

Getting There From Here:

A Feasibility Study of Establishing an Office to Serve Individuals with Autism and Asperger's Disorders in Delaware



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December 2008



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Executive summary

The Human Services Research Institute (HSRI) conducted a feasibility study for the Delaware Division of Developmental Disabilities Services (DDDS) in late 2008 in order to recommend a course of action that Delaware could pursue to enhance its capacity to serve people with diagnoses on the autism spectrum. Data sources for this study included a review of services provided and models used by other states, interviews with people interested in the autism spectrum in Delaware (providers, state staff, advocates and families), and a review of documents from Delaware and other states that described “the state of the state” in terms of serving people on the spectrum.

The review of states’ service models revealed characteristics of a system that seem to be connected with good quality. These features include: training of provider staff, state agency staff, and families; the capacity to collect, organize and use high quality data about the system and service outcomes; the capacity to provide to families and other stakeholders information that can be easily used to apply for services and to understand the structure and capacity of the system; opportunities for collaborating across state agency lines to provide comprehensive, coordinated services; the capacity to “grow the system”, in terms of offering training, importing best practices, and providing ongoing technical assistance; and an eligibility determination process that was effective in documenting strengths and areas of need and that was connected with realistic budgeting.

Interviews with Delaware stakeholders in many ways mirrored these findings. Several themes emerged: Training is a critical need, again across the system; the capacity to appropriately identify services needs is not currently present for people across the entire autism spectrum; information is difficult for families to find and sometimes inconsistent when it is available; collaboration between state agencies providing services is rare, with limited success described only with Delaware’s vocational rehabilitation agency; everyone on the spectrum according to the Diagnostic and Statistical Manual is not eligible for Delaware’s services and that must change; funding is a huge problem, both at present and in planning for future expanded capacity; and expert resources are not available to help with planning.

In combination with our review of state reports, HSRI used this information to suggest that Delaware adopt a model that we describe as **The Delaware Resource Center**. This Center would be staffed with autism specialists who would assist the state in revising definitions and eligibility practices, develop and provide training across stakeholders, develop and utilize data collection tools to help Delaware make future decisions, and create materials for families to use that were easy to understand and accurate. The **Resource Center** could be funded through a contract initially, that would provide one part time autism specialist, whose focus could be the work that Delaware

deems a first priority. As funding becomes available, the contract could expand to respond to each of the needs as presented. Eventually, Delaware might be able to secure state positions for the autism specialists, and it could expand the concept of the **Resource Center** to provide supports across the system to stakeholders regardless of diagnosis. In time, DDDS could seek support for the Center from other state agencies who would then be able to benefit from the expertise that the Center has to offer.

Introduction:

The Human Services Research Institute (HSRI) prepared the following feasibility study for the Division of Developmental Disabilities Services (DDDS) in the state of Delaware. This feasibility study examines several approaches to enhancing DDDS's provision of services to people with diagnoses on the autism spectrum and their families. Over November and December, 2008, HSRI staff examined models from several states that already serve this population, with a view to gathering information about what works. We describe those structures here, highlighting elements that we saw as important for Delaware to consider. We spoke with advocates, state and regional DDDS staff, and families to learn what they see as major issues that Delaware needs to address. Major findings from those interviews are presented, along with any related ideas that interviewees presented. Finally, we reviewed the Delaware Legislative Task Force Report on Adults with Autism Spectrum Disorders from Summer, 2008. Those findings are not summarized here, but we have referenced findings that connect specifically to this report. The final task of our feasibility study was to develop recommendations for Delaware that could enable DDDS to take some positive steps toward improving its capacity for serving young adult and adults on the autism spectrum. What emerged from the feasibility study was an initial design of a model that could enable Delaware to begin its journey in a way that is both responsive to the support and services needs of consumers and their families and respects the fiscal climate in which the journey must be taken. That model is described here.

