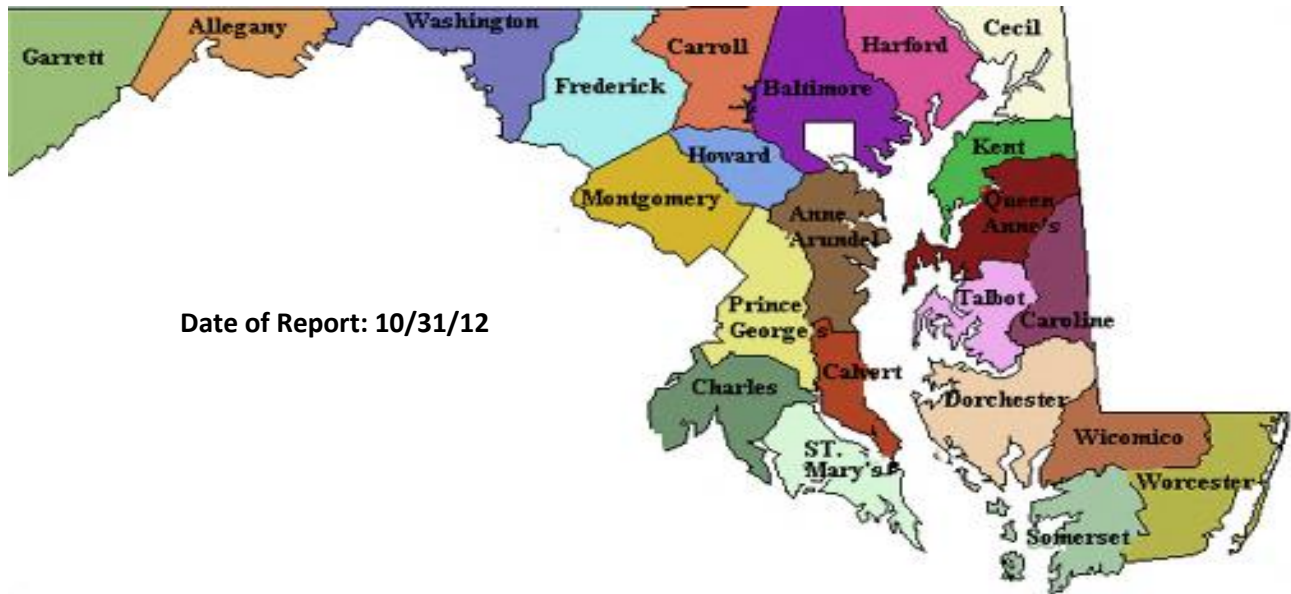


Low Intensity Support Services (LISS) in Maryland

An Assessment of Importance, System Function,
and Recommendations for Change



Date of Report: 10/31/12

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INTRODUCTION

According to the Developmental Disabilities Administration (DDA) website, Low Intensity Support Services (LISS) are support services established under Maryland Health-General Article §7-717. The program is designed to enable a family to provide for the needs of a child or an adult with developmental disabilities living in the home or to support an adult with developmental disabilities living in the community. LISS is intended to be flexible to meet the needs of individuals or families, and is funded with state-only dollars.

In November 2009, the Maryland Department of Legislative Services released an audit of the DDA which found that DDA needed to establish program guidelines for low intensity support services, then known as Rolling Access. These changes were implemented in 2009, and the service became known as Low Intensity Support Services (LISS). LISS regulations were subsequently developed and became effective on July 23, 2012.

Additionally, the audit recommended that DDA take steps to ensure equity and tracking of LISS funds. At the time of the audit, DDA had contracts with 50 providers to administer Rolling Access funds. To improve monitoring, DDA issued an Invitation to Proposal to ensure clear and consistent deliverables by contractors. Through this process, the DDA also significantly reduced the number of LISS providers, from 50 to 5, to increase consistency with administration.

The process for accessing LISS funding is the same in every county in Maryland. DDA funds this program with State-only funding and contracts with five DDA licensed Family and Individual Support Service providers to administer the program. Most Maryland residents who have a developmental disability or their family can apply, and it is important to note that not everyone that applies will be funded because there is a limited amount of funding available. Services are funded on a “first-come-first-served” basis where a need can be demonstrated, and no other funding source can be identified or accessed. Individuals must complete a Medical Assistance application unless the service is for a minor. People applying will need proof that they are a resident of Maryland and have a developmental disability. People do not need to fill out the DDA application for services in order to apply for LISS. The LISS providers may suggest that applicants consider applying for other DDA services that may be able to meet long-term or on-going needs, as LISS helps with short-term needs. People may make multiple requests for funding through the year and across multiple years. The program provides funding up to \$3,000 per person per year. DDA may waive this cap depending on the need.

