

Moving On –
Transition to Adult Living for
Young Adults with Disabilities



2020

WarmLine Family Resource Center

WarmLine Family Resource Center is dedicated to offering support, information and referral (at no charge) to families of infants, children and youth with delays or disabilities from birth to 26 years in 26 counties in Northern California.

WarmLine is staffed by parents who share the experience of parenting children with disabilities and can provide peer support to other parents and help them:

- **Connect** with other parents of children with delays or disabilities,
- **Navigate** unfamiliar services, such as Early Intervention, Special Education, Regional Centers and Public Benefits,
- **Empower** parents (and their children) to develop leadership skills and be active participants in their programs and services. Parents are their child's best advocates!

WarmLine is a Parent Training and Information Center (PTI):

A PTI is a federally funded resource for parents of children and youth with disabilities from birth to 26 years old. Every state has at least one PTI - California has 7. PTIs provide parents information and training about:

- Disabilities;
- Parent and children's rights under Special Education and other relevant laws, and;
- Resources in the community, state and nation.

WarmLine's trained staff provide individual consultation and can:

- Review documents related to Early Intervention, Special Education, etc.
- Assist parents with strategies to prepare for Special Education (IEP) and other related meetings by setting priorities and goals,
- Support parents' collaborative communication skills.

We invite you to connect with us:

- 916-455-9500 or (toll free) 844-455-9517
- Spanish: 916-922-1490
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Section One

“One of the most striking (and most stressful) aspects of transition for families of children with exceptional needs is that it focuses on relationships: beginning and ending them, leaving a comfortable situation and starting all over again.”

Brekken & Knowlton, Transition Issues: A Model for Early Childhood Special Education

“My son is now 21 years old and I feel as though I’ve been in denial about programs I should have been looking for when he was a teen. I wish that when he was younger I had known what questions to ask. Now I feel like I’m playing “catch up”.

Preparing for the Future

Preparing for your teen’s transition to the adult world should begin when children are young.

When typically developing children are young, we ask them what they want to be when they grow up. We know that it’s O.K. for a five year old to want to be an astronaut, at ten for her to want to be a chef and at 15, a veterinarian. Most of us changed our minds many times over the years. How many of us do the type of work today that we dreamed of doing when we were five?

An important part of growing up and becoming independent depends on having dreams and knowing how to make those dreams come true. It is as significant for children with disabilities as it is for typically developing children. It is our job as parents to support them as they learn to self-advocate and make their own decisions.

Self-Determination and Self-Advocacy

Self-determination and self-advocacy are terms, sometimes used interchangeably by professionals when discussing adults with disabilities. They sometimes are not well defined for parents.

Self-determination means that a person has decided what he or she would like to do and has set goals. For example, where to live and what job to have.

Self-advocacy is the ability to make those goals known to others and work on them.

Some ways to promote self-determination:

- Help children learn to identify their strengths, interests, and learning styles;
- Provide choices about clothing, social and family activities;
- Hold high expectations that all children can succeed in school and have options for independent lives as adults;

- Prepare children to participate in their education plan (IEP);
- Encourage everyone who comes in contact with the child to address him or her directly and ask the child for feedback and opinions;
- Involve children in family decisions;
- Allow the child to make mistakes and experience natural consequences.

Encourage Future Planning

- Talk about future jobs, hobbies, and family lifestyles;
- Discuss interests and goals. Encourage children to dream.

Promote Reasonable Risk Taking

- When considering choices, encourage the child to list risks, benefits, and consequences of choice;
- Support children to take responsibility for mistakes.

Promote Self Advocacy

- At each developmental level, provide information to children on their disability and how to communicate with others about it;
- Encourage children to express their thoughts and desires;
- Praise efforts of assertiveness and problem solving;
- Develop opportunities at home and in school for self-advocacy;
- Ask children their opinion on issues. Encourage them, even if their opinion differs from yours;
- Teach what accommodations they need and how to express the need.

Facilitate Development of Self-Esteem

- Create a sense of belonging within schools and communities;
- Provide experiences for children and youth to use their talents;
- Provide opportunities to youth to contribute to their families, schools, and communities;
- Provide opportunities for individuality and independence;
- Identify caring adult mentors at home, school, church, or in the community;
- Model a sense of self-esteem and self-confidence.

Develop Goal Setting and Planning

- Teach children and youth family values, priorities, and goals;
- Make posters that reflect values and that are age-appropriate;
- Define what a goal is and demonstrate the steps to reach a goal;
- Support children in developing their own values and goals;

Transition Services in High School

Under special education law, school districts are required to begin transition planning when the student is 16. However, most parents who have had teens with disabilities agree that the earlier you start thinking and working on transition issues, the better prepared your teen (and you) will be for adulthood.

By law, the student must be given the opportunity to participate in the transition IEP process!

Transition IEPs should include:

- Whether the student will be eligible to graduate with a diploma (which will end special education services) and when, or leave high school with a certificate of completion, which will allow special education services to continue until the teen reaches the age of 22,
- The student's plans to attend a post-secondary school and/or obtain vocational training,
- Adult goals with measurable outcomes identified, such as making choices and decisions, problem solving, goal setting and attainment, self-advocacy, involvement and participation in IEP, self-awareness and self-management,
- Goals/outcomes that identify what instruction will be provided at school and in the community,
- Instruction directly related to adult goals/outcomes in areas of curriculum based on the student's preferences, interests and priorities,
- A range of educational opportunities that are sufficient to encourage the development of the student's choices, interests, preferences and options for the future,
- The opportunity for paid work experience,
- The opportunity for both academic and community based/independent living skills curriculum,
- The opportunity for the student to be included with non-disabled peers,

- Statement(s) of transition services needed,
- Identification of other agencies involved with transition, i.e., Regional Center, Department of Rehabilitation.

If the student will leave high school with a certificate of completion, it is important that you and he continue to work closely with the IEP team to identify the goals that will help support as much independence as possible when he faces transition out of special education services at age 22.

As of 2011, the regional center will no longer provide services such as access to day programs and independent living services for students who leave school before age 22 without a diploma. (Exemptions are possible. For more information, visit Disability Rights California and search for publication #F050.1)

Student-Led IEP (“Student-directed” IEP may be a more descriptive term.)

The “student-led” IEP is a process in which the student takes an active role in the planning and implementation of his IEP. Studies have shown that when students are involved in crafting their own IEPs, they take increased responsibility for the outcomes and are more engaged in the learning process as they work toward their goals. (Teachers and parents also express greater satisfaction with the IEP process when the student is involved.)

Even young children can start to take part in their IEPs by drawing a picture or dictating a story to the parent that is delivered to the team. As they get older, parents can support them to become more involved.

There is important information for the student in order to be an active participant in her IEP at “A Student’s Guide to the IEP” on page 38.

Regional Center

The Regional Center (RC) system in California serves individuals with developmental disabilities throughout the lifespan. The regional center contracts with agencies and individuals who provide a wide variety of services, including developmental services, respite, supported employment and help with supported living.

According to the Lanterman Developmental Disabilities Act (AB 846), “developmental disability” means a disability attributable to; intellectual disability, cerebral palsy, epilepsy, autism, or other handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for intellectually disabled individuals. Such a disability originates before an individual reaches age 18, continues or can be expected to continue indefinitely, and constitutes a substantial handicap for such individuals. (“Substantial handicap” means a condition that results in major impairment of cognitive and/or social functioning.)

To read more about the Lanterman Act, go to www.disabilityrightsca.org and go to “Rights under the Lanterman Act”.

