



Asking for Directions: Frequently Asked Questions

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- Individuals with Developmental Disabilities
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- Moving
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- ICF

“The one who asks questions doesn’t lose his way.”

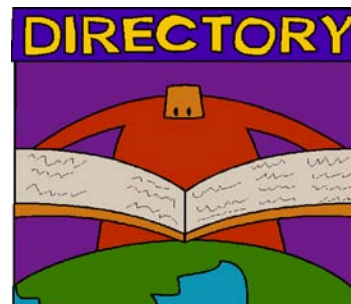
African Proverb

9. I've heard of the Medicaid Waiver, and don't understand what I'm waiving.

Answer You are choosing (or waiving) to not receive services in an intermediate care facility for the developmentally disabled. Instead you are choosing to receive them in your family home, in your own home, in a group home, in a foster home or in a residential rehabilitation center.

10. How do we know if our children are eligible for the Medicaid Waiver now?

Answer The best thing to do is to contact your Medicaid Eligibility office. They will be able to give you the most current information about eligibility. You can find the telephone number in the Statewide Telephone Directory in Chapter 10.



11. I live in an ICF and keep hearing the term "support plan" but don't understand. Do I have one?

Answer Support plan and habilitation (or hab) plan are the same. Both should include all of the supports and services that an individual needs. (Needs must meet the definition found in the section medical necessity.) You should always receive a copy of your support plan or hab plan. If it does not include all of your needs, you have the right to question why. Your legal options are explained in the "Due Process Rights" section of the Handbook, which is contained in Chapter 1 of this Notebook.

When you are on the one of the waivers, you also may receive a copy of your cost plan. Following the submission of your support plan to the district, a cost plan is approved based on the waiver services requested. By getting a copy of that, you will clearly see the money that the state has approved to pay each of your providers for the supports and services you are receiving.

12. How do we make sure there is "choice"?

Answer This is a very broad question. It may help to review the questions and answers in this section related to choice. Having a "choice" or say in a matter usually depends on the particular matter. Review the material in this notebook that explains the legal rights of persons with developmental disabilities in Florida in Chapter 7. After that, if you still believe that someone's rights are being violated, follow the process explained in the section titled "Follow the Line of Authority" in the Handbook contained in Chapter 1 of this notebook.

13. How much can the Guardian Advocate expect the Support Coordinator to do? I.e. how should the Guardian know what phone calls and various ser-

vices the Support Coordinator is supposed to arrange and which ones the Guardian is supposed to?

Answer Regardless of whether you are the parent of a minor child or the guardian/guardian advocate for an adult receiving services, the Support Coordinator should assist with the completion of a support plan/cost plan as well as coordinate and monitor all supports and services paid for through the Agency for Persons with Disabilities (APD). Support coordination is more fully discussed in Chapter 3 of this Notebook and in the catalogs, videos and DVD (part 2). Hopefully this information will help you to more clearly understand the support coordinators function.

Additionally, you might consider making a list of duties that you are unclear about and review this with the support coordinator for the person you both serve, and divvy up the functions. If you feel that he is not willing to do as many tasks as you feel he should, you should discuss your expectation and see if a compromise can be reached.

As a last resort, you could hire another support coordinator by contacting your district office. If you get to this point, you should be sure to go over your expectations with prospective new support coordinators and discuss that during the interview process.

14. Why is Shelly Brantley of APD against enclave work?

Answer Ms. Brantley is not opposed to enclaves. She is committed to assisting every person with disabilities to find and keep a job, if that is his or her desire. Jobs come in many forms and enclave work is one type of job. However, Ms. Brantley has asked her staff to work in partnership with Vocational Rehabilitation so that people desiring to work can access this resource, if needed. She believes that every person who wants to work in his or her community has the right to do so, and should be given the supports needed to be successful. Studies have shown people want to be employed, and she is encouraging providers to step forward and help with this initiative.

Enclaves have generally not led to as many positive outcomes in an individuals life. It is harder to make friends outside the enclave and people are still usually treated as a group rather than as an individual. While enclaves are an option and lead to improved outcomes compared to some other day services, it is the responsibility of APD to let people know about the outcomes of each service so they can truly make an informed choice on where to work.

15. What is the substitute staff policy of licensed group homes? I.e. how are homes monitored to assure that if staff are sick or have quit, that there is an adequate number on hand to meet the needs of the clients?

Answer Licensure requirements for group homes are addressed in 65B-6.010 of the Florida Administrative Code. The number of staff needed for each home de-

depends on the number of residents, the needs of the residents and the competency of the staff. However, each homes licensure agreement specifies required staffing patterns. Regulations do not address substitute staff, but rather how many staff should be present. As families, friends and waiver support coordinators visit with residents, they observe the number of staff present and the interaction of the staff with residents. If you have a concern, you should report it to the district.

In terms of monitoring, APD staff visits each group home in their district at least once a month. Those reviewers check each home to ensure that staffing and other licensure requirements are sufficient to ensure the health, safety and welfare of the residents. Additionally, an independent contractor, (Delmarva) conducts provider performance reviews on a regular basis. [Additional information about Delmarva can be found in Chapter 5: Quality Services in your Yellow Notebook.

Asking these types of questions of each potential new provider, as well as visiting and talking with residents/families, can be very valuable during the decision-making process.