On June 25th, 2012 the Maryland Center for Developmental Disabilities (MCDD) received a grant from the Maryland Developmental Disabilities Council (DD Council) to provide “An Assessment of DDA’s Low Intensity Support Services” in Maryland. The intent of this work was to investigate some questions related to LISS through stakeholder input using a variety of methods. Due to time constraints for this project, the DD Council and MCDD agreed that the overall assessment goal was to obtain information through a widely disseminated on-line survey; through facilitated interviews to obtain representative samples of perspectives from limited but critical groups of stakeholders (i.e., 2-3 people for each stakeholder group interviewed); and through public forums targeting families and persons with developmental disabilities. It is important to note that this assessment was not intended to be a scientifically valid and representative sample of ALL perspectives possible. Rather, it was intended to be a solid

collection of critical perspectives that represent major stakeholders in the LISS system, and to include those who also might have diverse opinions on how things in that system are working. The desired outcome of this assessment was to provide an initial evaluation that could be used by the DD Council and the DDA in future efforts to improve LISS and other aspects of the developmental disabilities system in Maryland.

METHODS

Surveys

The first assessment activity for the MCDD was to prepare a survey (with approval from DDA and the DD Council) and publish it to the Internet. Notice of the survey was distributed through email to a number of key email list-serves and contact lists, as well as through posting on the MCDD and DDA web sites. The survey included a set of questions that asked respondents to rate things (like how important LISS is) using a Likert Scale, and a set of open-ended questions (like what is working well with LISS) which allowed respondents to respond in an open text format. The survey received responses within minutes of being posted, and was continuing to get responses when it was turned off on 8/3/12. A total of 900 responses to this survey were received and were used in the analysis for this report. Those items that offered ratings were summarized quantitatively, and those that had open-ended responses were analyzed to identify themes and samples. Responses came from a diversity of locations (city and counties) and from a diverse set of participant/stakeholder groups. Table 1 illustrates the number of respondents from each of the county or city locations, while Table 2 illustrates the number and percentage of respondents from each of the targeted stakeholder groups.

Table 1: Number and percent of respondents by location (self-report)

County	% Total	Number	County	% Total	Number	County	% Total	Number
Prince George's	15.8%	141	Charles	3.8%	34	Talbot	1.5%	13
Baltimore County	15.4%	138	Calvert	3.6%	32	Queen Anne's	1.3%	12
Montgomery	14.2%	127	Carroll	3.2%	29	Caroline	1.0%	9
Baltimore City	11.5%	103	Statewide	2.8%	25	Garrett	1.0%	9
Anne Arundel	10.1%	90	Wicomico	2.8%	25	Dorchester	0.9%	8
Howard	9.2%	82	Cecil	2.0%	18	Kent	0.9%	8
Harford	6.8%	61	Allegany	1.8%	16	Worcester	0.8%	7
St. Mary's	4.6%	41	Washington	1.8%	16	Somerset	0.6%	5
Frederick	4.3%	38						

Table 2: Number and percent of respondents by stakeholder group (self-report)

Stakeholder Group	Percent	Number
Family Member of a Person with a Disability	64.7%	544
Service Provider	17.8%	150
Advocate	10.2%	86
Resource Coordination Agency Staff	10.2%	86
Person with a Disability	5.9%	50
County Government Employee	3.2%	27
LISS Provider	3.0%	25
DDA Staff	2.4%	20

Interviews

Telephone interviews were scheduled with key informants from the following groups: a) LISS providers, b) non-LISS DDA service providers, c) DDA staff, d) Maryland DD Coalition, and e) resource coordinators. Contact persons for each of the groups were provided by the DD Council with input from the Maryland Association of Community Services (MACS). Each of the informants was contacted to arrange for the interviews on a convenient day and time for that group. All of these groups were interviewed by telephone (with the exception of the DD Coalition which was interviewed in person) and each group had separate interviews for each of the four DDA regions (with the exception of the DD Coalition and DDA Headquarters). Each interview, which lasted about 1 hour, included discussion using the same questions as those on the survey with consensus development for the first four questions. Interviews began on 7/12/12 and were completed by 8/16/12. Notes and/or recordings for each of the interviews were used to inform this assessment process. Dates of each of the interviews are listed in Table 3 below.