The Lanterman Developmental Disabilities Act requires that a person over three years old who receives services from a regional center have an Individual Program Plan (IPP). The IPP is updated annually by the client’s service coordinator using person-centered planning. Person-centered planning is about listening to clients (and their families) about things such as where they want to live; how they want to spend their day; who they want to spend time with; and their hopes and dreams for their future. It is about supporting people in the choices they make about their lives and giving people the information they need to make those choices. After the service coordinator helps write the IPP, he looks for services and supports, and makes sure that they are the ones needed and wanted. (*See more about Person-Centered Planning on page 45.*)

A booklet titled, “Individualized Program Plan (IPP) Planning Guide “Your IPP – is available on the Disability Rights California website at www.disabilityrightsca.org (Publication # 5038.01) contains valuable information about the IPP process and how to prepare for the IPP meeting.

If your teen is not already a client of the Regional Center, you can contact your local one and ask for “Intake Services” for help determining if he qualifies for services. You can search for your Regional Center by visiting <http://www.dds.ca.gov/RC/RCList.cfm>.

Exploring Options for the Future

Making decisions about your teen's future can feel frightening and sometimes overwhelming. Transition to adult services means huge changes in both your lives.

Your support network will be able to assist you in planning for your teen's transition to adult services. Teachers, counselors, CCS therapists, Regional Center staff, agencies such as Department of Rehabilitation and advocates can also help you to plan for the future by providing you with resources about available services.

Many school districts offer "Transition Fairs" which give you the opportunity to talk with agencies which provide a variety of services to adults with disabilities. You and your teen can attend these fairs and learn about options.

Things to think about:

- Where your teen would like to live:
 - At home with you,
 - In her own home or apartment with supportive services,
 - In a group home (Community Care Facility),
 - Independently (with or without supportive services),
 - In a "Mentor" home,
- What your teen would like to do during the day:
 - Go to college,
 - Attend a vocational training program,
 - Attend a supported employment program,
 - Attend a day program,
 - Work at a paying or volunteer job,
- What financial assistance will your teen will require (if any) as an adult:
 - SSI
 - IHSS
- Who will provide medical care and coverage?
 - Private Insurance—If you have private insurance, find out how long, as an adult, your child will continue to qualify,
 - Medi-Cal—Apply when your young adult is 18 if private insurance is not available.

- Will your teen need help making decisions as an adult? From whom?
 Parents or other family members,
 Regional Center Service Coordinator,
 Other

Getting Help When You Need It

There are agencies to help you learn about transition services and how to advocate for your teen. Many of the same people who have helped you all along will still be a part of your team. You will also find new sources of support as to help you find and develop new resources.

Sources of support may include:

- WarmLine Family Resource Center
- IEP Team
- Regional Center Service Coordinator
- State Council on Developmental Disabilities
- People First California
- Disability Right California
- Office of Client’s Rights Advocacy (OCRA)
- California Foundation for Independent Living Centers

Transitioning to Adult Medical Care

“My daughter is 17 years old and has lots of medical needs. I worry about where to find doctors who understand her medical issues, can work with someone who is developmentally delayed...and who are accepting new Medi-Cal patients!”

When your teen turns 18, insurers might require that he switch from pediatric to adult medical providers. There are some things that parents can do in advance to make the transition smoother.

- Check with your insurance on how long they will cover your child. The policy may have age limitations.
- Find out the policies regarding age limits for your teen’s current doctors.
- Discuss the transition with your child and health care providers as early as 16.
- Teach your teen to take charge of her health care services to the extent she is able.

- Ask your pediatric/adolescent medical provider to recommend an adult provider who is sensitive and knowledgeable of special health care needs and disabilities.
- Find out how your insurer handles referrals and consultations for transition to adult health care.
- Check into Medi-Cal if your teen does not currently have private health insurance.

If your child does not already have a medical alert bracelet, consider ordering one so that emergency personnel can readily access health information. (This is also a useful tool in case the person becomes lost or disoriented.) Your regional center may pay the annual subscription.

Teens with developmental disabilities may not be able to manage their health care independently; however, the goal is to make them as independent as possible by helping them to acquire as many self-advocacy skills as they can. (See “Independent Living Skills” in Section Two.)

Questions to Ask a New Health Care Partner

Before your teen becomes a patient of a new health care partner, you may want to set up an appointment to meet and ask questions. Write your questions down and take them with you.

You may want to include some of the following questions:

- Have you ever had a patient with similar special health care needs?
- Are you comfortable providing care for my teen who has special health care and/or developmental needs?
- Are you able/willing to talk with my teen’s pediatrician/adolescent health care provider to gain an understanding of his/her unique health issues?
- Do office visits include a time to talk with you about any concerns?
- Is your office accessible to someone who uses adaptive equipment?

College

“My daughter has severe cerebral palsy and just graduated from U.C. Berkeley. She’s very bright – but she needed the support that she received from DSPS there.”

Even students with Intellectual Disability can go to college! Depending upon the school and the course of study, a student may earn a typical college degree or a specialized degree or certificate issued by the school. For more information, visit www.thinkcollege.net.

Disabled Students’ Programs and Services (DSPS)

Students with disabilities who continue on to higher education have a number of services available to them. Upon admission to college, the student should contact the DSPS office which will refer the student for services. Every public and private community college, college, and university has a DSPS office.

Possible Services:

- Priority scheduling
- Registration assistance
- Classroom accommodations
- Alternate course assignments
- Large type print
- Learning disability services
- Mobility services
- Note-taking

Eligibility:

Students with a disability must submit verification when registering with the DSPS office. Criteria used to verify the diagnosis will depend on the diagnosis. It is helpful to have copies of medical records and/or recent IEPs. Depending on the disability, students can be eligible for one or more services.

How to Apply:

Ideally, students will self-refer to the DSPS office of the campus they wish to attend. Check the school's website for contact information. Students transitioning from public school districts should be provided assistance as part of their IEP.

Vocational/Employment Programs

“My daughter thoroughly enjoyed the training at a bakery that she received through the (vocational education) program at her high school. I encourage families to consider those opportunities in high school in their resource options.”

You and your teen should communicate with the transition team members about what type of vocational training is desired and appropriate. While in high school, the district's transition or vocational training specialist can help arrange for your teen to be trained in any number of jobs that might interest her. Other members of the team while your teen is still in high school might include her regional center service coordinator and a representative from the California Department of Rehabilitation. Remember – you can invite anyone to planning meetings who you think will be helpful to the process.

For the student who has finished high school with a certificate of completion (rather than a diploma), the school district can still provide vocational education and job opportunities until age 22 through a school district based program. Both you and your teen should discuss those options with the transition specialist who is on the IEP team.

Your regional center has contracted with programs in the community to provide vocational training and supervised employment for consumers who have left high school with a diploma or are age 22. Talk with your teen's service coordinator for more information about available programs

Types of Employment Programs

1. Competitive Employment: A job in the community.

2. **Supported Employment:** Employment in a community setting such as a private business or public agency. (The client) receives ongoing support services from a supported employment agency. These support services are provided on the job site by a job coach. The amount and type of services vary depending on the type of support needed.
 - Support services may include helping (the client) find a job by matching (his) interests and abilities with different types of jobs.
 - Support services may include on-the-job training.
 - Jobs may be individual or group settings.

Supported employment may also take place in an “enclave” where 5 or 6 consumers share one job coach, but work in an integrated setting in the community.

3. **Work Activity Programs:** If (the client) is not quite ready for supported employment or competitive work, there are vocational or job-training services that are offered to prepare (him) for supported employments.

The work assignments offered in these programs are based on contracts made between employers in the community and the vocational agency. This type of work is done in a workshop setting and is designed to teach vocational skills.

These services are funded by and coordinated through the regional center.

Adult Day Programs

Typically, an adult day program is vendored by the regional center to serve its clients. There are different types of programs that provide training in self-care, self-advocacy, community integration and employment. Some programs are site-based where consumers participate in activities on site. Others are either community based or a combination of the two.

The programs vendored provide varied levels of supervision and staffing ratios. Ask your regional center service coordinator for more information about what programs are available.

Moving Out – Living options

There are several choices for living arrangements that might be available to your teen, depending upon his or her desire and level of independence.