16. Why has my child been on a waiting list for four years?

Answer Assuring that individuals with developmental disabilities are adequately served as well as serving individuals on the waitlist continues to be one of the Governors top priorities. Each year, the number of individuals who can be added to the waiver is contingent upon the funding authorized by the Florida Legislature. Under the leadership of Governor Bush, legislative appropriations available for this program have increased every year during his administration but it is important to point out that those individuals who have been eligible for the waiver, and have been waiting the longest time, will be served first.

I encourage you to contact your locate APD office in order to determine your child's current position on the waiting list, as well as to explore services in your community, as well as within your school, if your child is in school.

17. Who is responsible for getting notebooks to people?

Answer If a consumer applies for crisis services and is approved, or has been transitioned off the waiting list in the last year or receives only General Revenue funded services, their area offices social worker/support coordinator is responsible. If a consumer is receiving services through the Home and Community based Services waiver (HCBS) their waiver support coordinator is responsible and should also provide updates annually. If a consumer is receiving services through the Consumer Directed Care Plus waiver (CDC+) or Florida Freedom Initiative pilot (FFI) their consultant is responsible and should also provide updates annually. If a consumer is receiving services through and lives in a private or public intermediate care facility (ICF or DSI), the facility administrator or social worker is responsible and should also provide updates.

18. How can we get better notification of meetings such as this?

Answer Network with other families. Attend the Family Care Council meetings in your area. (Contact information for the council in your area can be found in Chapter 10 of the Yellow Notebook.) Become a recipient of the Agency for Persons with Disabilities eBulletin (www.apd.myflorida). Join the Florida Developmental Disabilities Councils mailing list (www.fddc.org). The more networking you do with others, the more knowledge you'll gain.

19. What will happen to individuals with major behavioral issues?

Answer In order for persons to have each of their needs met, they must be certain that their support coordinator is aware of all needs. If behavioral services are needed, be certain to document the situation(s) clearly and involve a behavioral analyst. If you are transitioning from a DSI, be certain to also talk with the transition manager or social worker. The analyst will be able to provide the necessary information for the persons needs to be met. (You may want to re-read about behavioral analysis services in Chapter 3: Service Stations: Waiver Services and Supports.) Regardless of the level of need (from minor reinforcements by family, friends and staff to the need for a specialized behavioral residence) each consumers needs will be met in the most appropriate manner available.

20. How difficult is it to become licensed as a group home? I have heard that they (the State) are not licensing new facilities.

Answer There are several resources available on the Internet that offer a great deal of information on this subject. First, go to the following site: <http://Fac.dos.state.fl.us/> to access Chapter 65B-6 of the Florida Administrative Code, which outlines the requirements for the licensure of residential facilities. You may also wish to review Chapter 393.067 of the Florida Statutes via the link: http://www.flsenate.gov/Statutes/index.cfm?App_Mode=Display_Statute&Search_String=&URL-Ch0393/SEC067.HTM&Title=->2002->Ch0393->Section%2015.

I also recommend that you access the Developmental Services Waiver Coverage and Limitations handbook, available at the following site: <http://floridamedicaid.acs-inc.com>. The handbook is a reference guide to the services that may be purchased for individuals eligible for the Developmental Services Home and Community Based Services waiver. The handbook describes consumer eligibility an enrollment on the waiver, provider enrollment through the waiver, each service, qualifications required for providers of each service, how services may be delivered, communication requirements, how the provider is paid, and many other important details.

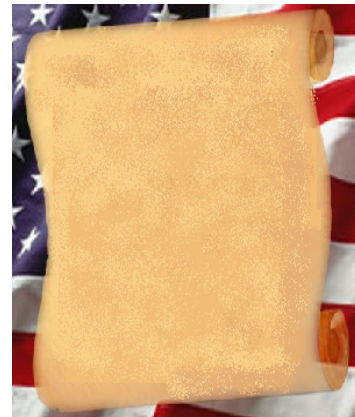
After you have had the opportunity to review this information, you can obtain an application form by contacting the Licensure Coordinator in your district office closest to you. District contact information can be found in Chapter 10 of the Yellow Notebook.

Answer It is best to begin looking at residential alternatives and other service needs before this occurs but a stroke or other illness can happen without warning. When this happens, if the individual is not yet receiving Medicaid waiver services, he or she may be served under the crisis determination. However, it is always less traumatic if major changes in a person's life can be planned for in advance.

In Chapter 2 the information titled "Overview of Residential Options for Consumers of Services from the Agency for Persons with Disabilities," there is information that presents the variety of residential options available to persons with developmental disabilities in Florida. Also, Chapter 1, Planning Ahead, and Chapter 4 have sections that address residential options. Many options exist and your support coordinator or local Agency for Persons with Disabilities office would welcome the opportunity to explain them.

25. Who enforces the Bill of Rights for severely handicapped?

Answer If the person, their legal guardian or parent believes that the rights of someone with a developmental disability have been violated, he may file a complaint with the Agency for Health Care Administration (AHCA) and/or with the Local Advocacy Council (LAC). Contact information for both of these groups are in Chapter 10. To file a complaint with the LAC, call the number noted in the directory. (Remember the area is defined by the county where the individual with a disability resides.) Be sure to ask for a complaint number and ask to be mailed a copy of their findings. Detailed instructions for filing a complaint with AHCA can be found in Chapter 4.