Table 3: Dates of interviews by stakeholder group and region

Stakeholder Group	Central	Eastern	HQ/Statewide	Southern	Western
LISS Provider	07/18/12	07/16/12		07/20/12	07/18/12
Non-LISS Provider	07/23/12	08/02/12		08/02/12	08/01/12
DDA Staff	07/20/12	07/20/12	08/16/12	07/20/12	08/13/12
Resource Coordination	07/30/12	08/01/12		08/03/12	07/30/12
DD Coalition			07/12/12		

Public Forums

The MCDD held two public forums for individuals with developmental disabilities and families on 7/25/12 in Columbia and 7/30/12 in Easton. Overall, an estimated 45-50 people took part in the forums. Of these individuals, 29 of the participants provided information related to their roles including 2 individuals who self-identified as a person with a developmental disability, 18 family members or parents, and 9 professionals. At these forums, the same questions as those on the survey were used to facilitate discussions. Notes were taken by staff

both on a laptop computer and on a flipchart to facilitate the discussions, and the conversations were recorded to allow the evaluators to have later access to the content of the conversations.

Data Analysis

Quantitative data from the surveys was analyzed using simple spreadsheets to generate summaries and graphs for the ratings on Questions 1 through 4. For the text responses on the surveys as well as the interviews and forums, all responses to each question were ultimately summarized into separate documents for analysis of themes. Overall themes were developed by inspecting all comments from all sources, and a final set of themes across the questions were used in the preparation of this report. It should be noted that while differences in responses across regions occasionally were evident, they were not consistently addressed in the analysis due to the data collection in the surveys and the fact that many respondents indicated being from (or serving) more than one region.

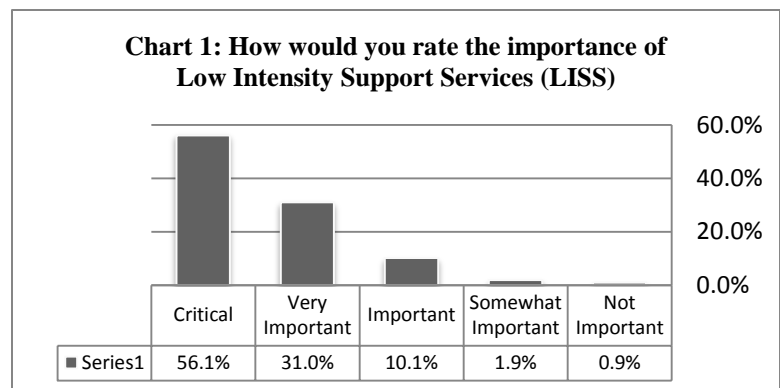
FINDINGS

The discussion below summarizes the information gathered through the study via all input processes. The first four topics discussed below include information gathered through use of a Likert Scale:

Question 1: Importance of the Program

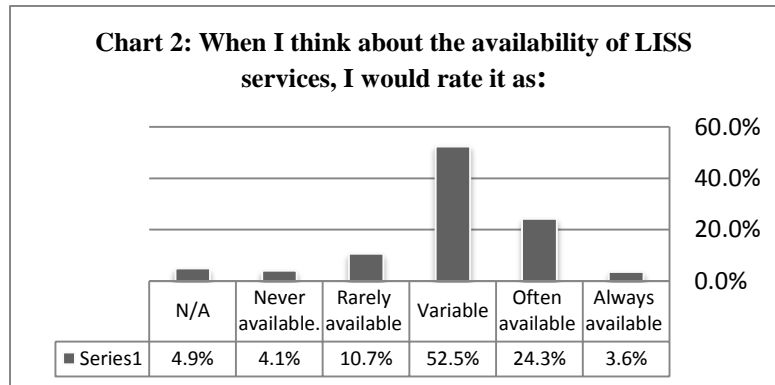
As indicated in Chart 1, the vast majority of respondents to the online surveys indicated that LISS was either important, very important, or critical. These findings were echoed in the public forums. While a few individuals were either unaware of the LISS funds or didn't use them, for families that used the system the funding was seen as integral to helping address one-time, periodic and emergency needs related to a variety of supports and services.

