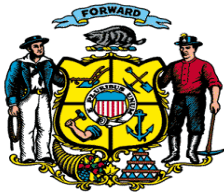


Report of the Governor's Task Force on Autism



Submitted to Governor Jim Doyle

December 2004

GOVERNOR'S TASK FORCE ON AUTISM

December 10, 2004

Governor Jim Doyle
115 East State Capitol
Madison, WI 53702

Dear Governor Doyle:

I am pleased to transmit the final report of the Governor's Task Force on Autism that you commissioned in April, 2004. The Task Force has made 38 recommendations. Nearly all of the recommendations are unanimous. Some recommendations have dissenting views and they are listed in the report as well. Each recommendation relates to at least one of the areas that you identified in your charge to the Task Force: service time, workforce, case management, the exceptions policy, services, parental fee sharing, and funding.

The Task Force members took their service on the Task Force extremely seriously and dedicated many hours to this effort. Their genuine desire to improve services to Wisconsin's children with autism spectrum disorders was obvious in every discussion. Although there are no easy answers to the challenges facing the state as it strives to serve these children, the Task Force made every effort to present thoughtful recommendations that would maximize the state's limited resources.

On behalf of the Task Force members, thank you for giving us the opportunity to contribute to this important effort.

Sincerely,



Karen E. Timberlake, Chair

GOVERNOR'S TASK FORCE ON AUTISM

Members of the Task Force

Linda Carmody, Green Bay
Kathy Draves, Madison
Rose Helms, Evansville
Kevin Klatt, Eau Claire
Diane Konkel, Brookfield
Deb Mandarino, Madison
Heather Marena, Brookfield
Paula Petit, Mondovi
Cynthia Thomas, Green Bay
Karen Timberlake, Chair

Staff: Donna Wong and Bonnie Feggestad of the Governor's Office, Jim Johnston and Dennis Rhodes of the Department of Administration (DOA), Beth Wroblewski of the Department of Health and Family Services (DHFS), and Dominga Surillo of the Office of State Employment Relations. The Task Force gives special thanks to the staff at DHFS for their assistance throughout the course of the Task Force's work.

GOVERNOR’S TASK FORCE ON AUTISM

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INTRODUCTION

Governor Doyle met with numerous parents in the early spring of 2004 regarding issues of treatment for children of autism through the state's Medicaid program. After meeting with these parents and listening to their concerns, he directed his office to create a Task Force to develop policy recommendations on several issues.

The Task Force met from May, 2004 until September, 2004. They identified problems with the current system as well as formed recommendation for solutions. This report discusses the recommendations of the Task Force as well as dissenting views. The recommendations are presented in the order of the Charge to the Task Force and the numbering should not be seen as any sort of prioritization.

There are several places in the report that refer to children with autism. References to children with autism in this report mean all children with autism spectrum disorders. In addition, many of the recommendations have fiscal impacts. While the precise fiscal impact is not indicated in each case, without additional funding, some recommendations could lead to waiting lists or fewer new slots available. The Task Force made efforts to craft recommendations that would maximize existing resources, while realizing that some recommendations would in fact require additional resources in order to preserve existing levels of services for families currently receiving services through the state Medicaid program. The following introduction was written by budget analysts at DOA.

The Children's Waivers

The Children's Waivers are Home and Community Based Services (HCBS) waivers that afford the state the flexibility to develop alternatives to placing Medicaid-eligible children in hospitals, nursing homes or intermediate care facilities for persons with mental retardation. The Children's Waivers allow for service options that are not available under regular Medical Assistance (MA). These service options are available in addition to services covered by regular MA. In general, waiver services are broader in scope and less medically oriented than community-based Medicaid fee-for-service or "card" services such as personal care. To be granted a Medicaid waiver, a state must demonstrate that the care it will provide for under the waiver will reduce Medicaid expenditures, or, at a minimum, be cost neutral.

The federal Centers for Medicare and Medicaid Services (CMS) approved three new Children's Waivers for Wisconsin on November 20, 2003 to serve children with developmental, physical and severe emotional disabilities. The three waivers are known collectively as "The Children's Waivers" and autism services are included under the waivers for children with developmental and emotional disabilities.

History of Autism Services

Wisconsin began covering intensive in-home behavioral treatment under the state's fee-for-service Medical Assistance program in 1994 for one child at a cost of \$2,400. By the end of fiscal year 2002-03, the program was serving over 1,000 children with a cost in excess of \$40 million, a level of service that other states did not provide. In response to statements from the federal CMS that a HCBS waiver was the appropriate means for a state to receive federal funds

for providing in-home autism services, DHFS transitioned children receiving autism services to a two-tiered HCBS waiver in second half of fiscal year 2003-2004. Budgeted at approximately \$32 million annually, the waiver provides up to 3 years of intensive in-home services to children 8 years old or younger and provides a range of on-going services to older children and those who have completed the 3-year intensive phase.