Questions about Guardianship

26. Why do they make it hard to be Guardians?

Answer It can be difficult to become a person's guardian, as well as difficult to perform all of the legal responsibilities of being a guardian or guardian advocate. Since both of these processes require legal assistance and court approval, it may appear cumbersome. However, it is designed for the protection of people's rights. In this case it is the protection of the person who is "alleged" to be unable to perform some legal function. Our legal system requires clear and convincing evidence that a person cannot perform certain functions, prior to taking his or her rights away. Further, the court retains oversight over the person to whom the responsibility has been delegated in order to prevent exploitation, neglect and abuse. It is possible to waive certain reporting requirements and an attorney should be consulted for more information related to this.

27. We were, through a court order in Illinois, named our 48 year old son's legal guardian. We have been told that it is not applicable in Florida, is this true?

Answer Not necessarily. Contact your local probate court staff. They can assist you with the process to follow to have Florida recognize your Illinois order.



28. Do parents have the right to an individual's evaluation?

Answer The major issue here is the age of your child. If your child is under 18 and your parental rights have not been removed, you have that right to a copy. If your son or daughter is over 18 and a court *has not appointed* a guardian or guardian advocate, he or she will need to give permission for you to have a copy.

If you have been appointed guardian or guardian advocate for your son or daughter you may have access to evaluation reports if you have legal authority over that part of his or her life. For example if you have legal authority over your son's health care, you have a right to access medical evaluations (doctor, physical therapist, speech therapist, behavior analyst or occupational therapist, etc.). If you only have legal authority over your son's finances, you do not have an automatic right to his medical evaluations. You must have his permission to receive it. If the evaluation has to do with applying for governmental benefits, you could get the evaluation if you have authority over your son's finances.

If someone other than you has been named your son's guardian you can request a copy of evaluations from the guardian. In other words, knowing what type of evaluation and who has legal authority over that part of the person's life will determine who has a right to those evaluations.

More and more laws are being passed regarding the sharing of confidential information. An excellent resource you might want to reference is the booklet entitled "Planning Ahead." Copies may be available through your local Family Care Council or on the Florida Developmental Disabilities Council website: <http://fddc.org/Services/Catalog.asp>.

Questions about Moving out of State

29. How do I move closer to my dad when there is not a place (ICF/DD) closer to where he lives that is as nice as where I live in now? (I like where I live now.) What services are available in Lebanon, Tennessee?

How would I move to Georgia near my guardian, near my sister in Maryland, or near my grandparents in North Carolina?

How do I make plans to move out of state, what forms need to be completed?

Answer The first step would be to talk with your family members, guardian, or friends and tell that you want to move closer to them. It is very important to have a circle of support or support network in place before you make the final decision to leave your current support system. If you have a strong support system in place in your new location prior to your move, they can help pave the way for your move, and make the transition easier.

The second step would be to contact Florida's Agency for Persons with Disabilities counterpart in the new state to which you want to relocate. That agency's name will vary from state to state. We used a search engine on the Internet called Google.com to search for agencies involved with developmental disabilities in each state. On the www.google.com website, type in "(name of the state) government agencies." You will find the name, address and telephone numbers for that state's agency serving people with developmental disabilities.

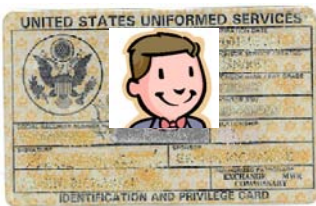


It is important to understand that availability of services varies from state to state. Some services available in Florida may or may not be available in another state. However, another state may offer services that are not available in Florida. Services do not necessarily transfer with you when you leave Florida. All of this should be carefully considered when making your decisions.

Questions about Military Identification Cards

30. How can I get a new Military I.D. card? (Dependent had one under her father but her father passed away and guardian is on active duty)

Answer Since the Agency for Persons with Disabilities does not handle the issuing of military I.D. cards, and we did not know from the question in which branch of the service the guardian serves, we called the Tallahassee Air Force recruiting office. The recruiting officer explained, "If your legal guardian is on active duty, he or she would need to make sure that his or her records have been updated through the Customer Service Unit at the base. Customer Service may then issue a document to your guardian, which must be presented at the time you go to a military base or unit to get your new I.D. (You may go to any military base or reserve unit to get the I.D., regardless of the branch of service to which your guardian belongs. You must have the correct documents and a government issued photo I.D, such as a driver's license or Identification card. Your guardian does



not need to be present.”)

Questions about ICF's

31. What is a public/private ICF?

Answer ICF's can be owned by the State of Florida or by private corporations. Public ICF's are the ones that are owned by the State of Florida, the staff are state employees and they are also known as developmental services institutions. In the last several years all state-owned institutions have become licensed (by the Agency for Health Care Administration) as intermediate care facilities (ICF) and are monitored as such except for the forensic units. Names of these facilities include Gulf Coast Center, Tacachale and Sunland Marianna. All of these facilities have quite large campuses and serve a total of approximately 1100 residents.

Private ICF's are owned and staffed by private companies. They too are licensed and monitored as ICF's by the Agency for Health Care Administration. There are around 90 private ICF's located around the state and they serve between 6 and 64 people each. There is one private ICF that serves 120 people. See Chapters 3 (Service Stations: Waiver Services and Supports) and Chapter 4 (Service Stations: ICF Services and Supports) for more information. Many people do not understand that a private and a public ICF are exactly alike in terms of the types of services they provide and the people they are appropriate to serve.