Family members and professionals alike indicated that everything from camps and respite care to housing and other basic living issues were being supported with these funds. Overall, it would be difficult to overstate the importance assigned to these funds by families and professionals alike as people struggle to put together comprehensive supports and services for themselves, their children, siblings, and other family members.



Question 2: Availability of Funding

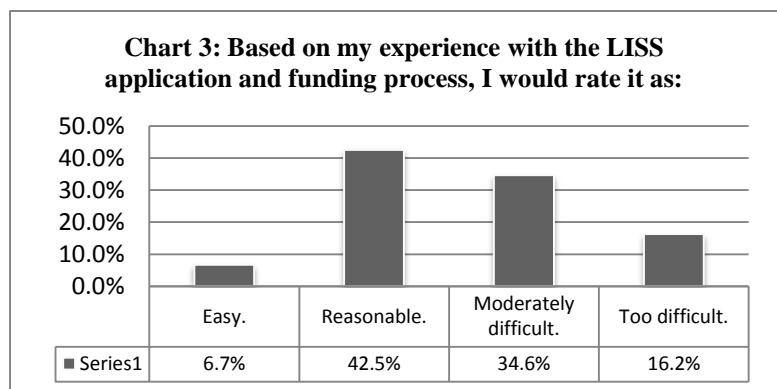
One of the key findings regarding LISS funding is that both family members and professionals felt that the availability of funds was highly variable (Chart 2). Many of the survey respondents, interview participants and forum participants indicated that availability of funds depended upon when an application was submitted relative to the state



funding cycle. That is, if the funds are dispersed to LISS providers on July 1 of the current year and an application is submitted on that day, there was a greater likelihood of getting funding than if an application was submitted later in the year when most or all of the funds have been spent. In addition, availability depended upon whether a person was familiar with the system and how to access it. Consequently, applicants with knowledge about the system are reported to be more likely to receive LISS funds than applicants with little or no knowledge of the application and funding process. In a related issue, many respondents and participants indicated that when the state allocated funding on a quarterly rather than annual basis, funds could be available to those who might have a need that arises later in the fiscal year. This was particularly true for needs like camps that might not accept applications until January, or for unexpected/urgent needs that arise later in a fiscal year. Still others said it depended upon where you lived in the state, and how much funding was allocated to that region.

Question 3: Ease of Application Process

One of the more interesting questions in this study of LISS related to the ease of the application process. As indicated in Chart 3, many (about half) respondents and participants felt that the application process was either easy or reasonable. On the other hand, about half felt that the process was either moderately difficult or too difficult. More

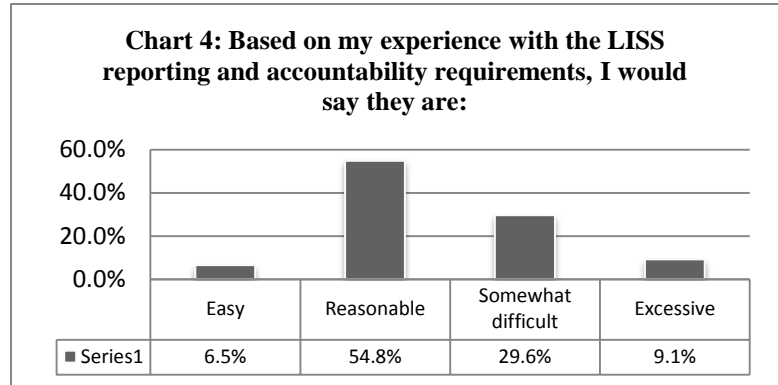


than a few participants in the interviews and public forums discussed how the process could actually collect *more* information than it currently does, and how that additional information could be used to simplify the approval process by providing a more complete application packet that could be available to those who need it for approval decisions. Many said the application paperwork itself is easy to complete, but the *process* overall becomes difficult due to the extent of documentation needed, approval process, waiting periods for communication with various staff and professionals and required timeframes for submission of supporting documentation. In addition, many respondents and participants related that the need to provide proof of eligibility

each year was cumbersome and sometimes emotionally difficult for families and consumers. For instance, some participants discussed needing to send in the same eligibility documentation, including clinical evaluations, each time that they applied, including psychological and other information that was sensitive and personal. For these families, this redundant effort was unnecessary and potentially embarrassing. For professionals, this process was time consuming, inefficient and does not take advantage of current information and database capacities.

