



Waiting List Task Force

Recommendations

August 2011

ISSUE 1: How can the waiting list be managed and what should the eligibility criteria be?

The current waiting list is over 19,000 people and includes people who signed up over 12 years ago. Recently over 250 people were targeted for the DD Waiver from the waiting list. Often it is difficult to contact people who signed up 12 years ago. How should we manage the waiting list, what steps should be taken to assure people have up-to-date information and know what can be done? What should be the criteria for eligibility to be on the waiting list? For example FSSA is preparing a policy statement that children under six can apply for Medicaid waivers but must come back into the office to have a Developmental Disabilities Profile completed to assure they are eligible.

PROPOSAL 1:

1. The Waiting List Management must move into an electronic environment to **supplement** the paper process:
 - a. Develop a website to apply for waiting list, update information and send requests
 - b. Add email and cell phone lines to current waiting list document
 - c. Ask community agencies to volunteer to host a web access point with info on other community natural supports on site and be available to families
 - d. Ask Community Centers to offer web access point with same info – could partner with community agencies to support
 - e. Send regular snail mail post card – annually to people on the list sharing info about website and need to update addresses
 - f. Every contact with individuals (or their guardians) on the waiting list should ask for their interest in getting more information about community supports and advocacy groups that relate to the individual who has a disability

- g. Seek support from BMV to host web access point and include info on DD services in BMVTV on site and to consider simple flyer in license plate renewal information – could focus also on employment and jobs
 - h. Add to states website at BMV info box on DDRS
 - i. Get all related Disability groups to add a box on their website
 - j. Twice a year have waiting list day or week when every agency in the state reaches out to families and consumers to sign up and update records:
 - i. March for Disability Awareness Month
 - ii. October for Employment of Awareness Month
 - k. Develop commitment from other disability groups to respond to requests for information from people on the waiting list for support
2. Who should go on the waiting list:
- a. There is a legitimate argument that it can give people false hope to be put on a waiting list that they clearly will not meet eligibility
 - b. There is also a legitimate argument that screening people just to be on the list is costly and very time consuming. For example if 2,000 people apply to be on the waiting list each year and it takes approximately three hours of staff time to schedule a DDP, conduct the DDP, communicate back to the family and then report on the findings; that would mean the state would spend approximately 6,000 staff hours or three full-time positions just to screen people to put them on a waiting list
 - c. In this case we believe the costs far exceed the value received and there is a middle way:
 - i. We recommend elimination of the DDP process for people applying to be on the waiting list
 - ii. Replace the DDP with a very clear explanation to families applying of the criteria, the information needed to be affirmed on the application to be on the waiting list, a clear statement that just being placed on the waiting list is no guarantee that you will meet future criteria at the time you reach the top of the list, and you will be responsible for keeping the contact information and child's status updated on the list

iii. Any of the following categories should qualify someone to be on the waiting list (again, not a guarantee of eligibility):

- a. A child receiving special education services with diagnosis or another appropriate DOE category
- b. VR eligibility with appropriate diagnosis
- c. Doctor's diagnosis with appropriate diagnosis
- d. Served by First Steps with appropriate diagnosis
- e. Other collateral information

- d. Some may feel this opens up the waiting list for exploitation by families looking to obtain something for which they are not eligible. We disagree. Trying to get on a waiting list that may be 12 years long is not something that will appeal to people that are looking to scam the system
- e. In addition to this process, we would suggest only giving a DDP to anyone that does not have documentation to support one of the above categories. BDDS would not have the documentation submitted to avoid the paper collection and storage process
- f. Again, there would be clear and strong language that getting on the waiting list does not promise eligibility at some time in the future
- g. Placing individuals on the waiting list also allows FSSA to maintain contact with people who then can be directed to natural supports, get electronic information about employment and other ways to develop greater independence and help people not need so many services in the future

ISSUE 2: How can individuals get help and information while waiting?

While waiting, how can we assist these people, (the over 19,000 on the waiting list) with other community supports and services – both state programs like Vocational Rehabilitation as well as non-paid supports and community involvement, and how do we help them connect with Medicaid and SSI when appropriate.

PROPOSAL 2:

1. When a person applies for the waiver they have to sign a release of information. A box should be added to the application that would indicate the individual would like to be contacted by an advocacy group to talk about what to do while you are on the waiting list. Then BDDS would give the contact information directly to the advocacy organization to make the contact after the individual/family had “opted in.”

Additionally, after an individual applies for waiver services, the confirmation letter they receive should include information including name, contact information and details about advocacy organizations --- not just a list, but an explanation of each group and how the group might help if you contact them. BDDS should also have an advocacy organization information page to distribute to families with details and contact information for statewide advocacy organizations.

2. Develop a presentation about community supports and other resources that could be given at a variety of events like kindergarten roundups, transition events, conferences like GPCPD and First Steps transition events (like Cluster G has). It would be important to give the presentation at events targeted for a variety of ages and in a variety of ways like in person and a webinar to reach the largest audience.
3. Utilize case conferences at all ages, much like VR does for transition, to provide information to families about community supports. It would be important to share this information at multiple ages and early while individuals are waiting for waivers like during First Steps transition, entering elementary school, and beginning Jr. High.