32. If we are in an ICF, how long do we have to use Medicaid Waiver money—indefinitely or time limited?

Answer Medicaid waiver funding is not used by people who live in an ICF. ICF funding is separate from Medicaid waiver funding. However, both levels of funding are determined annually by the Legislature.

33. Who can help me develop my HAB plan?

Answer Certainly your guardian or family should assist. If for some reason they cannot or you do not have either, you can designate a client advocate and he or she will assist. (Information about appointing a client advocate can be found in Chapter 8.) Let the administrator where you live know that you would like assistance and ask that they help you contact whomever you want to involve.

34. Who does Personal Outcome Measures in the ICF? Has not had one in 1.5 years, at least.

Answer Personal Outcome Measures (POM) are no longer being performed in ICFs. They were only done one time, in 1997, in anticipation of the closing of the ICFs. The intention was to have a base line POM prior to ICF residents moving into the community, and then they were to be done again after the person was settled

in the community. Since the ICFs were not closed, the system or structure was not in place to continue them. There are no plans at this time to reinstate the POM process into ICFs.

35. Will the assessment tool replacing Florida Status Tracking Survey (FSTS) be used in the Intermediate Care Facilities (ICF's)?

Answer No. The Individual Cost Guidelines tool is designed to predict an individual's costs for services on the Medicaid waivers, not for the assessment of needs. The FSTS will continue to be used for persons living in ICFs. However, if an ICF resident requests to move out into the community, at that time an Individual Cost Guidelines tool will be completed.

36. If I live in an Intermediate Care Facility (ICF), am I able to receive services from a doctor of my choice as opposed to having to use the services of the doctor chosen by the ICF/DD? If yes, what process should I follow in order to do so and who is responsible for the payment?

If I live in an ICF, am I able to receive dental services from a dentist of my choice as opposed to having to use the dentist chosen by the ICF/DD? If yes, what process should I follow in order to do so?

Is behavior analysis (an independent one) available in ICF's?

Answer Every resident of an ICF can request to be seen by a licensed practitioner of his or her choosing, whether it is a doctor, dentist, behavior analyst, speech therapist, etc. The ICF is required to work with each resident or guardian to accommodate the resident's request.

The process you would follow is to first request to be served by a different practitioner (doctor, dentist, behavior analyst, etc.) than the one the facility currently uses. If you have a particular one in mind, ask that he or she be contacted. If the facility is unable to obtain the services of the person you requested, they should check with some others and get back to you with alternatives. There should be some written documentation of their efforts and the reasons why they could and/or could not honor your request.



Who pays for the services depends on the services you need and the practitioner. Either the facility where you live will pay the practitioner or Medicaid will reimburse him or her.

37. To whom is the physician who sees patients in the ICF accountable?

Answer Every resident of an ICF can request to be seen by a doctor of his choosing. The ICF is required to work with each resident and his guardian to accommodate the resident's request. Ultimately, the physician should be working in the best interest of her patient and be accountable to him.

38. If I live in an ICF and I have been diagnosed as needing a particular therapy, am I able to receive services from a therapist of my choice as opposed to having to use the services of the therapist chosen by the ICF/DD? If yes, what process should I follow in order to do so and who pays?

Answer As long as the therapy is covered by Medicaid, this question is like the previous one and again involves the resident's rights. Specific federal regulations regarding ICF client rights are included on the two next pages.

The same process as above should be followed. Request to be served by a different therapist than the one the facility currently provides. If the facility is unable to obtain that therapist (or one other than the one currently providing services), there should be some written documentation of their efforts and the outcome.

Who pays for the services, again depends on what services you need and the therapist. Either the facility where you live will pay the doctor or Medicaid will reimburse the doctor.

39. My son (who has autism) likes to spend the weekend with us once he gets home. However, he physically resists getting in the car, and the staff feels that they cannot legally make him get in the car. Can a plan be developed to help overcome his fear without violating his rights? We are his legal Guardians.

Answer You and your son should identify all of his needs, goals and objectives in his Habilitation Plan: identify his visits with you on weekends as one of his goals. Objectives should focus on overcoming his resistance to getting into the car to go home. These objectives could then be placed into the Plan so the ICF staff can work on those objectives. Maybe a behavior analyst can provide some guidance to everyone (your son, you and the staff). If the staff does not adhere to the Habilitation Plan, you should discuss your issues with the ICF administrator.



As a last resort, and if the situation is still not corrected, you may file a complaint. Detailed instructions for filing the complaint can be found in Chapter 4 of this notebook.

40. Why doesn't the parent or guardian have more say in the child's medical care and diet? The parents feel like they have no say.

Answer It is critical that all medical and dietary issues are addressed in a resident's HAB Plan. The HAB Plan must be done annually, but should be updated if situations change. The ICF staff must work with the resident's parent or legal guardian to provide the appropriate medical care and diet that the resident needs.

If the ICF staff recommends a certain medical procedure or diet, the resident or her legal guardian have the right to request an evaluation by a specialist (i.e., doctor, speech therapist, occupational therapist, physical therapist, etc.). The evaluation will help determine whether the recommended procedure or diet is necessary and in the best interest of the resident. The resident or legal guardian then has the right to accept or reject the findings of the specialist.