If your teen needs help and supervision, but still wants to live in his or her own home, Supported Living Services (SLS) provide services which support his efforts to do so. Several agencies which provide SLS are vendorized by the regional centers. The individual pays for his or her own living expenses (rent, utilities, food and entertainment) out of SSI, work earnings or other personal resources. The regional center pays the vendor to provide the supported living services.

Supported Living Services (SLS) consist of a broad range of services to adults with developmental disabilities who, through the Individual Program Plan (IPP) process (through the regional center), choose to live in homes they themselves own or rent in the community. SLS may include assistance with selecting and moving into a home; choosing personal attendants and housemates; acquiring household furnishings; common daily living activities and emergencies; becoming a participating member in community life; managing personal financial affairs, as well as other supports.



Supported Living Services help individuals exercise meaningful choice and control in their daily lives, including where and with whom to live. SLS is designed to foster individuals' nurturing relationships, full membership in the community, and work toward their long-range personal goals. Because these may be life-long concerns, Supported Living Services are offered for as long and as often as needed, with the flexibility required to meet a person's changing needs over time, and without regard solely to the level of disability. Typically, a supported living service agency works with the individual to establish and maintain a safe, stable, and independent life in his or her own home. But it is also possible for some individuals to supervise their services themselves, to secure the maximum possible level of personal independence.

Individuals who choose to live in their own homes, and the agencies or other people who support them, often will need information about affordable housing options, sources of financial support such as Supplementary Security Income (SSI), and how to stretch a limited budget to meet living expenses. These are the ordinary challenges that are inseparable from a truly self-directed life in the community. For the many adults for whom SLS makes great sense, such challenges are often also road signs on the path to a satisfying life.

Independent Living Programs (ILS) provide services to adults with developmental disabilities that offer functional skills training necessary to secure a self-sustaining, independent living situation in the community and/or may provide the support necessary to maintain those skills. Individuals typically live alone or with roommates in their own homes or apartments.

Independent Living Programs, which are vendored and monitored by regional centers, provide or coordinate support services, referred to as Independent Living Services (ILS), for individuals in independent living settings. They focus on functional skills training for adults who generally have acquired basic self-help skills or who, because of their physical disabilities, do not possess basic self-help skills, but who employ and supervise aides to assist them in meeting their personal needs.

A Family Home Agency (FHA) approves family homes which offer the opportunity for up to two adult individuals with developmental disabilities per home to live with a family and share in the interaction and responsibilities of being part of a family. The individual with developmental disabilities receives the necessary service and supports from the family, agencies and the community to enable the individual to be a participating member of the family and the community where the family resides. The family home arrangement allows the sharing of food, shelter, experience, and responsibilities.

The FHA is a private, nonprofit organization under contract to, and vendored by a regional center. FHAs are responsible for recruiting, training, approving and monitoring family homes, as well as providing ongoing support to family homes. Social service staff employed by the FHA make regular visits to the family home to ensure that necessary services and supports are in place, and that the match between the family and the new family member is viable, and continues to be viable.

FHA and family home services and supports are a new option which enables adults with developmental disabilities to enter into partnerships with families that promote self-determination and interdependence

Community Care Facilities (CCFs) are licensed to provide 24-hour non-medical residential care to children and adults with developmental disabilities who are in need of personal services, supervision, and/or assistance essential for self-protection or sustaining the activities of daily living. Based upon the types of services provided and the persons served, each CCF vendored by a regional center is designated one of the following service levels:

- SERVICE LEVEL 1: Limited care and supervision for persons with self-care skills and no behavior problems.
- SERVICE LEVEL 2: Care, supervision, and incidental training for persons with some self-care skills and no major behavior problems.
- SERVICE LEVEL 3: Care, supervision, and ongoing training for persons with significant deficits in self-help skills, and/or some limitations in physical coordination and mobility, and/or disruptive or self-injurious behavior.
- SERVICE LEVEL 4: Care, supervision, and professionally supervised training for persons with deficits in self-help skills, and/or severe impairment in physical coordination and mobility, and/or severely disruptive or self-injurious behavior. Service Level 4 is subdivided into Levels 4A through 4I, in which staffing levels are increased to correspond to the escalating severity of disability levels.

Attendants & Supported Living Assistants

If your teen plans to live independently he may require attendant(s) to assist with the tasks of daily living or assistant(s) to provide support and/or supervision. Even if a teen continues to live at home, he or she might also require help as parents grow older and less able to provide all necessary care. If your teen is a client of the regional center your service coordinator may help guide you in the search to find attendant help.

Steps to follow when hiring a personal care attendant (PCA) or supported living assistant: (Adapted from Kentucky Commission for Children with Special Health Care Needs – KY TEACH Project)

- Tasks – Identify the kind of support or assistance that will be needed.
- Payment – Determine how the services will be paid and how much can be budgeted.
- Job Description – Write a list of what assistance is needed. Be specific when describing a task. Develop a sample daily schedule that lists what tasks will be required, and when they should be done.
- Qualifications – Make a list of what kinds of training and work experience that the applicant should have, including such training as First Aid, CPR, etc. and keep in mind that the more qualified, the more the services will cost.

- Finding an applicant – You and your youth may consult your regional center service coordinator for information about vendorized supported living services agencies, which can then help find applicants. You can also contact an employment agency, place an advertisement in a local newspaper, website, and newsletter or on a bulletin board in order to find a PCA. List the minimum qualifications that you expect. You may also want to know what kind of transportation the candidate has. Provide a phone number, email address or post office box for responses. (For safety, do not include your home address.)
- Interview – Prepare a list of question before the interview. Tell the candidate specifically what assistance/supports your youth requires. Show the candidate the sample daily schedule. For safety, consider holding the interviews at some place other than your home. If the youth conducts the interview independently, have someone nearby such as a family member or friend.
- Before the interview, ask the applicant for the following information:
 - Legal name
 - Address
 - Phone number
 - Social Security number
 - Driver’s license number
 - Date the person can begin working
 - Previous work experience, including employer(s) name and phone number
 - Education and training
 - Disclosure of previous felony convictions
 - Name and phone number of references

After the PCA/assistant has been hired, it is important that he or she be trained. If you and your youth are working with a supported living agency, it can help with training. Clearly explain is expected and let the PCA know if there is personal information that is confidential. Encourage your teen to be assertive when communicating his or her needs, feelings and decisions.

When training the PCA, video recordings of how tasks should be done can be very helpful.

Backup Support – Maintain backup support in case the PCA /assistant calls in sick, suddenly quits or it becomes necessary to fire him/her.

The parent of the youth with disabilities should allow her to take the lead in developing the job description and interviewing the PCA. Your youth must feel comfortable with the PCA because some of the tasks that he or she will perform might be very personal. While you can help to evaluate the choices, the decision should be up to the

youth. This is an important step in developing self-advocacy, self-determination and other independent living skills.

Supplemental Security Income (SSI)

SSI is a monthly cash benefit program administered by the Social Security Administration. California adds a State Supplemental Payment (SSP). It is not necessary to have paid into Social Security, but applicants must meet financial and medical eligibility criteria. Children who were not eligible under age 18 because the family income was too high may qualify on their own and should reapply after age 18. SSI recipients are automatically eligible for Medi-Cal.

A person can work and still get SSI unless his or her income gets so high that he or she is no longer financially eligible. SSI has generous income counting rules. One half of the earned income is not counted in figuring the amount of the SSI payment. A person can also reduce countable income and thus increase the amount of the SSI payment through Impairment Related Work Expense (IRWE) deductions. These are the charges the recipient pays out of pocket for assistance and treatment related to the disability and for the extra expenses someone has because of working and having a disability. For example, if a person lives in a board and care which provides care and supervision in addition room and board, the value of these services can be deducted from any earned income as an Impairment Related Work Expense.