Question 4: Reporting and Accountability Requirements

This question related to the reporting and accountability requirements of the LISS system, and was particularly relevant to the staff and professionals working at the LISS providers, the Resource Coordinators, and DDA regional offices where LISS applications are approved. As indicated in Chart 4, a majority of the respondents and participants felt that overall reporting and accountability



requirements were either easy or reasonable. However, a significant minority indicated these requirements were either somewhat difficult or excessive. Some of the difficulty regarding reporting or accountability had to do with the perception that there were redundant reporting requirements or data systems that could be streamlined. For instance, LISS providers keep information on who was provided with funding and the services that were funded. Resource Coordinators also have their own data and information. In addition, information might also be available in some form in DDA databases. Still others felt that the documentation required of families made the reporting requirements excessive and hard to manage.

The next three questions were posed in an open text format, where respondents provided input in their own words for the surveys as well as the interviews and the forums.

Question 5: What is Working Well

a) Money Matters: It is difficult to overstate how important most families and professionals think this program is to people in need of flexible funding for a small amount of supports and services. Almost universally, when asked what is working about LISS, the first thing to be mentioned is “the money”. Just having access to funds that can be used for a wide variety of needs is seen as the most important aspect of the program. It was not uncommon for both families and professionals to respond with a comment that people absolutely depended on these funds each year for critical life concerns. This was especially true for people on the DDA waiting list who do not have any other assistance.

b) Flexibility: Perhaps the second most cited and important aspect of what is working about LISS is the flexibility in how funds can be used and allocated to support people with disabilities. Examples of everything from camps and respite to assistive technology and emergency utilities were all mentioned. The intentionally comprehensive and flexible nature of the funding makes it particularly valuable to a wide range of people. This is especially true when considering the fact that while adults must apply for Medicaid and all applicants must provide evidence of a developmental disability, applicants do not need to be receiving DDA services to qualify for LISS funding.

c) Statewide Access: One of the more interesting points raised, particularly in the forums and interviews, was the notion that individuals and families can apply for LISS funding through any LISS provider and receive funding from any region. Though standard practice is for an individual or family to work with a local LISS provider to make an application, it is not a required process. In addition, if a person lives in one region and the funding allocation for their region is exhausted at the time of their application, they can apply and be approved for funding in another region that may still have available funds.

d) Local Collaboration: The findings from the survey, forums and interviews revealed that in some regions, local agencies collaborate well to make things work. For instance, some LISS providers and resource coordinators worked to make referrals to LISS, communicate with families throughout the process, provide follow up after application, and work with families to apply for and procure other resources that might be helpful. However, this level of collaboration was not expressed in interviews and forums in all regions, therefore, it may be a localized strength rather than a general strength in the system.

Question 6: What is Not Working Well

a) Confusing Standards: Perhaps the most common and strongly worded concern about LISS was the sense on the part of respondents, including families and professionals, that there is a lot of confusion and differing standards regarding the type of things LISS will fund. This seems to result from different issues, including: a) a lack of coordination regarding when and how a Request for Service Change should be used versus applying for LISS; b) application of rules differently from region to region; c) changes in the process and rules over time; and d) lack of clarity about what is an approved LISS service or not. Some families also indicated that expectations for documentation and information needed for the application process sometimes differed across providers and regions. These confusions and lack of clarity, particularly the issue of clarity of what is an approved service, seem to create barriers to people looking for responsive and important services and supports.

b) Best Kept Secret: The issue of who knows about LISS is interesting and perplexing. According to many families and professionals alike, not everyone knows about LISS, nor how to apply for funding. While there is indeed a specific section on the DDA website with information about the service and application process, most participants indicated that there was little time or effort dedicated to specific marketing of the program. Some commented that this might actually be a good thing by allowing limited resources to be tapped and used by those already knowledgeable of the process. However, the majority of comments indicated that the lack of

information resulted in those with the most need having no access to this resource, such as families new to the system and those with a need for more support to access services. In addition, several professionals commented that the lack of a comprehensive marketing effort and documentation of the number of people who might be un-served by LISS results in the state never knowing the true levels of need for this funding.

c) Money Goes Quickly: According to participants, the method for allocating LISS funds to providers has changed recently. Funding was previously allocated regionally on a quarterly basis. This changed recently to a July annual allocation for each region, with funds provided on a first-come-first-served basis. Many of the participants indicated that this has resulted in LISS funds being exhausted very quickly, with some regional funds being completely allocated within the first fiscal quarter. Still others said that distributing all funds in July makes planning difficult for many families, especially related to camp (a frequent use of LISS funds) because applications are often not available until January or February, well after the LISS funds have been exhausted. This system also leaves people without resources who may encounter an urgent/emergency need which was not known or anticipated at the beginning of the fiscal year.