If you have tried all the avenues and still have problems, you can always make a complaint to the licensure agency. Information on how to do this can be found in this notebook in Chapter 4.

41. For clients still involved with the public school system, can the support coordinator help assure appropriate services are received there also?

Answer It is the responsibility of the Exceptional Student Education (ESE) coordinators, employed by local school district, to ensure that the arrays of educational and related services are secured for students. However, some support coordinators are quite knowledgeable regarding the educational delivery system and may accompany parents to Individual Education Plan (IEP) meetings. If this is something important to you, you should consider raising this issue during your interviews with potential support coordinators.

Additionally, there are parents who work for the Family Network on Disabilities (FND)



that can offer advice and support in this area. For a local contact person representing that organization, please visit their website at <http://fndfl.org/> or call their toll free number 1.800.825.5736. Ask about the Parent Education Network (PEN). Also you could share this information with your support coordinator so that she may be better prepared to help other families in the educational arena.

42. Medical and diet decisions are forced on clients against guardian's wishes—how can this be done?

Answer If a resident has particular dietary needs recommended by a dietician or physician, the ICF should be following them. Make certain that these are a part of the person's Habilitation Plan, since this is the document that details each person's services.

If you are merely saying that the resident does not like the menu that is being served, we recommend you talk with the Administrator about this issue. However, please realize that all people have different likes and dislikes. The more people you are trying to please, the more difficult it is to please everyone all the time. But your preferences should be considered and probably will be.

43. Why are the Bill of Rights for severely handicapped not followed or incorporated into relationship (when making medical decisions) with the guardian for a child who can't speak for oneself?

Answer Staff of the ICF must respect the wishes of the legal parent or guardian (guardian advocate) of the child (or adult). Issues related to daily care and medical decisions must be discussed with the individual who has legal authority for the person. Discuss your concerns with the Administrator so that your issues can be addressed and corrected.

44. "Age appropriate" items have been taken away from my adult child, who is a resident of a private ICF. What can I do?

Answer We again suggest that you talk with the ICF's administrator. You may want to take a copy of the Code of Federal Regulations, Title 42, Chapter IV (provided with the Questions and Answers from 01/02 and also available on line at www.dcf.state.fl.us/ddp/publications/choice_counseling_v3/Answers_to_01_02_session_questions.pdf. Specifically I would talk about 483.420 a) 12) which addresses personal possessions. And if that does not work, follow the process explained in Chapter 4 of this notebook.

45. Does the staff of the ICF attend the Yellow Notebook Training?

Answer The staff of the ICF only receive training if they attend a session. These materials and information sharing sessions are designed for individuals served by the Agency for Persons with Disabilities, as well as their guardians and families to help them understand their options. We support self-determination and believe individuals with disabilities should be making decisions about their life and living situations.



46. How can more people know about the Yellow Notebook Information Sessions?

Answer Every legal representative and/or family member of an individual residing in an ICF receives a letter before each session. Suggestions about how to increase knowledge are welcomed.

47. How do we hold the staff accountable?

Answer This is a very broad question so a specific answer is difficult to provide. However, if you are having difficulty with staff accountability, we suggest bringing the situation to the attention of the ICF's administrator. Perhaps you could ask to review their policies on accountability. If that does not work, follow the process explained in Chapter 4 of this notebook.

48. A Hab. Plan has not been done on my child for some time and my child's abilities are regressing. What can I do?

Answer A Hab. Plan is supposed to be developed annually for each resident of an ICF to identify his or her specific service/support needs. If one is not being developed annually, we suggest you first bring this to the attention of the ICF's administrator. If that does not improve the situation, follow the process explained in Chapter 4 of this notebook. Also, when developing the annual plan, review previous goals and accomplishments. It is a good idea to review the plan at least quarterly.

49. If dental or other services are not being provided, but are supposed to be, is this a Delmarva or ICFs' responsibility?

Answer They are the responsibility of the ICF and you should first make certain that dental needs are included on the person's Hab. Plan. If the needs are on the Hab. Plan and are not being addressed, we suggest you first bring this to the attention of the ICF's administrator. If that does not improve the situation, follow the process explained in Chapter 4 of this notebook (Filing a Complaint).

50. How do we get more help with job training and goals?

Answer Your needs, goals, objectives, etc. must be on your Habilitation Plan. The ICF staff would then follow your Habilitation Plan. If not, you should talk with the ICF administrator. If the situation is not corrected, you may file a complaint. Detailed instructions for filing the complaint can be found in Chapter 4 of this notebook.

Be sure to review your plan quarterly.



51. Were the clients of Sunland guaranteed a place to reside for their lifetimes?

Answer People who were residents of Sunland Orlando on and after October 1, 1982 were guaranteed certain services for the rest of their life. They were not guaranteed

residency in Sunland. These services may be obtained at any ICF in Florida, public or private. The services may also be obtained in the community, should the person, along with his or her parent or legal guardian, decide that it would be better for the resident to leave the ICF and move into the community.