Review of states:

In order to decide which states to look at, HSRI sought guidance from several national organizations that work with and advocate for persons with autism. No state uses purely one model or another, but rather takes aspects of each to build what it offers to families of persons on the spectrum. What follows are descriptions of two models – the single office within the state through which everyone with autism passes and the distributed model in which persons with autism get services and supports through the same system that other people get them. We have described the benefits and issues of each model, and we have referenced individual states when they provide examples of a function done especially effectively.

Some states have a separate office within their Departments of Developmental Services that addresses the needs of persons with autism. This office coordinates all services for people on the spectrum who meet eligibility criteria. It manages the process of determining eligibility; it handles contracting, service planning, and monitoring; and it serves as the information point in the system for families and persons on the spectrum who are seeking information. Data is collected there, and when it's used, these data inform decisions about service expansion, training, and policy. For larger states, there

are regional satellite offices that are also connected to the regional Disabilities offices, so individuals can find what they need more locally than by having to use one central location. This also means that services organized through the local offices can take into consideration local population or environmental characteristics, such as language or public transportation, as plans and services are developed. Families report that they find it easy to get information, but that service quality and staff training continue to be issues.

One positive aspect of this model is ease of access. Families can readily find (or be directed to) information about what is available and can learn how to initiate requests for services. There is a clear relationship between the office and all the services that are offered for persons on the spectrum in the state, so monitoring can be consistent. Satellite offices can reflect local characteristics and therefore help people seeking services feel more comfortable. This ease of access extends to the state as well. The state can develop a real network, where elements of the network – for example, providers from across the state – can be connected readily with one another. Centralized training can be developed and distributed, and a set of policies can be consistently implemented statewide. Pennsylvania has a strong set of training and policy guidelines that provide an example of this benefit.

Another benefit for the single office model is consistency. States can easily collect the same data from across the system so it can be used to drive its decisions. Several states have developed tools for collecting information about quantity of services, quality of services, satisfaction, and cost. A single system that is used across the state means that data from across the state can be comparable; it can be aggregated; and it can be examined to understand variations in costs, service array, or number of persons served because standard definitions and data gather strategies are used. It can be used to report to consumers, families, funders, and legislators about the impact of services on the lives of persons on the spectrum. Vermont is a state where data has this kind of central role.

Consistency extends to other areas. It allows the state to define the competencies and experience expected of professionals to provide quality services to individuals with ASD across the lifespan and across settings. It ensures the inclusion of perspectives and voices of individuals with ASD and their families in all training since all training is centrally organized. Pennsylvania is an example. The single office model enables the state to ensure that there is a reasonable level of consistency across the state, so that families from one place have approximately the same experience as families from another place.

A final benefit is that the single office model provides the state with the opportunity to focus on the needs of one population. Stakeholders for the population can collaborate

on issues of policy and practice, and roles for each stakeholder can be clear and realized through policy. Training can be a focus. Several states, notably Vermont and Pennsylvania, have developed extensive training materials connected with the population of people on the autism spectrum; these materials look at agencies, provider staff and families and are readily available across the state (and outside the state); they represent a significant resource for the autism service system within the state. We did not find similarly comprehensive materials for people with other diagnoses.

Despite its strengths, problems can exist for this kind of centralized system. The first is segregation. Across the country, states are trying to provide supports and services based on need, recognizing that someone who needs help with employment who has intellectual disability may need services that are very similar to someone who needs employment services who has a language based learning disability. While their diagnoses are different, their services needs may be able to be met by one provider who offers similar services to each. The diagnosis may be helpful in determining how to provide services, but it is not always helpful in determining what to provide. The creation of “silos for services” based on diagnosis can mean the development of services that are diagnosis specific rather than need specific; it can foster a lack of coordination of service across silos. What ends up happening is that there is a benefit to having a particular diagnosis because there is a place for you to go

The second issue is funding. Direct services across the state for persons on the spectrum have costs associated with them whether there is a central office or not; however, administrative costs for the central office and or specialized regional offices can be a significant add on. Massachusetts has a separate budget for autism services, a separate budget for administration, and a network of autism centers across the state. The functions of the central office may duplicate functions that are already performed by other existing offices. Satellite functions may be duplicative as well. Eligibility, service planning, contracting, and monitoring are all satellite functions that are necessary for the general service recipient as well as for the service recipient on the spectrum. We do not have enough data to conclude whether or not this administrative expenditure results in additional benefits to the service recipient.