Services Available to Children with Autism

Children in intensive in-home slots receive one-on-one behavioral treatment only. No other non-treatment services are authorized for children in the intensive phase of the program.

Children enrolled in on-going autism slots may continue to pursue behavioral treatment. They may also receive other supportive services including adaptive aids, communication aids, consumer education and training, consumer and family-directed supports, counseling and therapeutic resources, daily living skills training, day services, home modifications, personal emergency response system, respite care, specialized medical and therapeutic supplies, specialized transportation, support and service coordination, and supportive home care.

Budget for Children's Waivers and Autism Services

Although autism services are included under the Children's Waivers, the budgets for autism services and the Children's Waivers are maintained separately by the state. The non-autism components of the Children's Waivers are budgeted at approximately \$1.5 million for the biennium. The funding supports implementation costs including development of a functional screen, quality assurance, and database revisions; 25 waiver slots in Milwaukee County; 7 waiver slots in each of 4 pilot counties; and, 40 statewide waiver slots for crisis situations.

The budget for autism services was developed to serve an average monthly caseload of 1,225 children in 2003-2004 and 1,403 children in fiscal year 2004-05 for a total of \$66.5 million over the biennium. This includes \$2 million over the beinnium that DHFS added at the Governor's direction in order to reimburse providers for their travel costs. Following standard DHFS waiver policy, counties are allowed to take up to 7% of the daily rate they receive for operating the waiver for administrative costs. Costs for case management, also referred to as support and service coordination, are built directly into the daily rate. The budget assumes an average of 4 hours of support and service coordination a month for intensive slots and 2.5 hours a month for on-going slots.

Katie Beckett Eligibility

The Katie Beckett Program is a special eligibility process that allows certain children with long term disabilities or complex medical needs, living at home with their families, to obtain a Wisconsin Medicaid card. Children who are not eligible for other Medicaid programs because the income or assets of their parents are too high, may be eligible for Medicaid through the Katie Beckett Program, if they meet certain criteria, including a level of care at home that is typically provided in a hospital or nursing facility. As services transitioned to the waiver, 90% of the children had their MA through the Katie Beckett special Medicaid eligibility process.

CHARGE

The Governor charged the Task Force with forming recommendations on the following:

- A) Identify activities included in service-time for recipients of in-home intensive treatment.
- B) Identify options for building a qualified workforce of in-home intensive service line staff.
- C) Identify options for ensuring adequate state coverage by in-home intensive treatment providers.
- D) Identify options for providing case management to participants in waiver programs.
- E) Discuss the newly developed exceptions policy.
- F) Discuss options for parental fee sharing.
- G) Identify services available to all children with autism.
- H) Identify other means of funding autism services.

ACTIVITIES INCLUDED IN SERVICE TIME

The Task Force was asked to address concerns raised by parents and providers regarding necessary activities related to treatment that are presently being counted against a child's allotted treatment hours in the intensive phase, or against the child's overall budget in the post-intensive phase. Of particular concern were reimbursement for travel and reimbursement for collateral contacts. The Task Force attempted to form recommendations that maximized face-to-face treatment time with children while compensating providers for activities that are a necessary part of providing treatment.

Travel

In the intensive phase, each child receives an allocation of total hours. The total hours may include face-to-face treatment time, collateral time, and travel. Most new children entering the intensive phase are authorized 35 hours of face-to-face time with increased hours in areas where more travel time is necessary. Children in more rural areas are allocated more time if needed due to increased travel demands. However, since the three types of time are bundled in the intensive phase, parents and providers have expressed concern that necessary reimbursement for travel time and collateral contacts is cutting into valuable treatment time. To address travel issues in the last budget, the Governor directed DHFS to add \$2 million over the biennium to reimburse providers for their travel costs. None the less, travel issues remain. For example, Task Force members observed that some families in the intensive phase are reducing contact with senior therapists in order to conserve resources.

In the on-going phase, children receive a total budget for services rather than an allocation of hours. Travel cannot currently be billed separately in the on-going phase. Accordingly, service time is affected since some of the child's budget in the on-going phase must go to travel reimbursement.

1. **Recommendation:** Direct DHFS to identify alternative funding sources for travel, especially funds that could be targeted to assist rural families and children in medically underserved areas.
2. **Recommendation:** Direct DHFS to investigate options for locating treatment programs more centrally when distance to a provider is a problem.

Although the Task Force was not charged with identifying the role of schools in treatment, they agree that schools could house centrally located treatment centers, and they recommend that the state examine the feasibility of this option.

3. **Recommendation:** Allow flexibility in treatment delivery locations and modalities, with parent and provider consent, in order to reduce need for travel.

Currently, treatment in the intensive phase must be provided one-on-one in the child's home. Allowing treatment to be provided in a workshop or group model may reduce the need for travel and increase families' access to providers, especially in rural areas. Group workshops could include treatment and social skills classes. The Task Force stressed the importance of parental consent when allowing treatment to be provided in a workshop model.