52. Are private or public intermediate care facilities (ICF's) going to be closed?

Answer The Agency for Persons with Disabilities has no intention of closing any types of residential options that consumers need and choose. However, the great majority of people who receive services prefer to do so within their home community. This trend is not unique to Florida, but is occurring in the majority of other states, too. Because of our system of government in Florida, the APD is directly dependent on the Legislature to provide sufficient funding to meet the needs of Floridians with developmental disabilities. During the administration of Governor Jeb Bush, the Legislature, the Governor, and the Agency for Persons with Disabilities have been partners in working to assure the health, safety and well-being of all persons with developmental disabilities. As a matter of fact APD's primary mission is support persons with developmental disabilities in living, learning and working, in all aspects of community life.

We do realize that there are residents of public ICFs that are interested in moving. In order to meet that need, APD has developed meetings entitled Bridges to Opportunity. These meetings are taking place to educate residents and their family, legal representatives and friends about what options are available to residents who are leaving the institutions and will be residing in the community. If you have any questions please call the specific DSI directly for clarification. Additional information can also be found on APD's website.

53. Why are they closing Gulf Coast Center?

Answer Since 1971 people living in Florida's public institutions has dropped from 6,045 to approximately 1,200. The closure of Gulf Coast Center is one part of the proposed Brown vs. Bush settlement agreement, which is a consumer-driven trend toward people with disabilities being able to live in their community (regardless of disability or medical condition). Gulf Coast Center is slated to phase down beginning July 2005 and will close by July 1, 2010.

Additionally, the Florida Legislature has directed the Agency to assist people to move out of unnecessary institutionalization. Statistical data shows that most people, who live in the community, achieve a higher quality of life. On an average people with disabilities who live in their community have more friends, spend greater time with their family and participate more in their community. The Agency's commitment to the residents of the Gulf Coast Center is: (1) to provide information about all residential options available, (2) to assist residents (and their family and friends) to explore and visit as many various options as possible, and (3) to assist residents to move to the one that most appropriately meets his/her needs so as to achieve a quality of life that is as good or better than what has been experienced at Gulf Coast Center.

Regardless of where a Gulf Coast resident decides to move, the transition will be smoothest for people who have the support and involvement of a strong team (their family, friends and Gulf Coast staff).

54. What type facility are they being sent to?

Answer No one will be sent anywhere.

APD wants the person and his/her family to decide what residential option will work best for them. Gulf Coast staff will be working with each resident (and his/her family, if they so choose) to assist him/her to choose. The Yellow Notebook materials are a key piece of this process, since they provide objective information about all of the various residential options. For more information, see Chapter 3: Service Stations: Waiver Services and Supports and Chapter 4: Service Stations: ICF Services and Supports.

Once the type of living setting is identified, the team can focus on what area of the state is best. It is APD's sincere desire that this re-location be as smooth as possible, which requires all stakeholders to work together. We hope the Yellow Notebook helps.

As in many of the previous answers, we strongly encourage visiting as many places as you can and talking with potential provider staff and residents.

55. What is the difference in the level of activities at group homes and at ICFs?

Answer Each ICF and each group home varies according to the levels of need of the residents and their interests. Generally, people with more significant behavioral involvement or medical involvement live in ICFs. Therefore, due to their condition, would more than likely not be so active in their community as persons living in group homes. When considering either of these residential options, again we recommend visiting the specific facility or home so that you can question the staff, residents and/or observe what their usual routine is.

56. What are the plans to emotionally prepare the residents of Gulf Coast Center for transitioning to a new residence?

Answer There is a process that each resident will go through to prepare for this move. It includes being provided information about options, visits to different locations that provide different service options, counseling, etc. Residents will participate in the daily activities of their new chosen residence during day visits prior to their actual move date. Additionally, a Transition Manager from Gulf Coast Center will be following each resident for at least 30 days after the resident moves to the new location for support and assistance.

If residents would like to move together to a new location, that option will be accommodated to the extent possible. When Landmark closed some staff moved with consumers and staffed their new residence, when all parties were in agreement. I'm sure that Gulf Coast will help with this option as well.

Regardless of where a Gulf Coast resident decides to move, the transition will be smoothest for people who have the support and involvement of their family and friends. Thank you for beginning that increased involvement by attending the Yellow Notebook group session and hearing how this resource can assist during this transition time.

57. For those of us who have loved ones at Gulf Coast, are there other people who have been through this that we could talk to in order to find out what the experience was like and to perhaps to get advice from?

Answer Due to confidentiality requirements, we are unable to provide the names of consumers or their families who have been through this process. However, I recommend that you get in touch with the Family Care Council in your area. Contact information for each area office is located in Chapter 10 of the Yellow Notebook. Members of this organization are either consumers or families/guardians of consumers and more than likely; some of those individuals may have experienced major life changes such as yours.

Additionally I would recommend that you network with other consumers, or parents and siblings of persons residing at Gulf Coast so that you and they can support each other.

Lastly, Gulf Coast staff will be supporting each resident and their family through this process. They will be sharing information and resources that have proven helpful to Landmark residents and their families as they transitioned. There will be individual meetings, as well as group meetings held that are designed to assist everyone through this process. If you have not heard about these meetings by now, please call David Phelps at (239) 690-3653.

58. How would I find a place similar to Gulf Coast?

Answer The first and most critical component is to list the services and supports that are needed by your family member that are provided by Gulf Coast. Secondly, use the Yellow Notebook or video/DVD to review the various residential options. (Specific locations for this information have been noted in several of the previous questions.)

