities need to develop habits that promote healthy living. These include:

- Exercise at least three times a week for 30 minutes
- Get eight hours sleep a night
- Brush teeth and floss regularly
- Learn how to choose healthy foods and have a balanced diet
- Understand the physical and emotional changes that occur during puberty
- Understand how to prevent pregnancy and avoid sexually transmitted diseases
- Learn techniques to relieve stress

Attainment of these skills might be incorporated into an independent living skills component of your child's transition plan.

### **What about our child's special health care needs?**

Many individuals with developmental disabilities have chronic medical conditions, such as seizures, high blood pressure, diabetes, or digestive disorders. Parents should ensure that their adolescents who have such problems get the information they need to manage their conditions. It is particularly important that the adolescent:

- Understands his medical condition
- Understands what regular treatments or preventive procedures he needs to receive
- Understands his medications, when and how to take them, and their side effects
- Learns how to talk to his health care providers (especially, when and how to ask questions)
- Knows where and how to access specialist health care providers
- Knows what to do in case of a medical emergency

### **How can we help our child learn to speak up with health care providers?**

To help ensure that they receive the best medical care, all people need to learn how to talk to their physicians and other health care providers. They need to know how to ask questions so they understand their conditions and the treatments and medications they receive.



They also need to assertively express their concerns and needs. Parents should encourage their adolescent to talk directly to the doctor or other health care provider, and encourage the provider to speak directly to the adolescent. Parents should also involve their adolescent in decision-making related to his own health care.

### **What types of preventive health care services should our son/daughter receive?**

All people should receive basic preventive health services on a regular basis. Parents should begin educating their adolescents about the importance of preventive care and how to access it. Basic preventive services include:

- Annual physical examination
- For women, an annual gynecological examination
- Recommended immunizations
- Semi-annual dental examinations and teeth cleaning
- Periodic vision and hearing evaluations.

You can find information about what should be included in periodic health exams on the Web site of the American Academy of Family Practice, [aafp.org/exam.xml](http://aafp.org/exam.xml)

### **Does our daughter need to have gynecological exams?**

All young women, whether or not they are sexually active, should have a gynecological exam at least once a year starting at age 18 (earlier if sexually active prior to that age). It is essential for you to help your daughter understand the importance of such an exam and what the experience will be like. You should also try to help her find a physician with whom she can feel comfortable.

Some sex education classes teach young women with developmental disabilities about what to expect during a breast or pelvic exam. Attending a class such as this may help your daughter feel more comfortable about having such an examination. The regional center currently has a peer support program wherein trained peers help other female consumers learn about the importance of reproductive health and understand what to expect during a gynecological exam. You can talk to your Service Coordinator or the staff of the Koch-Young Resource Center to find out about classes that might benefit your daughter.

You might also want to ask the SC or KYRC staff for the names of gynecologists in your area who have experience with women with developmental disabilities. Information on medical providers can be found in the Community Resource Directory on the Lanterman Web site ([www.lanterman.org](http://www.lanterman.org)). You might set up an appointment before the exam to allow your daughter to get to know the physician.

## **How can we help our child find an adult primary care physician?**

Families need to prepare for their child's transition from a pediatrician to an adult primary care physician. Having a "medical home" (one person or medical group coordinating all of his health care needs, including referral to specialist providers) is particularly critical for individuals with serious health concerns, or who may need support in managing their own health care.

Finding a physician with whom your child feels comfortable requires research. You may start by asking the Koch-Young Resource Center or your Service Coordinator about local physicians who specialize in treating people with developmental disabilities.

## **Will our child's medical insurance change?**

As your child approaches the age of 18, you should plan for changes in his medical insurance coverage and, possibly, in primary health care providers. In many cases, a child's coverage under his parents' health plan ceases when he reaches age 18 or, for a young adult in school or college, age 23.