d) Redundant Efforts for Families: Many of the participants in the interviews, forums and respondents to the surveys indicated that the annual application process was too onerous and redundant. With each annual LISS application, families are required to resubmit the same disability determination documentation, even though the person may already have been determined eligible for DDA services or for LISS services in the past. In addition, some commented that these documents could be archived, thereby saving time, effort and expense. One father talked about the emotional distress he experiences when having to submit the same psychological evaluation each year, which contains a great deal of personal information regarding his son. Others commented that many families with the greatest need and typically under significant stress from their family situation are simply overwhelmed by the application process. Still others commented that some families, especially elderly care givers, are reluctant to request assistance and the documentation required during the application process presents a significant barrier. Most felt that information and database technology should allow for one-time applications and documentation to be stored and used in future application and approval processes.

e) Communication Problems: Another issue was that of how families are involved (or not involved) in regular and timely communication with providers. While a few families and professionals were very happy with the communication and responsiveness of those involved in the LISS system, most participants indicated that the system offered poor communication between agencies and families. There were many complaints that applicants never receive feedback about whether their application was accepted or rejected. Resource coordinators echoed this concern, and commented that they must provide the follow-up for the applicants they assist, generally requiring multiple calls and emails. In addition, applicants noted that they are not aware of how and when vendors receive payment for the service. Some participants indicated that they had absolutely no feedback regarding receipt of their application, disposition of application or whether payment was made. Indeed, according to more than one participant, applications were approved and payment was made without the family or resource coordinator knowing, and the person therefore did not receive the service.

f) The Process: Finally, there were some general comments regarding the overall LISS process that did not fit neatly into a category. These included: 1) having regional LISS providers makes the process less personal; 2) applicants are not able to receive the assistance they need to submit an application and to identify appropriate resources to meet their needs; 3) providers are less informed about local resources; and 4) providers are not familiar with the family and unable to help them think through what they may actually need. Additionally, many participants indicated that the requirement to mail applications and supporting documentation takes too much time, and that the need for an original signature is excessive.

Question 7: What Needs Changing (according to participants)

a) Ongoing and Standardized Training: Due to the participants' sense that confusion and a lack of standardized expectations and training exist in the system, many recommended ongoing and standardized training with standard definitions of what would qualify for funding. This standardized training might also include instructions for vendors on how and when they will be paid. Some families recommended creating a more specific list of what qualifies for funding and what does not than is currently available on the DDA website. Additional recommendations include providing a list of approved therapies, providing clear guidelines for requesting services through LISS as opposed to requesting a change in current services and providing a standardized method for making changes across the system.

b) Increased Information and Marketing: Some participants felt that a substantial and consistent effort to increase public information and marketing regarding LISS would be a good idea. One even suggested that the DDA think of LISS as an entry point for families to start learning about DDA.

c) Funding Distributions: While most of the families and professionals consider LISS as a critical funding source for flexible family needs, many recommended that the DDA consider going back to quarterly funding distributions. This would make the money last longer into the year for families who need to access it in the spring for things like camps and to accommodate unanticipated urgent needs.

d) Funding Eligibility: Many participants noted that LISS funds are available to people who are currently receiving waiver and non-waiver services through DDA. Given changes to the DDA system in recent years, the needs of these individuals should be met through the Request for Service Change process. Consequently, these individuals would not need LISS funding, making more funds available to people who are on the DDA waiting list or for people who have not applied to DDA for services. Still others suggested that LISS only be available to people on the waiting list. Finally, it was suggested that all applicants should apply for Medicaid regardless of the age of the person receiving the service. This would result in additional resources for children through Medicaid services.

e) Improved Data or Information Systems: The LISS application and service funding processes would be enhanced, according to many participants, with improved data and information management systems. These would reduce redundant efforts that are required of

families by providing appropriate access to needed documents across application years. This improved data collection and management effort should also include the ability to keep and use eligibility documents from one funding year to another. Some participants also thought that DDA could use data regarding how funds are used and in what frequency as part of an annual review of funding and allocation priorities. Another data management improvement would include improving access to the DDA PCIS-2 data system to allow access for all those who involved in the eligibility and approval processes. Finally, some participants mentioned using this same data system to keep track of local resources and contacts so that families and resource coordinators could be better served in a more timely fashion.