Many states have seen situations in which one disability group competes with another for funding. When there is a separate office within the state agency, then that competition takes place within the agency, making it very difficult for the agency to do agency wide planning and development. There are often mandates connected one population served by an agency that also result in inequity in service access across the agency. Policies that apply to some of the service recipients do not apply to others. Funding levels are different within the agency. For families with two children – one with autism and one with intellectual disability – the process of seeking and getting services for their children would be different.

The other model that states use to organize services for people on the autism spectrum is through the same system that is available to everyone with developmental disability. The benefits to this system lie in equity. Everyone seeking services has the same opportunity to receive services. The same network of providers is available to everyone, the same eligibility process applies to everyone, and the funding that is available for services is equally there for everyone. Services are made available based on need rather than on diagnosis. The “silo” effect mentioned above exists only to the extent that it already exists in the service system; no new silo is added. If the state provides good quality information for parents and families seeking services, this same level of information is available regardless of specific diagnosis.

What works less well in this model is its capacity to respond to the needs of a group of people with similarities. There is little specialized training available, so providers have few resources to help them when two people with Asperger’s syndrome or non-verbal language disorders are added to their caseloads. Case managers throughout the system bring the same level of experience to each of the people they work with, so those people with specific strengths or problems cannot expect a case manager with relevant expertise. Since resources for training are limited, training materials are often generic and of little statewide use beyond basic health and safety content. For families seeking information, the same generic material is often available to meet all information needs. It is often difficult to find anything that is uniquely relevant to a specific population or situation.

Information for the state is also an issue in this model. Data may be collected by provider; or perhaps by individual service type, but it is often not collected by diagnosis. Questions such as “how does the state serve adults with autism?”, or “how much does the state spend serving persons on the autism spectrum?” may be difficult if not impossible to answer. Imposing standardized criteria across a system for providers of services to people with autism is also difficult when providers are serving people with many diagnoses. Sometimes state agencies are required to address the needs of a particular population that represents a subset of everyone it serves. It is difficult both to target funding to some of the people on the services list, treating inequitably everyone else. It is also difficult to look at questions of quality for a specific diagnostic population across a system in which diagnosis plays little role.

Interview findings:

Dr. Joseph Keyes suggested twelve people for us to talk with, and in the course of our conversations, we identified two additional advocates. We conducted telephone interviews because we thought that we would be better able to pursue new ideas that might come up than we would with a written survey. We were not able to interview one of the people on the list; otherwise, we spoke directly with everyone whose name was

suggested from any source. We developed a set of questions to be used with each interviewee to ensure that we would collect similar information from each person we spoke with; we also developed three additional questions for DDDS staff that addressed internal system issues. All interviewees responded to the questions; we also followed some interviewees into territory that offered new observations or creative solutions to problems being discussed. People were uniformly generous with their time and their opinions, and we learned a lot about Delaware and its strengths. We also had a chance to explore some ideas that our interviewees had about areas of concern, and a summary of our findings follows.

Our initial question to everyone we spoke with was whether there *should be a separate office* within DDDS that deals with the needs of people with autism and their families. Responses to this question were mixed. The advantage of greater visibility was mentioned as a positive thing by advocates, because it might result in greater funding and greater oversight. It could also serve to guide families into the system with greater ease than they now experience. Several people pointed out that there would also be greater accountability and easier access to information for families with an identified office to go to. The office could draw experts in autism into the Delaware system so that resources to improve supports and services would be “in house” and available to anyone who was supporting someone on the autism spectrum. It was also suggested that a separate office would indeed be separate and not as likely to get caught up in overall agency problems. These comments enabled us to look at the functions that might be provided by a separate office, rather than focusing on “separateness” for its own sake.