SSI and PASS Plans

With a “Plan for Achieving Self Support” or PASS, income or an excess resource can be sheltered and not counted in determining eligibility for SSI. The income or resources sheltered can be used to pay for tuition, equipment needed to work, etc. Persons interested in seeing whether a PASS would assist them, and particularly persons not now eligible for SSI, should be referred to someone with expertise in writing and implementing Plans for Achieving Self Support.

Services:

- Medi-Cal

- Monthly cash benefit

Eligibility:

- Must be blind or have a physical or mental impairment resulting in marked and severe functional limitations and expected to last at least 12 months
- Have limited income (below \$500/month for a child) and limited resources (less than \$2,000)
- Meet citizenship and residence requirements

How to Apply: Call 800-772-1213 Web site: www.ssa.gov

In Home Support Service (IHSS)

IHSS is a county program designed to keep people who might otherwise be institutionalized in their homes. It provides payment to a care provider who can be a family member or someone hired specifically to help care for the person with disabilities. The number of hours for which someone can be paid is based upon the time it takes for the provider to do the tasks that have been authorized. No time will be authorized for services that are solely for the “comfort” of the IHSS recipient. The maximum number of hours is 283 per month.

The county has a formula for determining “time for task”. In order to prepare for the application /evaluation, it is recommended that you keep a log of the amount of time it takes to do each task with which the recipient requires help in order to make sure that you allot enough time for each task. People often do not realize all of the tasks involved in care and the length of time they take. For instance, if there are bathroom accidents, the clean-up time is not just the time for cleaning the person, but also the time it takes to take out the cleaning supplies and put them away again. Also, the time involved in certain tasks may vary from day to day. For instance, it may take twice as long one day to dress a person with spastic quadriplegia cerebral palsy as it does the next day because of differences in limb flexibility. The IHSS authorization will be based on an average time, so it is important to know the range of time a task may take.

In addition to paying someone to help with tasks for the client, IHSS may also pay for “protective supervision”. Protective supervision is watching people with severe mental impairments so they don’t hurt themselves at home. An IHSS provider may be paid to watch a disabled person to prevent injuries or accident when the person needs 24 hour supervision and can remain safely at home if it is provided.

For more information on IHSS and how to plan for “time for task”, read “In-Home Supportive Services: Nuts & Bolts Manual”. <http://www.disabilityrightsca.org/pubs/PublicationsIHSSNutsandBolts.htm>

Safety Skills

People with disabilities are statistically more vulnerable to abuse than other populations. As your teen spends less time with you and more time in the community you will want to give her the tools to be prepared to deal with people who may be unscrupulous.



Your student’s Transition IEP or the regional center (IPP) after age 22 can address needed safety skills.

Teach your teen:

- Not to be alone in an isolated place and what to do if he is being followed,
- About inappropriate touching or actions and who to tell,
To only take safe routes to and from busses or stores,
About the buddy system,
- How to call 911 from a cell phone or landline
- That it is okay to question someone who is in an authority position if he does not feel right about being told to do something.

Consider purchasing a self-defense device for your teen, such as a personal alarm or whistle.

You may purchase a Medic Alert (800-432-5378) bracelet and teach your teen that the phone number on the bracelet can be called for help if she is ever lost. (Medic Alert bracelets can be purchased for people who have cognitive needs in addition to those who have medical needs.) The regional center may help pay the annual subscription.

Friends & Relationships

Just because your teen has a disability doesn't mean he or she won't be interested in having a boyfriend or girlfriend. It may mean, however, that you have to be more vigilant in communicating with your child what is appropriate social behavior and what isn't. It may also mean that you may be involved in facilitating dates by providing transportation, attendant services etc. depending on your teen's capabilities. Relationships are an important part of life - help your teen to maintain contact with friends he or she has made in school.

There are many community recreation programs for adults with developmental disabilities, as well as travel opportunities for persons with disabilities. Your school district or regional center may offer a program to help with social/recreational skills.

Service Dogs



These are specially trained dogs that are matched with an individual's disabilities. The dogs can do things such as open and close drawers, pick up dropped items from the floor and assist individuals with disabilities in many other ways such as helping those who are blind, hearing impaired or who have seizures. The dogs are allowed by law to go anywhere the person with a disability goes, including restaurants. Families or individuals typically must go through an application and training process before being matched with a dog. For more information, please visit <http://www.cci.org/>

Limited Conservatorship and Alternatives

When your teen turns 18 years old, she is legally an adult in the eyes of the law – no matter how disabled.

Parents want to protect their disabled adult child, and frequently choose conservatorship as a way to do so. Whether or not to apply for conservatorship is a personal decision for each family and there are no right or wrong answers about whether to conserve an adult child. Some families chose to do so as soon as their teen turns 18, some chose to do so later, and some chose not to do it at all.

There are, however, alternatives to conservatorship (which is a legal process and extremely difficult to reverse) which it would benefit families to learn about.

The following is condensed from “Limited Conservatorship and Alternatives” (Disability Rights California, Publication #5578.01)

1. What is a conservatorship?

A conservatorship is a court process in which a judge decides whether or not you are able to care for your health, food, clothing, shelter, finances, or personal needs. A judge may take some of these important rights away from you. A responsible person may be appointed by the judge to make decisions for you. The court calls that person a “conservator.” The court calls you the “conservatee.” Conservatorships are only for persons 18 years of age or older.

2. What are the different types of conservatorship?

There are several types of conservatorship in California:

- General Probate Conservatorship
- Lanterman Petris Short Act
- Dementia Conservatorship
- Limited Conservatorship

3. What is a limited conservatorship?

A limited conservatorship is a type of conservatorship created for people with developmental disabilities. It is created to make sure you are as self-reliant and independent as possible. It allows you to keep some rights so you can make some decisions about your life. A judge will decide what decisions the conservator will make.

4. Who can be appointed as your limited conservator?

A limited conservator must be 18 years of age or older and act in your best interest. You may suggest someone you know such as a family member or friend, but a judge decides who will be your limited conservator. The judge may appoint more than one limited conservator (co-conservators). In some cases a private professional conservator is appointed. The county public guardian may be appointed if no one else is available.

5. How is a limited conservatorship established?

- A proposed conservator files a petition with the court,
- A copy of the petition must be given to you,

- Copies of the petition are sent to some of your relatives and agencies such as the regional center,
- A court investigator is assigned to your case,
- You must go to the hearing, unless the judge approves an exception,
- A judge will appoint an attorney to represent you.

6. What is the court investigator's role in the limited conservatorship process?

A court investigator must:

- Explain and review the petition with you.
- Interview you and tell you about the conservatorship process.
- Determine whether you:
 - Are able to attend the hearing.
 - Want to challenge the conservatorship.
 - Object to the proposed conservator or prefer another person.

7. What is the regional center's role in a limited conservatorship?

With your consent, the regional center must assess you and submit a report to the court.

The report must include:

- The nature/degree of your disability,
- What assistance you need,
- Your physical condition,
- Your mental condition and social well-being,
- Recommendations about the specific rights requested in the petition,
- A copy of the report must be sent to you and your attorney at least 5 days before the hearing.

8. What are my rights in the limited conservatorship process?

You have the right to:

- Be told what rights will be taken away and how the conservatorship will affect your rights,
- Receive a notice and copy of the conservatorship petition at least 15 days before the court hearing,
- Have an attorney represent you. If you don't have an attorney, a judge must appoint one for you,
- Receive a copy of any reports given to the judge by your family, friends, regional center and others,
- Be at the conservatorship hearing,
- Challenge the conservatorship,

- Have a jury trial if you request one.

9. What rights can the judge take away from me in a limited conservatorship?

The judge may take away some or all of these rights:

- To determine residence,
- To have access to confidential records,
- To get married,
- To enter into contracts,
- To give consent for medical treatment,
- To control social and sexual contacts,
- To make educational decisions.

10. How can I show that I don't need a conservator?

You can show that you are able to care for your health, food, clothing, shelter, finances, or personal needs. You can use supports and services such as alternatives to conservatorships including supported decision-making to help you. See **question 12** for a list of alternatives to conservatorship.