The good news is that when your child reaches 18 he will probably be eligible for health coverage through the Medi-Cal program. If he has special health care needs he may also receive help from California Children Services (CCS). CCS helps families pay for certain medical care expenses for sons and daughters under 21 years of age.

Some children may begin receiving Medi-Cal benefits prior to age 18. If this is true of your child, you need to reapply for this coverage when he reaches age 18. To continue receiving Medi-Cal benefits, or for a first time application, the young person needs to apply to the Social Security office in the month he turns 18.

Some children may receive Medicare benefits through a parent's eligibility (if a parent is retired, disabled, or deceased and has paid into Social Security). These children may continue to qualify for Medicare services after age 18.

Of course, if your child does become employed, he may also receive health coverage as an employment benefit. Many part-time or entry-level positions, however, do not offer health insurance, so you need to be doubly sure that your son or daughter will not lose his or her existing coverage because of employment.

## **Developing Adult Relationships**

- Will our son or daughter with a developmental disability have adult relationships?
- How can we help our child to have healthy relationships?

- What kinds of programs can help us to teach our child about sexuality?
- Can our adolescent with a developmental disability become a parent?

### **Will our son or daughter with a developmental disability have adult relationships?**

Many people wrongly assume that people with developmental disabilities are asexual, and thus not interested in intimate relationships. Love, affection, and sexual feelings are a normal and natural part of life for all humans, including people with developmental disabilities. You may expect your son or daughter to go on dates, have relationships, and possibly get married.

### **How can we help our child have healthy relationships?**

Almost all parents feel protective of their adolescents when they begin dating. When the adolescent has a developmental disability, parents may have additional fears that their young adult does not fully understand relationships; that others may take advantage of him or her, emotionally or physically; that the adolescent will not uphold family morals and values, and that the result will be pregnancy or a sexually transmitted disease. These concerns are shared by most parents.

Since adolescents with developmental disabilities often do seek relationships, their families need to help prepare them to deal in a healthy way with the situations they will encounter. Parents need to express their values and morals concerning relationships and sexuality. They also need to teach adolescents about their body and how it functions. They need to help adolescents understand why their body is changing, and how to care for themselves through grooming, nutrition, and health maintenance. They need to help their sons and daughters develop positive feelings about themselves and learn how to relate to others.

### **What kinds of programs can help us teach our child about sexuality?**

Teaching a young adult about sexuality is challenging for any parent. Fortunately, help is available. Sex education programs can help people with developmental disabilities learn how to cope with their emerging sexuality. These programs teach adolescents how to act responsibly in relationships, how to develop positive relationships, and how to make good, safe decisions.

Individuals with developmental disabilities usually need specific explanations about what are considered appropriate or inappropriate sexual behaviors. For example, sex education programs can teach people about private body parts and about specific situations when it is appropriate or inappropriate to touch private body parts. They can also teach the difference between private and public places, and help the young person understand what types of behaviors are appropriate for which environments.

Sex education programs may also provide information about preventing pregnancy and sexually transmitted diseases. They explain the concept of sterilization and explore the responsibilities of becoming parents. These programs can provide basic information about sexuality, but they cannot replace good communication with your son or daughter about your family's beliefs and values.

Participation in a sex education program may be an appropriate goal for your adolescent's IEP/ITP. Talk with your child's Service Coordinator or teacher about sex education programs available in your area.

### **Can our son or daughter with a developmental disability become a parent?**

Unless a parent has a legal conservatorship that applies to that aspect of their son's or daughter's life, the young adult with a developmental disability has the right to bear children.

Some adults with developmental disabilities are able to bear healthy children. Others may be unable to have children or may be at high risk for giving birth to a child who also has a developmental disability. Families need to explain to their adolescents the effect of their disability on their capacity to become parents. They should also discuss the challenges associated with parenthood and the resources that are required. As with anyone considering pregnancy, the young person with a developmental disability should have a genetic screening and counseling.