The primary *concern about a separate office* is reflected in this statement: Delaware should be working to break down disparities in service, not creating an office that might increase disparity. Delaware should be focusing on “inclusion”, and many interviewees thought that a separate office would enhance the “silo effect” - segregating one population from others that DDDS serves. This, in turn, would undermine the sharing of expertise across the system and the coordination of services across DDDS and the Office. It would fly in the face of the goal of a consistent, integrated system of service and supports. Many people discussed at length the problems that a separate office would bring: the redundancy of intake, service planning, contracting, and all the other services the DDDS now provides, greater confusion about where to go to access services, make complaints, and gather system wide data. Almost all interviewees identified funding and oversight as needs across the system, and were concerned that a separate office might unfairly draw funding and attention away from DDDS as a whole. It would be far better to serve people based on their need rather than on their label. Again, interviewees provided us with many opportunities to look at functions.

We asked interviewees whether they saw people with autism as having separate needs, as a group, from others whom DDDS serves. While a few people mentioned behavioral and language as separate, most people reported that the issue was severity of need, not separateness of need. This led to conversations about supports, and there was almost universal agreement about *what would improve supports and services*. Most often mentioned was training. Training about autism for DDDS staff and provider staff would enable both to better serve the needs of families and consumers. Current training is intermittent, and not always directly relevant to issues that arise for either families or providers. Several people also mentioned training for families, focused both on the disorder but also including the ways Delaware's service system works. This should begin while consumers are in school, and should address the differences between entitlement and eligibility, the structure of the adult system, and how one accesses services, so that families and consumers are better prepared when they leave the education system. Most people also mentioned technical assistance as critical to improving services. Intermittent technical help would allow families to be responsive to changes that might arise with their family members; it would also allow providers to have access to help when individuals they are serving exhibit new problems or capacities. Interviewees' main concern was that the training and technical assistance be provided by experts, who knew current best practices across the spectrum, who had experience working with families and providers, and who could respond quickly to situations that might arise. The Statewide Autism Program run by Delaware's Department of Education was mentioned as a source for some of this expertise.

Almost everyone interviewed said that *getting information to families* about how to access services was a central issue in Delaware's design of its autism capacity. Several suggestions were made about how to improve what presently happens. Most commonly mentioned was the way advocacy organizations work. While there are several advocacy organizations that work with parents, families that know about them get information while other families struggle. Their efforts are not coordinated with the DDDS, so DDDS doesn't always connect families to advocacy organizations that could help them. Creating a section of the DDDS website with information for families involved with autism was a suggestion several interviewees made. A section of the website identified as "information about service for people with autism" could provide families with information about DDDS eligibility determination, possible services and supports, contact phone numbers, and advocacy organizations' information. Another way to inform families is through the education system. Many people interviewed suggested that DDDS work more cooperatively with the education system. Since most families with children under age twenty one are receiving services from Education within the state, using that education connection to organize and provide information makes good sense.

When asked about how various *state agencies work together* to service the population of persons on the autism spectrum, the response was unanimous: they do not. While people on the spectrum may have need for services from DMH, Vocational Rehabilitation, DDDS, or Aging, there are hard lines between the agencies and rarely are those lines crossed. Some lines result from the laws that created the agencies, such as restrictions from serving persons with cognitive impairment imposed on the state's Aging agency. Some seem to be more the result of present practice. Sometimes collaboration with the VR agency works; sometimes it doesn't. Rarely is there collaborative service provision with DDDS and DMH. Several people suggested that funding concerns support the separateness of the agencies, while others suggested that expertise did not exist in other agencies to serve people on the spectrum anyway. Several people also stated that in a system based on need for service, such lines should be broken down. They also suggested that this is a long term project, not something that DDDS can undertake on its own.