11. If the court determines that I need a limited conservator, what are the conservator's duties and responsibilities?

A conservator has a high duty to do what the judge has appointed him or her to do, which is make decisions in your best interest. This may include:

- Helping you get support services, education, medical and other services that will help you become as independent as possible,
- Responding to a crisis when needed,
- Helping you manage your personal or financial needs.

12. What are less restrictive alternatives to a limited conservatorship?

Before a person can ask the court to become your conservator, that person is required, by law, to consider alternatives. Alternatives may postpone or eliminate the need for a conservatorship.

Supported Decision-Making:

Supported Decision-Making (SDM) is when you use trusted friends, family and professionals to help you understand situations and choices in your life. It is a way to increase your independence. It encourages you and gives you the power to make decisions about your life as much as possible.

SDM also helps you:

- Make things happen in your life.

- Make choices about where, how & with whom you live.
- Make choices about where you want to work.
- Take action in your life instead of someone acting for you.
- Have a more positive quality of life.
- Increase your employment opportunities, independence in daily life, and community integration.

Durable Power of Attorney:

This is a legal document where you give someone you trust the legal right to make decisions for you. It is a way for you to get help with the supports and services you need to live independently. You can give someone the right to make one kind of decision, like medical or financial, or give them the right to make both kinds of decisions.

Other General Alternatives:

You can:

- Join self-advocacy groups such as People First, or get self-advocacy training to help you learn how to communicate and advocate for what you need.
- Have your choices written into your IEP or IPP.
- Prepare for your IEP or IPP by practicing role playing and talking about what your needs and desires are with someone you trust.
- Find facilitators to assist you make decisions.

Specific Alternatives

Alternatives for getting services in your IEP or IPP:

You have the right to invite people to your IEP or IPP meeting that will support you in advocating for the services you need to be independent. Advocates can be:

- Your service coordinator.
- Your family and people in your circle of support.
- A trained advocate.

Alternatives for deciding where and with whom you live:

Discuss your desires and options/choices with someone you trust such as your:

- Circle of support (people you trust and who support you).
- Independent Living Services (ILS) provider.
- Supported Living Services (SLS) provider.
- Community Care Facility or Intermediate Care Facility staff.
- Ask trusted people how you can get help with rent or applying for Public Housing Assistance.

- Advocate at your IPP and get your choices written into your IPP.

Alternatives for access to your confidential information:

If you would like someone you trust to get your confidential information, you can give permission by using one of these options:

- Sign a HIPAA medical release form.
- Sign a consent to release form for information or records.
- You and another person can call the agency together and you can give your permission over the phone.

Alternatives to help you manage your money:

- You can sign a power of attorney for finances. This authorizes someone you trust to make decisions about your finances and money. The financial power of attorney must be notarized. You can end it whenever you want.
- You can pick someone to be your SSI/Social Security benefit representative payee.
- There are laws to help protect your SSI/Social Security benefits.
- You can have services written in your IPP to help you with managing your money, like your independent living services worker.
- A Special Needs Trust can be created for you. A trustee would then manage your money.
- Joint bank accounts: you can set up a joint account with someone you trust to help you write checks, make deposits or withdraw money.

Alternatives to help you with your healthcare needs:

- You can sign an Advance Health Care Directive, so that your desires will be followed. It requires either two witness' signatures or to be notarized and can be changed or ended whenever you want.
- Since you are the patient, doctors must tell you the risks and benefits of a treatment, other available treatments and what happens if there is no treatment.
- If you are unable to make a decision:
 - Your closest relative available (such as a parent) can authorize healthcare.
 - Your regional center can authorize some medical, surgical, or dental care in some situations.
 - Doctors or dentists can make decisions in an emergency.
 - Court authorization is required for specific medical operations.

Alternatives to help you with your social/sexual relationships:

Services in your IEP or IPP could include supports to help you with relationships such as counseling, independent living services, and supported living services. You could also get education in the areas of social skills, safety awareness, and how to have healthy relationships with others. This can include relationships with boyfriends and girlfriends.

Alternatives to help you with your educational decisions:

You can give someone you trust the right to make your educational decisions. You can have a durable power of attorney or an assignment of educational decision making authority.

13. Do I have to pay court fees and costs in my conservatorship case?

The court will determine whether you must pay filing fees, legal services fees and court costs.

14. What powers are NOT available in a limited conservatorship?

A conservator cannot:

- Control your wages from a job or salary,
- Approve harmful medical treatment,
- Force medication therapy on you,
- Have you sterilized so you cannot have a baby,
- Have you committed to an institution,
- Agree to electro-convulsive shock therapy (ECT),
- Agree to psychotherapy,
- Have any other powers NOT specifically ordered by the court.

15. What rights do I keep in a limited conservatorship?

You keep your right to:

- Control your own wages or salary,
- Make or change a will to say who gets your personal items when you die,
- Get married unless the judge specifically takes that right away,
- Receive personal mail,
- Vote unless the judge specifically takes away that right,
- Be represented by an attorney,
- Ask for a new conservator,
- Ask for the conservatorship to end.

16. What can I do if I disagree with my conservator or want to end the limited conservatorship?

- Call your attorney, probate court investigator, regional center, day program, support staff, or Office of Client's Rights Advocacy (OCRA).
- Ask for a court hearing.
- Ask your regional center service coordinator for an IPP meeting.

17. When does a limited conservatorship end?

- When ended by a judge.
- Upon the death of the conservator or conservatee.
- A court order saying that the limited conservatorship is no longer needed.
- Conservator files a petition with the court to resign.

18. How can the Clients' Rights Advocate help me?

The Clients' Rights Advocate can help by:

- Telling you about your rights,
- Telling you or your family about limited conservatorship alternatives,
- Talking to or helping you talk to your attorney, probate court investigator and others who could help you.

19. How will I know if a limited conservatorship has been ordered by the judge?

- You will receive a copy of the judge's order.
- The judge's order will tell you what rights have been given to the conservator.

20. How will others know that I have a conservator?

The conservator must give other people an official copy of the Letters of Conservatorship. The official copy must include the completed certification section of the Letters of Conservatorship before they can be treated as a conservator.

For further information, call Disability Rights California

Toll Free: (800) 776-5746

Office of Clients' Rights Advocacy Toll Free: (800) 390-7032

Estate Planning Disabilities Trust

When you have a teen or young adult with a disability, estate planning can be tricky. If you haven't begun to plan already, you might think about doing so as soon as possible. Because many adult children with developmental disabilities will

rely on public benefits for medical and living expenses, it is important to protect these assets. A disabilities trust allows a person with developmental disabilities to inherit money or assets without jeopardizing those benefits. Parents leave resources to the trust which is then managed by a trustee on behalf of the adult child. Even if you don't think you have enough assets now to set up a disabilities trust, consider talking with an estate planning attorney about options, including how other people such as grandparents, aunts or uncles may also leave gifts to the disabilities trust for your teen or adult child.

Adapting Your Home for an Adult with a Disability

Your teen may already have outgrown you, in size and weight. If he plans on continuing to live at home as an adult and has mobility issues, you should start early to plan for what type of assistance and adaptive equipment your teen will need as an adult, especially if he is currently a client of California Children's Services (CCS) since CCS covers children only up until age 21.

Voter Registration

"My son, who has cerebral palsy just voted for the first time. He took the process very seriously and is so proud of his knowledge of the issues!"

Anyone can vote as long as he meets certain conditions. The person must:

- Be a United States citizen,
- Live in California,
- Be at least 18 years old,
- Not be in prison or on parole for a felony,
- Not have been told by a court that he or she cannot register to vote.



A person can register to vote online through the California Secretary of State's Office.

Selective Service Registration

Almost all male U.S. citizens regardless of where they live, and documented or undocumented immigrant men residing in the U.S., are required to be registered with Selective Service if they are at least 18 years old but are not yet 26 years old.