ISSUE 3: What is the most effective and fair way to distribute resources?

Evaluate the current recommendations including priorities, waiting list and monies available and then make recommendations back to FSSA.

PROPOSAL 3:

The current recommendations start from the premise that we are making short-term recommendations regarding the waiting list, and we need to develop a more transparent and clear process for making determination based upon need before any major change is made. The identification of need and the extent of that need must be done in an open and clear process to avoid families and consumers misunderstanding the process and becoming both discouraged or disbelieving that there is any process. A lack of transparency and understanding gives way to the idea that somehow preferential treatment is given to some cases and denied to others in some subjective manner.

1. SSW:

- a. Continue what is being done to bring as many people on the SSW as possible. Allocate some portion of the waivers for those leaving high school using a sub-list, since the state is emphasizing obtaining employment, and the remainder to those on the waiting list based upon date of application. Allocation to be determined based upon the total number of slots available
- b. Do NOT eliminate SSW allocation to students who are still in school. Continue with the sub-waiting list for those coming out of high school
- c. Make Medicaid available to children under 18 to help families better cope with the additional costs of caring for a child/children with significant disabilities. Particular emphasis should be given to children with significant medical or behavioral needs that if left unsupported will lead to sooner out-of-home placements
- d. Provide service coordination to those on the waiting list who are over 18 in a coordinated effort to access community supports and programs through Medicaid, Vocational Rehabilitation, and SSI to provide greater access to work and community participation

2. DDW/Autism Waiver:

- a. Being targeted for a waiver should be primarily needs based rather than length of time on waiting list
- b. Continue priority waivers for emergency placement situations (previously categorized as Health and Welfare Threatened, Loss/Incapacitation of primary caregiver, Ageing primary caregiver, and crisis management.) Utilize a group (like the Human Rights Commission) to determine whether a case meets the level of crisis. Other priority categories including no longer need/receive active treatment in a group home, transition from 100% state funded, aging out of DOE/DCS/SGL, and institutional transitions need to have some evaluation to determine the level of need and the critical nature of the situation

- c. Remainder of waivers should go to those who have been on the waiting list the longest
- d. Make Medicaid available to children under 18 to help families better cope with the additional costs of caring for a child/children with significant disabilities. Particular emphasis should be given to children with significant medical or behavioral needs that if left unsupported will lead to sooner out-of-home placements
- e. Provide service coordination to those on the waiting list who are over 18 in a coordinated effort to access community supports and programs through Medicaid, Vocational Rehabilitation, and SSI to provide greater access to work and community participation
- f. Allocation to be determined based upon the total number of slots available – but the first priority is the crisis cases
- g. Develop a means to communicate with those waiting about the process and publish the results of targeting/ priorities and what can be done while waiting

ISSUE 4: What eligibility factors should be taken into account to receive waiver services?

Language in the recently passed Budget Bill H.B. 1001 directs FSSA to study the issues of parental income and suggests a co-pay for families of minor children who earn over 500% of the federal poverty level – approximately \$110,000 per year for a family of four. What should our position be on this issue?

PROPOSAL 4:

1. The Arc of Indiana has looked carefully at the issue of establishing, for the first time, a co-pay system for the parents of minor children receiving Medicaid waiver services.
 - a. Considerable pressure on the Medicaid system necessitates The Arc of Indiana and FSSA to continue to find ways together to develop a more cost effective system
 - b. The Arc strongly believes requiring families who earn over 500% of the federal poverty level to make a co-payment for Medicaid waiver services for their child who has a significant disability is neither cost effective for the state nor the waiver
2. A study of families currently receiving waiver services would show a very small number with incomes over 500% FPL – some estimates are as few as 60 families.
 - a. Relatively few children under the age of 18 are currently on the DD or Autism waiver, and even fewer are in families above 500% FPL meaning a system to collect financial data and assess and collect co-pays would not be cost effective when measured against the amount of time and money spent to develop and maintain the system
 - b. We believe the cost would far exceed what might be collected from a reasonable co-pay, and might have unintended consequences. For example, many families continue to carry private health insurance for their child even after they become Medicaid eligible. When faced with a co-pay, families might be forced to give up private health insurance for their child in order to afford the co-payment. This would result in a greater cost to Medicaid to cover the child's health care needs – far more than what would be collected from a copayment
3. The Arc and the Task Force strongly believe that requiring a co-pay goes against a primary goal of a community-based system - to allow children to live with their families rather than in children's institutions. The cost to care for a child in a children's facility now approaches \$500 per day in state funds as these facilities are not Medicaid funded. Moreover, keeping families together is the right thing to do.
4. The Arc of Indiana and the Task Force strongly oppose co-pays for children under age 18 receiving Medicaid waiver services. We do support and are actively engaged in creating system reforms that will address the overall cost effectiveness of the waiver program.

The Arc of Indiana

Waiting List Task Force

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