Thirdly, talk with your family member about these options, using the Yellow Notebook as a guide. Next, meet with a Gulf Coast transition specialist to discuss your expectations. Finally, visit places that match the criteria you first developed, network with other families and talk with potential provider staff and residents. By following these steps, you are more likely to find a place that your family member and you like as much as Gulf Coast.

59. Do the waiver wait list numbers include the slots that will be needed to relocate the Gulf Coast residents?

Answer No. The waiver wait list does not include Gulf Coast residents intending to transition into less restrictive community settings. The Agency has received separate funding from the Florida Legislature to enroll a specified number of individuals directly onto the waiver. Individuals moving from Gulf Coast will receive services on the waiver immediately upon leaving.

60. What is the staff to client ratio in group homes as opposed to Gulf Coast Center?

Answer Group homes can vary in size from 4 residents to 14 residents while most of the dwelling units utilized by Gulf Coast's homes have 24 residents each. Residential staffing (for both group homes and Gulf Coast units) will vary according to the specific needs of the individuals living in those homes and will vary from shift to shift. Gulf Coast average 3 residents for every 1 staff during daytime shifts, and 8 residents to 1 staff during sleeping hours. Depending on the level of need of the residents, group home staffing ratios would be typically comparable to the Gulf Coast numbers.

Before deciding upon any type of residence, staffing ratios are an important issue to raise, as well as talking with the existing residents (and their guardians/families) to see if they are pleased with the services their family member is receiving. Licensure standards can also be helpful and are available from each area office. If staff to client ratio is your only consider, do not overlook supported living homes where the staff to client ratio is as low as 3 residents to 1 staff or 2 residents to 1 staff, whenever residents are at home.

61. Is the lawsuit still pending for closing of Gulf Coast?

Answer There is a settlement agreement that has been signed on August 11, 2005 by all parties in the Brown versus Bush lawsuit.

62. How is the transition from Gulf Coast going to be done?

Answer There is a process that each resident will go through to prepare for this move. It includes being provided information about options, visits to different locations that provide different service options, counseling, etc. Residents will participate in the daily activities of their new chosen residence during day visits prior to their actual move date. Additionally, a Transition Manager from Gulf Coast Center will be following each resident for at least 30 days after the resident moves to the new location for support and assistance.

If residents would like to move together to a new location, that option will be accommodated to the extent possible. When Landmark closed, some staff moved with consumers and staffed their new residence, when all parties were in agreement. Gulf Coast staff will help with this option as well.

Regardless of where a Gulf Coast resident decides to move, the transition will be smoothest for people who have the support and involvement of their family and

friends. Thank you for beginning that increased involvement by attending the Yellow Notebook group session and hearing how this resource can assist during this transition time.

63. What area will be first?

Answer As much as possible, the people who are class members of the Brown lawsuit will be the first persons transitioned. Class members are people who have requested to move into the community and who the support team agrees that the move is appropriate. As a person (or his legal representative) expresses an interest in moving, his or her transition manager will work with the resident, their family/friends and the Gulf Coast staff so that the transition will be smooth. As explained in the previous question, Gulf Coast staff is available to accompany residents to visit the various options in the Ft. Myers area. Hopefully families and friends will also visit these options, as well as explore the possibility of their family member moving closer to family.

Class members who reside at one of the other public ICF's will follow a similar process to ensure the smoothest transition possible for them as well.

64. How can a provider get the support from the District to help the family make a placement change from ICF to Med-Waiver when medical issues are involved?

Answer The decision about where to live should be made by the person with that legal authority: either the individual, if no court has determined otherwise (or they have not assigned that right) or another party. Once the party with authority has made the decision that the individual with a disability wants to move out of the ICF, written notification needs to be provided to the district. Please refer to Chapter 8 in this notebook, which explains in detail what needs to be done. Pay particular attention to the appropriate form, which needs to be provided to the District office.

65. How difficult is it to make a change from a private or public ICF and make sure supports and services are in place before the move?

Answer The length of time involved will be directly related to what supports and services you need to be safe, healthy and secure, as well as the availability of providers of those various services. It may take longer than you think it should, but your support coordinator should be able to help you make a list of the things that need to happen and how long each should take, so you can better understand the process. Your safety is the most important factor. No one should move before all their supports and services have been listed on their support plan, the related costs have been approved by the Department or alternative funding is secured, providers of all services have been interviewed and hired, and all of the supports and services are in place.



The length of time it takes each person is different. But, your support coordinator should be able to assist you in determining time frames.

66. What happens if I move from a private or public ICF and I don't like it? Can I come back?

Answer You may choose to move back into a private or public ICF at any time. However, you cannot be guaranteed of being able to go back to the one where you used to live in because there may not be room there anymore. You would be offered as many choices as are available, and if you only wanted to go back to one particular one, you could request to be notified only when a vacancy occurs there.

67. How can someone at Gulf Coast be ready for independent living/group home living if for 20 years that person has not been able to take medication unsupervised, count money, or perform other necessary daily living tasks?

Answer The ability to successfully complete activities of daily living is not a prerequisite to living in the community. Evidence of this fact can be seen within the aging community where older adults hire people to assist them so that they can remain in their home — thereby avoid moving into a more restrictive institutional placement such as a nursing home, or assisted living facility.