The easiest and fastest way for a man to register is to register on-line. A young man can also fill out a registration card and send it to the Selective Service System.

Here are some places to register:

- On-line with Selective Service at www.sss.gov
- At The Post Office – Fill out the Selective Service registration forms available at any U.S. Post Office.

Disabled Parking Placard

A person can be certified disabled by a physician if he or she has limited mobility or one of the following conditions:

- Heart or circulatory disease,
- Lung disease,
- A disease or disorder that significantly limits the use of lower extremities,
- Specific visual problems, including low vision, partial-sightedness, or blindness,
- The loss, or loss of the use, of one or both lower extremities or both hands.

Disabled license plates are available only to those with permanent disabilities. There is no fee for the plates other than the normal annual vehicle registration fee.

Both permanent and temporary disabled parking placards require a doctor's certification unless the person has lost a lower extremity or both hands, and goes in person to the local DMV office to obtain a placard or already has a California disabled person (DP) or disabled veteran (DV) license plates.

To Apply for a Disabled Placard or License Plate:

- Download and print a copy of the "Application for Disabled Person Placard or Plates",
- Have a doctor sign the disability certification,
- Mail the completed application to the address indicated on the form.

Renewals:

Placards for permanently disabled persons are automatically renewed by the DMV.

Parking privileges for DP placard, DP plates or DV plates:

- In parking spaces with the International Symbol of Access (wheelchair symbol),
- Next to a blue curb authorized for handicap parking,
- Next to a green curb for as long as you wish,
- In an on-street metered parking space at no charge,
- In an area that indicates it requires a resident or merchant permit,

In addition to parking privileges, service stations must refuel a disabled person's vehicle at self-service rates unless the service facility has only one employee on duty.

Driver's License

Under the Americans with Disabilities Act (ADA), driver's training companies must make "reasonable accommodations" to people with disabilities. After driver's training, the person must also pass both a driver's test and a written (with accommodations, as necessary) test with the Department of Motor Vehicles (DMV).

The Association for Driver Rehabilitation Specialists (ADED) supports professionals working in the field of driver education/driver training and transportation equipment modifications for persons with disabilities. To locate a trainer who is registered through ADED, visit the website.

California Identification (ID) Card

DMV issues ID cards to persons of any age. The ID card looks like a driver license, but is used for identification purposes only. Visit the California Department of Motor Vehicles for information about how to obtain an ID card.

Public Transportation

There are two systems included in the term "public transportation" under the ADA. They are fixed route (i.e. the regular bus system, including rapid and light rail) and demand responsive (i.e. dial-a-ride).

Fixed route is a public transportation system for transporting people that operates along a prescribed route according to a fixed schedule.

A demand response system means a public transportation system that is not a fixed route system, such as dial-a-ride.

Paratransit means comparable transportation service required by the ADA for individuals with disabilities who are unable to use fixed route transportation systems.

For information about public transportation options in your community, contact your regional center service coordinator or search online for “accessible public transportation” in your area.

Utilities

There are many state and federal programs designed to help you manage your utility bills. These programs include:

- California Lifeline Deaf and Disabled Telecommunications Program (DDTP)
- California Alternate Rates for Energy (CARE)
- Energy Savings Assistance Program Low Income Home Energy Assistance Program (LI-HEAP)
- Family Electric Rate Assistance (FERA)
- Medical Baseline Water Company Assistance

For links to these programs, visit the California Public Utilities Commission Consumer Information Website.

California LifeLine Program

California LifeLine provides discounted/free home phone and cell phone services to qualified households. For details, search online for California LifeLine.

Section Two

“The more independent our students are, even in small ways,
the better care they will get.” Tom Neary, Special Education Program Specialist

Helping Your Teen to Independence

The job parents is to help their child become as independent as possible. Your teen with disabilities will need many self-help skills for the adult world (and will continue to learn into adulthood).

Not all of the skills listed will be possible for every young person with disabilities. The worksheets are meant as general guidelines for you to use to give yourself a better idea of skills your teen currently has or needs to work on. The worksheets cover various skills and resources your teen will need for the future. Your teen may already be working on many of these skills in school. If you aren't sure how to go about helping your teen learn a skill, talk with her teacher to get some tips. *(Don't forget that other parents may have great suggestions for teaching independent living skills.)*

Jobs & Post-Secondary Education & Training			
Skill	Independent	Needs Help	Needs Someone To Do This
Can use a computer, search the internet			
Can advocate for self, regarding accommodations needed in school, work, community or home			
Has a resume			
Can complete a job application and can interview for a job			
Has had vocational training or performed volunteer service			

Has developed the interpersonal skills necessary to maintain employment			
Can apply and register for college			
Can access disability support & counseling services			
Recreation & Leisure			
Has developed a variety of recreation & leisure skills			
Has spectator or audience member skills			
Can identify affordable recreation & leisure activities			
Can arrange social activities			
Has identified social supports through family, peer group, mentors, community resources			

Skill	Independent	Needs Help	Needs Someone To Do This
Medical Care/Health Skills			
Describe medical condition(s)			
Understands how his special needs affect daily life			
Can prepare and ask questions of health care providers			
Knows: <ol style="list-style-type: none"> 1. The medications he takes 2. When to take them 3. What they are for 4. How to refill them 			
Can perform own treatments, therapy or exercises			
Can manage own (special) diet			
Can make appointments for medical or dental care			
Can recognize signs & symptoms which require a doctor or dentist visit, such as infection, breathing problems, skin breakdown, urinary tract infection, high fever, allergic reaction, toothache			
Can recognize signs & symptoms of medical emergency and can activate EMS (Emergency Medical System)			
Knows what equipment she uses, what it does and who to contact for repairs			
Understands basic sexuality concepts			
Other:			
Other:			
Insurance			
Knows insurance plan name, case manager contact information and is responsible for insurance ID card			
Other:			
Other:			
Providers			
Knows names of primary care providers (dentist, specialists) and how to contact			
Knows how to make medical appointments			
Knows how to order medications from pharmacy, equipment from providers, etc.			
Keeps summary medical file			

Independent Living/Self-Advocacy			
Skill	Independent	Needs Help	Needs Someone To Do This
Interview, hire, instruct, evaluate, terminate attendant/helper			
Has appropriate social skills			
Understands about inappropriate touching or actions and who to tell if it happens			
Has driver's license or state ID card			
Able to pay for item(s) in store or restaurant			
Able to use public transportation			
Has safe, affordable housing			
Can budget money and pay bills			
Make bed			
Uses telephone			
Launder clothes			
Wash dishes			
Shop for food			
Cook food			
Feed self			
Dress self			
Choose appropriate clothing for occasion or weather			
Self-Care			
Use toilet (clean, intermittent catheterization or bowel program)			
Shower or bathe			
Brush teeth			
Brush hair			
Inspect skin for breakdown			
Mobility			
Ambulate independently			
Ambulate with use of aids			
Use wheelchair independently			
Transfer			

A Student's Guide to Participating in the IEP Meeting

(Excerpted from "A Student's Guide to the IEP by Marcy McGhaee-Kovac, www.nichcy.org)

Introduction

Welcome to learning to participate in your IEP. Being a part of the team that writes your IEP is an important thing to do. It's your education and your future – you should have input into how it looks! Participating in your IEP is not hard once you've had some practice. Your first time, you'll probably need quite a bit of help from your parents and/or teachers, but after that, it will be much easier.

What is an IEP?

IEP stands for Individualized Education Program (IEP). The IEP is a document that describes the educational plan for you, as a student with a disability. Your IEP includes information about your disability, what skills you currently have and what skills you'll need to work on over the next year. It also tells what services the school will be provided and where.

What is the Purpose of an IEP?

The purpose of the IEP is to make sure that everyone - you, your family, and school staff knows what your educational program will be this year. It is a legal document and the school must follow what is written in it.