Everyone said that *transition* from school does not work for families or for students on the autism spectrum. Families do not realize that the adult system is different from the school system. Families do not understand the elements of the adult system, successful strategies from the school system are not carried forward into the adult system, and preparation is not done while the young man/woman is still in school to help make the transition more successful. Several interviewees saw a role for advocacy here: in creating a transition work group in which DDDS and education participated, plans could be made and realized for supporting families, young adults, and teachers/providers to be more successful in achieving appropriate transitions. Perhaps a month long "transition period" could allow for the school and adult services system to help young adults take their school successes and bring them into the adult system.

When asked if there were *resources within the system* that could be better used, interviewees across the board identified two. One is the **Center for Disabilities Studies**, College of Human Services, Education, and Public Policy at the University of Delaware. Many people mentioned it as a place where experts in autism could be trained, where allied health professionals like speech/language providers could receive relevant post graduate training, and where general, statewide training could be provided. While there was no clarity about how that might happen, the university is seen as a place that could support DDDS's plans for change. The other is the Statewide Autism Program, managed by the Delaware Department of Education. This program was mentioned many times, particularly around its success in providing educational services to people on the spectrum with significant disability. It was seen as a source of information for parents, skills training for providers, and consultation and technical assistance across stakeholders. Another resource, one that seems to be only occasionally available but which several people mentioned as a real asset, is short term

funding; it is used to see people through the transition period between school and adult services or the transition from home to services, as well as for responding to short term needs for those who live at home. Several people ascribed success experienced by people in the system to this kind of short term funding. In the area of resources within the system, one caution was offered by most who talked about existing resources. Interviewees do not see either the educational or DDDS system as particularly skilled at responding to the needs of persons with Asperger's Syndrome, and so were unable to suggest that there were resources within the system that could be tapped for this population.

Advocacy organizations and state agency staff agree that another *untapped resource is Delaware's families*. Because it is a small state, Delaware can make use of statewide resources easily, and it was suggested by many that knowledgeable, informed families from around the state could be involved in several areas. One is mentoring new families, or families new to the adult services system. Another is looking at quality, perhaps through working with DDDS in an advisory capacity; perhaps through working more closely with providers serving young adults/adults on the autism spectrum. Two interviewees suggested that families might make capable facilitators of person centered plans, since they have experience with being on the participant side of that planning process. Everyone agreed that continued legislative advocacy was important, both around funding and around possible service organization. And finally, families can have a powerful role in celebrating successes. When an individual with autism achieves his first successful job placement; when a current employee completes additional training related to autism; when there is a new provider agency particularly well suited to serving the needs of persons with Asperger's syndrome – these events deserve to be publicized as important steps toward success. Interviewees said that this celebrating could be best done by families, because they are known already for other kinds of advocacy.

In addition to training, supports, and capacity, interviewees were asked about the biggest problem in better responding to the needs of persons with autism. Their answer was *funding*. The funding climate in Delaware and across the country was the number one issue on interviewees' minds. Regardless of other comments, everyone said that there just aren't the funding streams available to radically alter the system to become more responsive. Several interviewees also mentioned that the ICAP as a tool for determining rates is inadequate and doesn't account for real costs or the real array of services and supports that people need. So even if funding were more available, current tools would not adequately identify funding needs. Several people also said that recent changes with the DDDS system were positive and should be continued, but that without significant new funding, there is no way to really change what happens in Delaware, and that DDDS has had a recent cut of about \$20 million to cope with. Many interviewees said that regardless of what other states were doing, their plans were

made in a looser fiscal time, when funding was more available and with states who were ready to try things out. Those times have changed, so Delaware will have to be careful about what it decides to do and how its decisions will support its mission of inclusion and full participation.

Two final areas were mentioned frequently. One is *data*. Almost everyone talked about how important the collection of good quality data would be to the success of building/increasing Delaware's capacity to serve young adults and adults with autism. Some of these data are available now – the number of people graduating from the education system, who have detailed records about their needs. Other data need to be gathered: the successes, as mentioned above; detailed information about gaps in services in various parts of the state; outcome data about particular services; the match between what consumers choose for themselves and the supports that are available. These and other data sets will enable Delaware to make decisions about next steps informed by the outcomes that resulted from earlier decisions, supporting the practice of taking the long view rather than coming up with 'quick fixes' to problems.