If a person with a developmental disability does have a child, the regional center can offer services and supports to help the person more effectively carry out his or her parental responsibilities.

### **Financial Resources**

- What sources of support are available to my son or daughter?
- What effect does employment have on eligibility for SSI and Medi-Cal?
- Could our son or daughter be eligible for other benefit programs?

### **What sources of support are available to my son or daughter?**

When your adolescent reaches adulthood, he will need a source of income and access to health coverage. While some adults with developmental disabilities will go on to employment, sometimes with health benefits, most will receive income support through Supplemental Security Income (SSI) and health coverage through Medi-Cal (California's Medicaid program). If a person with a developmental disability is 18 or older, his eligibility for SSI and Medi-Cal is determined based not on his family's income but on his own income and resources.

To qualify for SSI benefits, a young adult must be blind or disabled, have limited income and resources, and meet citizenship and residency requirements. If the person has a disability, the disability must make him unable to work and must be expected to last at least 12 months or result in death.

Most people who qualify for SSI also qualify for Medi-Cal. We encourage all families to pursue SSI and Medi-Cal for their sons and daughters with a developmental disability. If you have questions about the appropriateness of these programs for your son or daughter, talk to your Service Coordinator, contact the local Social Security office, or go to [www.socialsecurity.gov](http://www.socialsecurity.gov)

### **What effect does employment have on eligibility for SSI and Medi-Cal?**

If your son or daughter obtains a job, he or she may continue to receive monthly payments from SSI, as long as the total income does not exceed a specified limit. Currently, when an employee with a disability reaches an income level of \$800 a month, his SSI income is reduced \$1 for every \$2 of earned income over that amount.

Most people with a developmental disability may continue receiving Medi-Cal benefits when working, even if they exceed the income limit for SSI. Each state determines the amount of money a person can earn before losing Medi-Cal benefits. Your Service Coordinator can answer your questions about Medi-Cal. Another good resource, if you are having difficulty obtaining or keeping Medi-Cal eligibility for your son or daughter, is the Health Consumer Center of Los Angeles ([www.healthconsumer.org/LosAngeles.htm](http://www.healthconsumer.org/LosAngeles.htm)), a publicly-funded advocacy organization that helps low income people gain access to health care.

If your son or daughter becomes unemployed, he or she simply informs the Social Security office of his or her new employment status or income level, and requests full benefits again.

### **Could our son or daughter be eligible for other benefit programs?**

A person with a developmental disability may, under certain circumstances, be eligible for Social Security Disability Insurance (SSDI) or Medicare. SSDI benefits are available to people with disabilities who have paid into Social Security through their employment. Young adults with work experience may qualify for these benefits if they lose their job and are unable to work. Some people may also qualify for SSDI as an adult based on a parent's record of receiving this benefit. If a person receives Social Security disability benefits for more than two years, they may also qualify for Medicare benefits.

Talk to your child's Service Coordinator for more information about the types of benefits that may be available to your son or daughter.

## Legal Issues

- What is the age of majority for a person with a developmental disability?
- What is a conservatorship?
- How can we provide financially for our son or daughter after we are gone?

### **What is the age of majority for a person with a developmental disability?**

When adolescents reach age 18, the age of majority, they acquire the rights and privileges of adulthood. This is true for people with developmental disabilities as well. As adults, they have the responsibility and the authority to make decisions about all aspects of their lives. For example, they may enter into contracts (and assume the corresponding liabilities), they may vote in local and national elections, and, if they are male, they must register for selective service. If they are in school, they may sign their own IEP/ITP documents. In addition, the school has a responsibility to teach them about the rights and responsibilities of adulthood.