Where is the IEP Developed?

The IEP is developed during an IEP meeting.

Who Comes to the IEP Meeting?

There is a team of professionals who will help you write your IEP. You are not required to attend, but learning as early as possible how the IEP process works will help you learn self-advocacy skills which will be needed and helpful your whole life.

- You,
- Your parents,
- At least one of your regular education teachers, if you are (or may be) taking part in regular education,
- At least one special education teachers (or special education providers),
- Someone who can talk about your evaluation results, what they mean and what kind of instruction you need,
- Someone from the school system who knows about special education services and educating students with disabilities,
- People from transition service agencies (such as vocational rehabilitation) if you're going to be talking about what you plan to do after leaving high school and what you need to do now to get ready,
- Other people who know you your strengths and needs and who can help you plan your educational program.

How often is the IEP Meeting Held?

At least once a year, but you, your parents, or the school can ask for more IEP meetings, if necessary.

Why Should I Participate in the IEP Meeting?

It's your educational program everyone will be discussing in the meeting. Your opinions are an important part of this discussion. Also, it is never too early to learn important self-advocacy skills.

How Do I Help Develop my IEP?

There are five basic steps:

- Talk to your parents and teachers.
- Review last year's IEP.
- Think about your strengths and needs in school.
- Write your goals for this school year.
- Practice what you want to say at the meeting.

What to Do Before the IEP Meeting

- Tell your family and teachers that you are interested in participating in your next IEP meeting. Ask your parents or teachers when yours is due to be reviewed.

5. What goals have you NOT met? You may need to ask your parents and teacher(s) about this.

6. On another piece of paper, make a list of:

- Each class,
- Which classes are easy or hard and why,
- What are your strengths in each class (ask your teacher for help, if needed),
- What are your needs in each class (ask your teacher for help, if needed.)
- What accommodations would make you more successful? (There is a list of accommodations below.)
- Develop new goals for this year, using the list of strengths and needs you and your parents and teachers developed.

7. What do you want to do after finishing high school (for example, college, job, etc.)?

8. What do you need to do this year to get ready for what you want to do after high school?

9. Work with your parents and teachers to write a draft IEP document that includes all the information above. Make copies for everyone who will be at the meeting

Accommodations

Accommodations are things the school or your teacher can do to make it easier for you to learn by adapting or adjusting what you're learning or how they're teaching. Some common accommodations schools make for students with disabilities are listed below.

Support

- Check for understanding
- Instructions/directions repeated/rephrased
- Present one task at a time
- Preferential/assigned seating
- Use of assignment notebook or planner
- Provide with progress reports
- Supervision during unstructured time
- Cues/prompts rules/procedures
- Offer choices
- Note taking assistance
- Access to computer on campus
- Use of scribe/note taker
- Use of a calculator
- Peer tutor/staff assistance with assignments
- Behavior Support Plan (BSP)
- Home/job/school communication
- Reminder to take medications
- Medication taken under supervision

Accommodations

“lighten” the work load.

Modifications

change what is being taught (curriculum) and expected of student.

Supplementary Aids

- Specialized equipment
- Planning time for staff collaboration
- Staff training

Responses to Materials & Instruction

- Reduced/shortened tests/assignments
- Extended time on tests/assignments

- Use of notes/open book for tests/assignments
- Spelling errors not counted

Settings

- Access to study carrel for tasks/assignments/tests
- Free from visual distractions
- Quiet environment
- Small group environment

Presentation of Materials & Instructions

- Audio books
- Assignments/tests modified
- Large print
- Closed caption
- Manipulative/study aids
- Test questions/assignments given orally
- Test questions/assignments rephrased
- Tests/assignments read orally
- Tests/assignments shortened
- Tests/assignments given in smaller parts
- Preview of tests/assignments

Getting Ready for the IEP Meeting

1. Practice with your parents or teacher about what you want to say. Things for you to talk about at the meeting:
 - Describe your disability and how it affects your learning,
 - Talk about your strengths and needs,
 - Describe how you learn best and what gets in the way of your learning,
 - Tell team members the accommodations you need and why,
 - List your educational goals and talk about your plans for the future.
2. Talk to your special education teacher or regular education teacher about setting a time, date, and place for the IEP meeting. Make a list of who should be there.
3. Once the meeting is set, send everyone on your list an invitation:
Please come to my IEP meeting and share your ideas.
Date: Wednesday, October 2, 2012
Time: 2:30 p.m.

Place: Meeting Room 4

If you cannot attend this meeting, please let me know when we can meet to talk about my IEP. Thank you.

Signed, Your name

At the IEP Meeting

- Make sure everyone knows each other. You may introduce them or have them introduce themselves when the meeting starts.
- Speak up and maintain good eye contact.
- Talk about the things you practiced (see above):
- Ask for additional suggestions and comments on your IEP content. Be sure everyone has a chance to talk and share their ideas.
- Listen to ideas and suggestions from the other IEP team members. If you don't understand something, ask for an explanation.
- Share your feelings about the goals and objectives the other team member suggest. Try to come to agreement about what goals and objectives are important to list in your IEP. (If you cannot finish in the time you have, set a time and date for another meeting.)
- Write down (or have someone else write down) everything that's been decided, so that a final IEP can be written.
- When the meeting is over, thank everyone for attending.
- Get a copy of the IEP for your records.

After the IEP Meeting

- Go over your copy of the IEP and make sure you understand what it says.
- Keep this copy of the IEP, so you can look over it whenever you need to.
- Work to accomplish the goals in your IEP.
- Review your IEP throughout the year. If anything needs to be changed for example, you've met goals in a class and want to write new goals, or you need more help with a subject ask your special education teacher, your regular education teacher, or your parents to help you schedule another IEP meeting.

Person-Centered Planning (PCP) (Excerpted from www.pacer.org)

In Person-Centered Planning, groups of people focus on an individual and that person's vision of what they would like to do in the future. This "person-centered" team meets to identify opportunities for the focus person to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed to achieve these goals. Person-Centered Planning depends on the commitment of a team of individuals who care about the focus person. These individuals take action to make sure that the strategies discussed in planning meetings are implemented.

In a nutshell, Person-Centered Planning assists in identifying what is important **to the individual** whereas assessments identify what is important **for the individual**. Support plans that include what is important to the individual have a far better chance of success than supports plans that just include what is important for the individual.

Purpose

- * To look at an individual in a different way.
- * To assist the focus person in gaining control over their own life.
- * To increase opportunities for participation in the community.
- * To recognize individual desires, interests, and dreams.
- * Through team effort, develop a plan to turn dreams into reality.

Who is involved in Person-Centered Planning?

The focus person and whoever **they** would like can be involved. It is best when there is a facilitator and a person to record what is being shared. The facilitator should be a person that is neutral and unbiased, leads the group through the process, handles conflict and assures equal opportunity for all to participate. Others that may be included are parents/guardians, other family members, friends, professionals, and anyone else who has a personal interest in the person.

Where is Person-Centered Planning done?

At focus person's home or somewhere comfortable, informal and hospitable.

When should Person-Centered Planning take place?

Any time in a person's life. It is best done before transition services are decided. Person-Centered Planning can be a useful tool to develop the transition plan.

Tools needed for Person-Centered Planning

A flip chart or large pieces of paper to record the information shared. Several different colored markers.

The Steps of Person-Centered Planning

Develop a history or personal life story of the focus person. This is accomplished by everyone sharing past events in the person's life. The focus person's parents and family may share the largest amount of this information. Things such as background, critical events, medical issues, major developments, important relationships, etc., may be shared.

Description of the quality of the focus person's life is shared next. This may be accomplished by exploring the following: Community participation, community presence, choices/rights, respect and competence.

Personal preferences of the focus person. Things the focus person enjoys doing. Also including the things that are undesirable to the person.