The final comment is that Delaware has an opportunity now to make decisions that will have a long lasting impact on services. Right now, it is focusing on the needs of persons on the autism spectrum and their families. It is looking to expand its capacity for people whose diagnoses meet criteria. But there are a lot of other people in Delaware with unmet needs. People with PDD/NOS or non-verbal learning disability also need help and they are not included in Delaware's definition of autism. Rather than focusing exclusively on the needs of persons with autism, interviewees suggested thinking more broadly about a system that would better serve persons with autism now, since there is an appetite for that, but one that could be responsive to other populations as that need arises. It was clear to almost everyone we spoke with that *building a system* should be the concern, one in which eligibility is based on both diagnostic criteria and functional criteria, one in which services and supports are available based on need, not label.

A model to consider:

There are risks and benefits from either a separate office or a new focus with the existing DDDS. In this fiscal climate, however, decisions about next steps must be taken with a view that balances what is affordable with how to be responsive to need. Of the states we reviewed, no one system was seen as a perfect fit for Delaware to adopt. A great advantage for Delaware is its people: they think creatively about what Delaware can do to improve. Although Delaware has regional differences in resources and some urban/rural variations, it is a small state, so sharing resources across the state is feasible. Finally, there are many resources already available; they need to be brought together in a way that enables maximum benefit from what already exists.

Interviewees were essential in formulating the model that HSRI is suggesting. The initial concept came from several people and was refined over all the interviews. The model is built on the template of a *resource room*, an educational tool that offers students and teachers special help in teaching and learning. The resource room has expert staff who are responsive to need when it arises, are engaged with other members of the school team to improve teaching and learning, and are involved in planning for the future of the children they serve. HSRI proposes that DDDS establish **The Delaware Resource Center**, an entity within DDDS that would offer expert advice, training, and system support to improve the quality of service to persons on the autism spectrum. It would not create a separate entry point into Delaware's service system for persons on the autism spectrum; rather, it would support Delaware across the system to become more responsive to the needs of persons with autism.

Here's how the model would work. Experts in autism and Asperger's syndrome would staff the office. These autism specialists would be available to the entire DDDS system in several ways:

- *As consultants to work with families.* When a family with a member whose diagnosis is on the autism spectrum needs help with a problem, the Autism specialists could work with the family support personnel to respond effectively to the problem. If they need help finding resources, case managers could connect with the Center staff to identify resources that might be useful to the family. As family consultation takes place, data would be collected by the **Resource Center** about needs and responses in such a way that it could be used by DDDS for future planning.
- *As consultants to DDDS.* A number of issues have been identified that DDDS should address in order to be more responsive to the needs of people on the autism spectrum. A primary issue is eligibility. Who by diagnostic label is appropriate for services from DDDS and how is eligibility determined for those people? The Delaware Legislative Task Force Report suggests that Delaware do several things around eligibility: accept as eligible a broader range of individuals who meet the functional limitations of diagnostic criteria (to include PDD/NOS and non verbal learning disability); include both diagnostic and functional impairment criteria in determining eligibility; and review the ICAP to determine whether it is the most appropriate tool to use for eligibility determination. Autism Specialists will be invaluable to the state as it addresses both these issues. They can also ensure that the state keeps current with evolving definitions, descriptions, and diagnostic criteria related to the autism spectrum.