### **What is conservatorship?**

If parents wish to continue to have legal authority over their son or daughter after he or she reaches age 18, they can petition the court to grant a conservatorship. In California, the law provides for a *limited conservatorship* for persons with developmental disabilities. This type of conservatorship gives parents or some other responsible party (the conservator) the right to make decisions for the person with a developmental disability (the conservatee), but only in one or more of seven specific areas of the person's life, as agreed to by the court. A limited conservatorship gives the conservator one or more of the following authorities:

- To determine the conservatee's place of residence
- To have access to the conservatee's confidential records
- To control the conservatee's right to marry
- To control the conservatee's right to enter into a contract
- To give consent for the conservatee's medical treatment
- To control the conservatee's social and sexual contacts and relationships
- To make decisions concerning the conservatee's education

A petition for conservatorship may be filed either when the adolescent becomes 18 or shortly before his 18th birthday. If the petition is filed and approved before the 18th birthday, the conservatorship becomes effective on the person's 18th birthday. If you are considering this option, you may ask your Service Coordinator to put you in touch with the regional center's legal consultant. Information on conservatorship is also available at the Koch-Young Resource Center.

### **How can we provide financially for our son or daughter after we are gone?**

As their adolescent enters adulthood, many families start to think about what will happen when the parents are no longer living. How will the person support himself, and how can parents provide for additional financial support when they are no longer there to oversee matters?

If parents leave financial resources and property to their child with a developmental disability through a will, the inheritance may affect the child's eligibility for government benefits, including SSI and Medi-Cal. Depending on the amount, an inheritance may make a disabled adult ineligible for government benefits, yet not be sufficient to provide for his life-long needs.

An alternative to this type of inheritance is a special needs trust. Parents can designate a trustee to control the funds and resources set aside for the disabled adult. Because the person with a disability does not directly control the resources, his or her government benefits are not affected. With this type of arrangement, funds can be stretched to provide maximum support over time.

Lanterman Regional Center provides workshops on setting up wills or trusts. To find out about such workshops, or for a list of attorneys who specialize in these types of legal matters, contact the Koch-Young Resource Center (1-800-546-3676 or [kyrc@lanterman.org](mailto:kyrc@lanterman.org)).

## *Conclusion*

The most important thing that families can do to help their child transition to adulthood is plan ahead. Furthermore, the best transition planning happens when students, family members, professionals, and other individuals in your child's circle of support work together as a team. The regional center can be an active team member, providing your family support, needed services, and information throughout the transition process.





## Transition to Adulthood Worksheets

### Looking at My Child

1. My child's greatest strength is: \_\_\_\_\_
2. My child truly loves to: \_\_\_\_\_
3. My child tries to avoid: \_\_\_\_\_
4. My child's favorite class(es) and hobbies are: \_\_\_\_\_
5. My child's chores at home include: \_\_\_\_\_

Circle the number that best describes how true each statement is.

My child:	Always True	Often True	Not True
Prefers to be outdoors	1	2	3
Prefers to work as part of a group	1	2	3
Prefers to work with people	1	2	3
Prefers to work with animals	1	2	3
Prefers to work with plants	1	2	3
Prefers to work with things	1	2	3
Prefers to keep neat and clean	1	2	3
Can repeat a task without losing interest	1	2	3
Enjoys learning new things	1	2	3

(Any other strong preference) \_\_\_\_\_

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## *Work and Leisure*

Complete the following items for each type of work you discuss with your child.

Kind of job: \_\_\_\_\_  
\_\_\_\_\_

Understanding of job duties: \_\_\_\_\_  
\_\_\_\_\_

Likes about this job: \_\_\_\_\_  
\_\_\_\_\_

Doesn't like about this job: \_\_\_\_\_  
\_\_\_\_\_

Complete the follow items for each social, leisure or creative activity you explore with your child:

Social, leisure or creative activity: \_\_\_\_\_  
\_\_\_\_\_

Previous experience with this activity: \_\_\_\_\_  
\_\_\_\_\_

Likes about this activity: \_\_\_\_\_  
\_\_\_\_\_

Doesn't like about this activity: \_\_\_\_\_  
\_\_\_\_\_