The meeting to develop the personal profile usually occurs before the planning meeting so the participants have time to reflect on what is shared. The meeting, which takes about two hours, may use graphic symbols in place of words to help stimulate creativity and encourage participation.

- Here are some sample questions that might be used to create the personal profile:
 - Dreams: What are your hopes and dreams for the future?
 - Fears: What will stand in the way of what you want?
 - Abilities: What are your strengths, gifts, talents, likes, dislikes and skills?
 - Needs: What is needed to make your dreams come true?
 - What leads to success?
 - What helps you do a good job?

The Next Step...the planning meeting

- Reviewing the personal profile. The group at this point has the opportunity to make additional comments and observations.
- Review trends in the environment. Identify ongoing events that are likely to affect the focus person's life.
- Share visions for the future. Through brainstorming participants are challenged to imagine ways to increase opportunities.
- Identify obstacles and opportunities. Things that make the vision a reality.
- Identify strategies. Action steps for implementing the visions.
- Getting started. Identifying action steps that can be completed within a short time.
- Identify the need for service delivery to be more responsive to individual needs.

For a plan to be successful it is best if:

- The people have a clear and shared appreciation of the talents and capacities of the focus person.
- People have a common understanding of what the focus person wants.
- The group involved agree to meet regularly to review activities.
- The group include a strong advocate or family member assuring that the interest of the focus person is being met.
- That the group include a person committed to making connection to the local community.

This is the beginning of a process that continues throughout a lifetime. Not a product.

The Person-Centered Plan workbook called “It’s My Choice” can be found at https://mn.gov/mnddc/extra/publications/choice/Its_My_Choice.pdf.

Person-Centered Toolbox – Center for Community Inclusion.
<https://ccids.umaine.edu/resource/section-five-person-centered-planning-toolbox/>

Questions to Ask When Visiting A Day or Supported Employment Program

Program Name: _____

Address: _____ Phone: _____

Contact Person/Director: _____

Does the program offer: (Describe each)

- Community integrated activities:
- Site-based activities:
- Employment training:
- Paid employment:
- Support for participants who have various levels of developmental disabilities:
- Activities during the day with enhance independent living skills:
- Other:

1. What communities does the program serve?
2. How long has the program been in business?
3. Are there other sites?
4. Ratio of participants to staff?
5. Qualifications/experience of director/manager?
6. How is new staff trained?
7. Is there ongoing staff training?
8. Does the program provide transportation?
9. Average age of program participants?
10. How many current program participants?

11. How does the program communicate with parents/caregivers?
12. Is the program completely accessible?
13. Do all staff know how to communicate with non-verbal participants?
14. What self-care abilities are required of the participants?
15. Does the program administer medications during program hours?
16. How is medication administration documented?
17. What medication documentation does the program need from the doctor?
18. Does the program collect money for activities?
19. If yes, how will money be accounted for?
20. How are the participants grouped together?
21. What are the attendance requirements?
22. What are the program's hours?
23. If this is an employment program, what are the employer's expectations?
24. What behavior interventions are used?
25. How are participants' rights taught and built into the program?

6. Please tell me about the staff people who would help me?

7. Can I pick the staff person I want to work with me?

8. Who would I call if I need help at night or on the weekend?

9. Have you ever stopped someone's support services? Why?

10. What do you expect from me or my family?

11. How many other people does your agency support?

12. Can you give me the names and phone numbers of other people you have supported so I can speak to them?

13. If I choose, will my family and friends be able to come and go in my house whenever I want them to?

After you talk to the agency, ask yourself these questions. This may help you to decide which agency is best for you.

What did you like about the agency?

What did you dislike or feel worried about?

Do you have other questions you would like to ask them? If so, you can write them here:

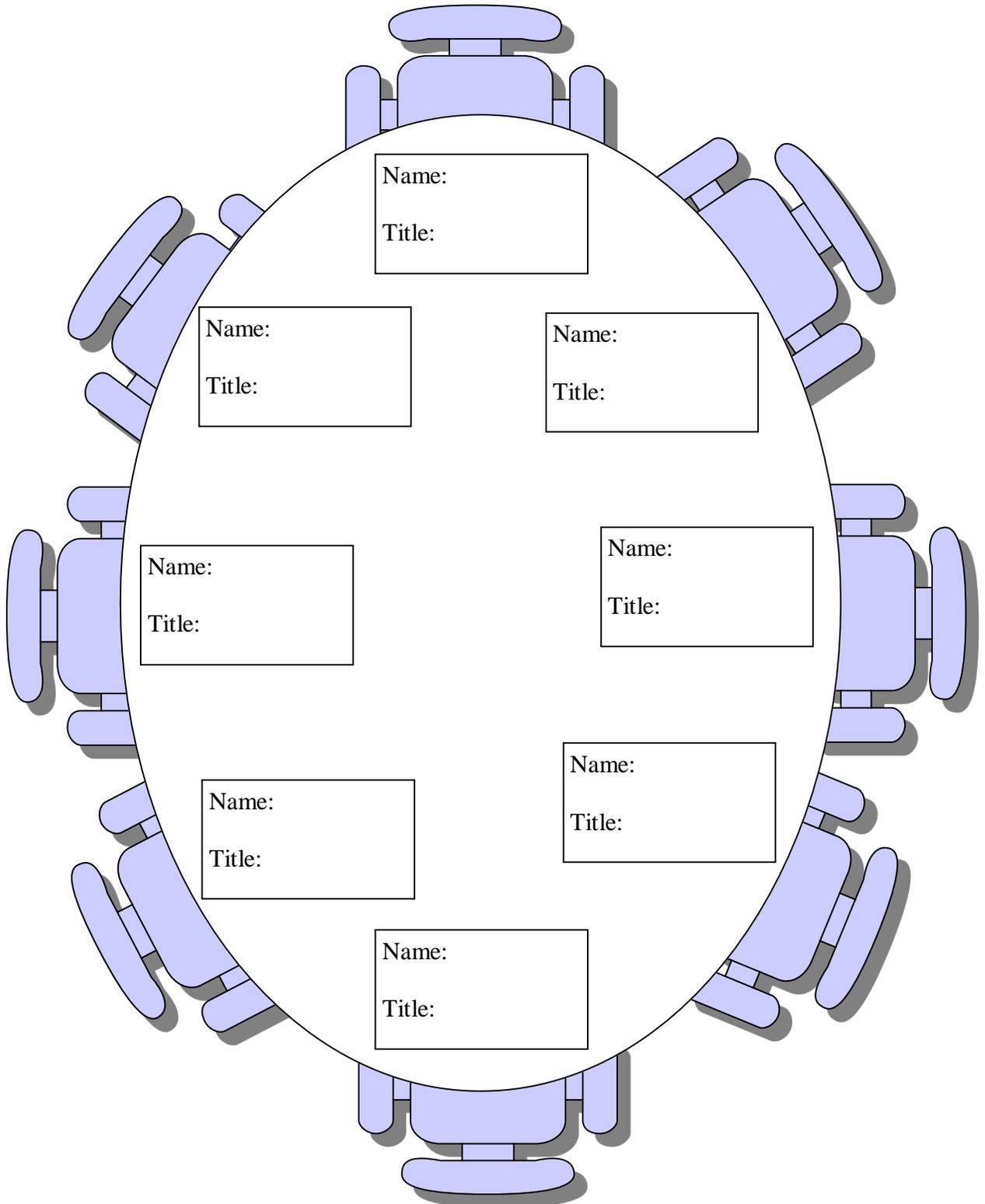
My Circle of Support

My Family Members	
Name	Phone Number
My Friends	
Name	Phone Number
My Service Partners	
Name	Phone Number
My Doctors/Dentist	
Name	Phone Number
Other Support People	
Name	Phone Number

Meeting Participants

Topic: _____ Date: _____

Location: _____



Name: _____
Title: _____

WarmLine Family Resource Center

2424 Castro Way, Sacramento, CA 95818

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