- *As consultants to provider organizations:* While there are some providers within Delaware with success in serving people with autism, there are other providers who have little or no experience in this area. Autism Specialists could consult with providers about particular service needs of someone the provider serves or they could engage with a provider to prepare its staff to venture into the field of serving individuals on the spectrum. Further, Center staff could work with existing or new providers to develop models of services that might be effective for people within the system who are presently not served well, such as people with Asperger's syndrome. As experts, Center staff will know the "state of the art" strategies in providing services and can ensure that best practices are employed within Delaware.
- *As technical assistants.* Separate from the consultant role, Autism Specialists can be called upon to look at new models of services, to work with DDDS to find pilot funding for these models, to develop evaluation protocols for the models, and then to promote as appropriate those models that provide more efficient, effective services. This function would provide technical assistance to DDDS as it examines the way it structures services and supports; it might also inspire new ways of thinking about funding.
- *As coordinators.* While there are many excellent services in Delaware, coordination across the state and among the state agencies that offer these services does not happen. In consequence, there are duplications of services, expertise from one agency is not available to another agency, and consumers who need services from several agencies have a very difficult time accessing them. The **Resource Center** could take on the task of bringing various state agencies into discussions about how to better coordinate services. There would be no authority to enforce coordination, but conversation that brings light to some of the barriers to coordination and benefits of coordination could be useful in moving toward a system in which agency lines do not get in the way of addressing consumer's needs. One interviewee went further to suggest that there might be a benefit to Delaware in creating a mid-Atlantic Conference, in which states near to Delaware got together on a yearly basis to talk about program developments, new resources, sharing resources and expertise, and funding strategies.
- *As trainers:* Almost everyone interviewed mentioned the need for training around meeting the needs of people with autism. While the state has some resources that can be called upon within the education system, as well as some families who are very capable as trainers in the Autism Spectrum, these resources are insufficient to meet training needs for DDDS staff (applicant service office staff,

case managers, family support specialists), provider staff, and families. Other states, notably Pennsylvania and Vermont, have developed training materials that could be used effectively in Delaware; Center staff can be charged with identifying what is available, determining what is relevant to Delaware's needs, and borrowing or purchasing existing materials. Should additional materials be required, the Autism Specialists can be involved in the developing those materials.

Family training was identified as a critical need. Center staff can be a resource in this area by:

- Ensuring that advocacy organizations have access to current information by creating a simple list-serve for distribution of information and materials. This list-serve might be a model for information sharing across the DDDS/advocacy network.
- Creating a practical guide for families on the Delaware DDDS web site and describes clearly Delaware's philosophy and guiding principles and provides direction for action. South Carolina has developed such a guide, and it could serve as a model for Delaware. The initial focus of the guide could be for families of persons with autism, and the guide could then be expanded to address the needs of persons with other disabilities.
- Preparing short brochures that explain how DDDS serves individuals with autism and their families that could be made available at schools across the state.
- Collaborating with education staff to offer workshops for families as their sons and daughters turn 16. This would give families several years to plan, ask questions, connect with other families, and generally prepare for the transition of their children from school to adult life. Families who have already gone through the transition process could be involved in these workshops, as could advocacy organizations.
- Facilitating person centered planning meetings. One creative suggestion was made about a specific role for families. Those families who have gone through person centered planning with their sons or daughters could be trained as facilitators for person centered planning meetings for others. They would be able to connect well with family issues, they would know about autism and

Asperger's syndrome, and they would know about the system of supports that is available in Delaware.

Advantages of a **Resource Center** are several. Primarily, this model uses the existing system that DDDS has in place. It does not create a new division within DDDS, so it does not reinforce disparities between "regular" recipients of DDDS services and service recipients with autism. It does not require the replication of existing systems for contracting, eligibility determination and person centered planning. It supports the notion that for many people with autism, existing services can meet the need, while expanding Delaware's capacity to provide additional support for those who need it. It provides access to new models and additional training that will be required. Most importantly, the model enhances the capacity of the whole system to expand the quality and appropriateness of its services by providing *support to the system* for improvement. Autism Specialists at the **Resource Center** can enhance the capacity of the entire system to work with persons across the autism spectrum, and therefore enhance the capacity of the system to work with people who share similar goals or needs, whether they have the autism label or not.