f) Communication with Families: Due to the strong feeling on the part of families that communication regarding the application process was a weakness, DDA should consider having and enforcing standards regarding communication with families. This might include providing information that an application was received, approved and payment was made. It might also include providing support to families with filling out the application, gathering eligibility documentation, finding resources including alternative sources for funds, and thinking through real needs.

g) Flexibility in Funding Priorities: Finally, some of the participants mentioned the notion of allowing more flexibility in approving LISS funds in a timely way to respond to emergencies and to respond in individualized ways. This seemed to be about making it easier for the system to be more responsive to requests for unanticipated expenses that could create a crisis for the family. It was also suggested to set aside separate funds that are available throughout the year for such emergencies. Many of the participants indicated how important LISS funds were in preventing family crises, and that LISS funds should be focused on this priority.

LIMITATIONS OF THE EVALUATION

While the evaluation consultants and the DD Council attempted to design and implement an evaluation that would provide meaningful information, there are nevertheless a number of limitations to this study and its findings that are worth noting. These include:

1. This evaluation did not utilize a general random sample method. Although respondents to the online survey could be construed as a random sample, it is logical that those that took the time to respond may be biased in some way and the evaluation consultants have no way to measure that bias given the current sample and protection of anonymity inherent in the survey process.
2. The overall time constraints of the design and implementation of this study imposed some limitations on the evaluation consultants' capacity to undertake follow up efforts with those involved in the interviews and the public forums. While this is not specifically a methodological flaw, it could have prevented the participants from having the opportunity to offer details to comments that could have enriched the findings.
3. It should be noted that evaluators have no ability to verify the truth of any perceptions of strengths and weaknesses in the system as reported by participants on the survey, the

interviews, or the public forums. Rather, this report simply tries to collect and reflect to the DD Council and DDA these perceptions in an organized way that might promote both improved understanding of important issues and increased capacity to make decisions based on multiple public perspectives.

RECOMMENDATIONS

The recommendations listed below are based on the perceptions and opinions expressed by participants in the surveys, interviews, and forums outlined previously. Our recommendations, based on the evidence outlined previously (and considering the limitations listed), include the following:

Strengths

1. Importance of Funding: Based on the responses to the surveys and other evaluation efforts, LISS funding was overwhelmingly described as very important or critical to persons with developmental disabilities and their families. This type of flexible and personalized funding stream, even in its limited amounts, seems to be critical to persons with developmental disabilities and their families and should be maintained if possible in some form.

2. Flexibility: A number of issues related to flexibility were discussed and should be considered both strengths of the system and things to maintain where possible. The flexible nature of the LISS funding itself was noted, with it being used for a number of diverse items of importance to persons with developmental disabilities and their families. In addition, LISS funds can be accessed from any region in the state, regardless of where a person lives. These flexibilities should be considered valued aspects of LISS to maintain and encourage.

Opportunities for Improvement

1. Improved Training: Given the importance of having consistent information and decision-making in this and other human service systems, participants' perceptions indicated the need for improved and standardized training for all professionals involved in the application, approval, and other aspects of the LISS system.

2. Improved Use of Data and Information Systems: Improved data and information systems would support the LISS system to improve marketing and information dissemination, reduce redundant efforts on the part of families, streamline the application and documentation processes and improve information and application access for all.

3. Improved Communication with Applicants: Through improved training and information systems, along with other efforts, DDA can make a sustained effort to make quality and responsive communications with applicants a priority. These communications should focus on confirming receipt of applications, funding approval or rejections, and information about resources that can be used to reduce crises and meet current needs.

4. Further Investigation: In order to inform decisions regarding improvements in the LISS program, it is recommended that additional and continuous evaluation efforts be conducted over

the coming years. These evaluation efforts should investigate a) the ongoing needs for, and utilizations of, LISS funds, b) the impact of annual versus quarterly fund distributions, c) the need for funding to address emergencies, d) the roles of regional differences in service utilization and outcomes, and e) the role of variables in the current regional model such as how different agencies partner at the local levels to help families access LISS funding, access other services, and provide follow-up to ensure adequate communication. This last item is particularly relevant to how local conditions such as how agencies were familiar with families and their needs changed as a result of the new system of providers which is fewer providers but much larger case loads of applications per provider and less opportunity to get to know families.