People with disabilities are no different in that regard and are able to create similar supports in places where they would like to live but need assistance to do so. See Chapter 3 (Service Stations: Waiver Services and Supports) and Chapter 4 (Service Stations: ICF Services and Supports) for more information.

However, there are two critical pieces that must be completed prior to someone moving from one residential setting to another: (1) accurately match the person's needs with supports and services, as well as (2) not moving until all supports and services are in place. To ensure that these events occur when someone plans to move from a public ICF (like Gulf Coast) into community, APD has developed a procedure for this purpose, which can be found in Chapter 8.

Finally, if at all possible, the resident who is moving from Gulf Coast and his friends and family, should visit as many new residential options as possible and talk with the residents before deciding upon which option to choose.

68. If Tacachale closes, can I be assured that there will be a place closer to me for my brother and will he be cared for and have a good quality of life?

Answer At this point there are no plans to close Tacachale. However, if for some reason that decision were made, APD would work with each resident (and their family) and guardian to find an appropriate alternate residence.

If you are interested in your brother moving closer to you, I recommend talking with him and the staff at Tacachale to see if your brother is interested in moving and if a move would be appropriate. The great majority of our data indicates that when families live close to each other and watch out for each other, the quality of life for each member is better.

69. Will the family bear more of the financial burden associated with his care than they do now?

Answer No. Every person that is served by APD (over the age of 21) is no longer the financial responsibility of his/her family. The great majority of people receiving services from APD also receive assistance from the Social Security Administration, due to their disability. Depending on where they live, a portion of the social security income is set aside (as their personal allowance) to spend on extras (such as a television for bedroom, small gifts at birthdays/holidays, etc). See Chapter 8 for additional information.

70. Where will I find resources to help me provide for him?

Answer APD has various funding sources available (like federal waivers) should someone prefer to live in their community rather than in an ICF. We hope the Yellow Notebook will be a good resource for you about these funding sources and the variety of services that are available to meet your brother's needs.

Additionally there are other resources available (outside of APD) if someone is interested in getting a job, buying a home, etc. When someone chooses to be on a waiver, and needs assistance identifying resources, he could request support coordination services, that would assist in identifying additional resources both within APD and within his/her community, county, and state. Support coordination is explained more in depth in Chapter 3: Service Stations: Waiver Services and Supports.

Another way to find out about additional resources is through networking with other families. Contact your local FCC to find additional information about resources.

71. How can my husband and I keep our daughter at Tacachale?

Answer As long as the Legislature continues to fund people to live at Tacachale, people may continue to choose to live there. The Agency believes that there are specific circumstances under which ICFs may be appropriate residential settings for some people. At the same time, we also recognize that most people prefer to live close to their family within their community and typically realize a higher quality of life when they do so. For these reasons, APD works diligently to integrate people with disabilities into the decision-making process (with the support and assistance of their family and friends). The Yellow Notebook is specifically designed

supports people being happier, healthier and safer when they live close to their family and friend.

Since Gulf Coast Center is in Lee County and if your relative resides there, he will have a social worker (or community inclusion specialist) that is working directly with him and who will be able to assist you and your relative with this change. If your relative does not know or can't remember, you would contact Gulf Coast directly by calling 239.690.3652. Also, Chapter 8 in the Yellow Notebook includes a procedure that should be followed when someone is moving (transitioning) from a public intermediate care facility (DSI) into the community. We hope this procedure will be helpful to you during this process.

However, if your relative currently lives in a residential habilitation center, group home, apartment or own home, she should have a waiver support coordinator (WSC) that helps with services and supports. Ask your relative the telephone number for his WSC. If your relative does not know or can't remember, you would contact District 8 by calling 239.338.1572. This number and other numbers for staff of District 8 are in Chapter 10 of the Yellow Notebook.

80. If a consumer is transitioned out of Gulf Coast and it does not work out, what is recourse?

Answer Where and with whom someone lives is a very important part of everyone's life. And, we all know that change is not easy. For these very reasons, we believe that the involvement of family members and friends in the decision-making process before, during and after the transition increases the success of the person moving. Consider the recent hurricanes and numbers of people who are having to find a new home. If you lost your home in a hurricane, what would you consider when looking for a new one?

Transition is a life changing experience for everyone whether they have a disability or not. It is not unusual for someone to take several months to become comfortable with all of the changes that occur. Providers and Area APD office staff will continue to review the needs of individuals to ensure appropriate services are in place for successful community life. You may want to read Chapters 3 and 4 (Services Stations: Waiver Services and Supports and ICF Services and Supports) for information, if your family member is wanting to move onto the HCBS waiver. This is a critical service that should be very helpful during this transition. Another helpful resource mentioned in the Yellow Notebook is APD's policy relating to Procedures for Transitioning from Public ICF/DDs to Community Services in Chapter 8.

Additionally, we cannot over-emphasize visiting each setting you think might be right for your family member, as well as once you have decided on the licensure type (foster home, group home, supported living) visit specific homes to see how that particular provider meets the regulations. Do the people there seem happy? Does the place look nice? Are the staff friendly and interacting with the residents? Checking out as much as you can before someone moves can make the difference between success and failure.

Recourse for people who move and do not like the outcome or for people whose needs change and their initial choice is no longer appropriate, would always be to reconsider their options and move again: either to another location with the same type of license, another type or one without regulations.