The model is flexible. It can begin with a focus on autism and address one issue that Delaware determines to be of greatest priority. Then, as funding and need suggest, additional Autism Specialists can be hired to address additional priority areas, as identified by the Delaware Legislative Task Force or by DDDS itself. If the model proves successful, Delaware may decide to expand the **Resource Center's** capacity by including staff with expertise in other areas – head injury, sensory deficits, and mobility. These staff would also be available system wide, and so would help to improve the services across the system. This is an opportunity for Delaware to create the capacity to respond to a wide range of person-specific issues, rather than building a *system* that is tailored to a specific disability.

This description of the model requires adequate funding, but in funding as well as services, the model is flexible. It is a model that can be incremental. Delaware could begin with a contracted staff person, available perhaps part time, with a limited job description and even a single area of focus. Contracting allows Delaware to select someone as the first autism specialist who might be available electronically most of the time and in person only occasionally, depending upon how Delaware prioritizes the work. Here is an example of how this might work. The Delaware Legislative Task Force Report identifies eligibility as a critical issue. Delaware might decide to prioritize this as the work for the contracted autism specialist. Initial efforts could be directed toward creating a way for both diagnosis and function to be accounted for in determining eligibility. Then, the autism specialist could extend the work to engaging with DDDS to ensure that the full range of persons identified on the autism spectrum in the DSM are included under DDDS's umbrella. As additional funding becomes available, the contract

could be expanded to include training of case managers and family support specialists who work for DDDS, then members of the provider community, then parents. Perhaps the contract would be expanded to include significant additional time or additional autism specialists to accomplish the work. Eventually it might be possible for DDDS to hire staff directly into the office who would then, again over time, take on the various tasks that this report and DDDS identify. Limited capacity at first would require that Delaware prioritize the work to be done, so progress initially would be slow. However, this might also mean that progress would be clear and there would be new practices that would have a real impact on at least one area of the system. While the advocacy community may be looking forward to more rapid movement, accomplishing some of the foundational critical changes would prepare Delaware to undertake some of the more complex work around training and service model development that is deemed to be necessary by all the stakeholders in the system. Finally, the model responds to the fiscal situation in Delaware. With limited funding, there is still real work that can be done; with additional funding, more can be built on the basic foundation to result in a system that has the capacity to be more responsive and more relevant to the needs of both persons on the spectrum and families.

Massachusetts

Carrie Ann Harsh who is the Director of the Autism Division in Massachusetts.

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Pennsylvania

We did not speak with an individual. Information was gathered from the following site:

<http://www.dpw.state.pa.us/Resources/Documents/Presentations/PATC3.pdf>

South Carolina

Spoke with Collie Feemster (864) 594-4907 as well as Daniel Davis, Director Autism Division (803)-898-9639

Most of the information was gathered from *The South Carolina Department of Disabilities and Special Needs PRACTICAL GUIDE TO SERVICES For People with Severe, Lifelong Disabilities*

<http://www.state.sc.us/ddsn/service/contents.htm>

Vermont

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She provided the following links: Quality assurance process:

<http://www.ddas.vermont.gov/ddas-policies/policies-qmu/policies-qmu-documents/qm-plan> - Report to the legislature on ASD:

<http://www.ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/autism-legislative-report>

Persons interviewed by telephone: DDDS

Albert Anderson, Kent Regional Director, Community Services

Vanessa Deloach, Acting Director, Community Services

Warren Ellis, Director, Adult Special Populations

Roy Lafontaine, Deputy Director

Sequaya Tasker, New Castle Regional Director, Community Services

Pat Weygandt, Director of Development

Persons interviewed by telephone: organizations and families

Mary Ann Agazadian, Director, parent Information Center of Delaware

Theda Ellis, Executive Director, Autism Society of Delaware

Judy Govatos, Executive Director, Arc of Delaware

Tony Horstman, Chair, Governor's Advisory Council

Pat Maichle, Executive Director, Delaware Developmental Disabilities Council

Melissa Martin, Lower Delaware Autism Foundation

J. Kent Riegel, Chair, Legislative Task Force on Adults with Autism