4. **Recommendation:** Direct DHFS to reinforce travel billing guidelines with counties.

Although DHFS recently sent a memo to counties clarifying the travel billing policy, the policy is not being followed consistently. As discussed extensively in the Case Management section of this report, the Task Force discussed many examples of inconsistent practices in administration of the waiver from county to county. These inconsistencies are a major source of frustration for parents and providers alike and, in the judgment of the Task Force, have contributed to the decisions of some providers to discontinue providing services under the waiver.

5. **Recommendation:** Direct DHFS to create an ombudsman position, independent of the waiver program, to mediate travel and administrative issues.
6. **Recommendation:** Allocate any new travel funds made available first to all children in the on-going phase and then to new children in the intensive phase.

Many children currently in the intensive phase already received an increase in their approved hours so that they would receive the same amount of face-to-face time under the waiver as they received under the card service.

Currently, in the on-going phase, as noted above, children receive an overall budget for services. That budget has not been increased to account for travel. In addition, the average budget for services in the on-going phase is approximately one quarter of the average budget in the intensive phase. Accordingly, children in the on-going phase are affected disproportionately by travel expenses, especially in rural areas. This recommendation would effectively increase a child's budget in the on-going phase.

Collateral Contact

Collateral contact is defined as time spent by the provider regarding a specific child where the child does not have to be present. For example, a meeting among the members of a child's treatment team about the child's treatment is considered collateral contact and is billable under the waiver.

The central problem the Task Force identified with collateral contact is that while collateral contact is necessary for treatment, provider billing for such contact is debited against the child's allotted hours. Similarly, under the current waiver, children participate in the intensive phase for 3 years, and any billing on the child's behalf starts this 3-year clock. Although parents are currently allowed to pay for additional collateral contact time, this option is not feasible for every family depending on its available financial resources.

The following recommendations are made for children in the intensive phase.

7. **Recommendation:** Cap billing for collateral contact at no more than 20 percent of the child's calculated 6 month average allotted hours.
8. **Recommendation:** Direct DHFS to further clarify billing for collateral contacts to counties, providers, and parents. Develop additional policies to clarify.

For example, team meetings by teleconference could qualify for reimbursement. Such an approach would conserve travel time. A memo was distributed to counties, but the policy is still not clearly understood.

9. **Recommendation:** Start the intensive phase clock when the child begins receiving 20 hours of face-to-face treatment per week.

The Task Force discussed the need for providers to receive reimbursement for time spent assembling and training a child's treatment team. The Task Force attempted to balance provider needs with families' interests in maximizing resources devoted to treatment. This recommendation would allow providers some start-up time to assemble and train the treatment team without being offset against a child's allotted treatment or services.

BUILDING A QUALIFIED WORKFORCE

The Task Force was charged with identifying strategies for building a qualified workforce of treatment providers for children with autism. The Task Force focused on two broad issues under this topic: provider supply and provider training.

The Task Force noted the concerns that many families have expressed in not being able to find providers to treat their children. Task Force members also shared anecdotes based on their own experiences, as well as those of other families who contacted them during the course of their work, describing numerous situations where families experienced long gaps in treatment or were otherwise unable to realize the full benefit of the treatment resources allotted to them because of a provider's inability to fully staff a treatment team over time. This problem was described as being particularly acute for those families who wish to continue to pursue treatment in the on-going phase.

The Task Force also discussed the need to expand and improve training opportunities for current providers as well as those interested in becoming providers of treatment to children with autism. The Task Force's objectives in focusing on provider training were to maximize the efficient use of the limited state and provider resources available for provider training, deepen the pool of trained professionals and line staff from which providers can draw, and continue to improve the quality of services provided to children and families.

Staff Training

10. Recommendation: Direct DHFS to form a workgroup consisting of providers and DHFS staff to further analyze the impact of various staff training proposals on cost, provider supply, and other issues. Direct the workgroup to recommend high quality training approaches.

The Task Force developed many proposals on staff training but did not want to make a formal recommendation in this area because they felt more input was needed from a wide range of providers.

Some of the ideas the Task Force identified for consideration by the workgroup include: applying for outside training grants; cross-provider training; senior therapists training parents and parents training line staff; provider networks to sponsor training for parents with the goal of parental independence; and Wisconsin colleges, universities, and technical colleges offering basic line staff training courses and integrating line staff internships into curriculum and course requirements.

11. Recommendation: Reimburse the first 30 hours of initial line staff training with waiver funding. The first 15 hours of training would be general training and therefore would not count against the child's total hours. The second 15 hours would be child specific training and would be credited against the child's hours.

Currently, providers may be reimbursed for line staff training if a senior therapist supervises it and the child is receiving direct treatment. However, providers are often not able to bill for all training time because the provider must also meet the minimum requirement of at least 20 hours

of face-to-face treatment of the child. High line staff turnover requires providers to train new staff frequently adding to providers' overhead expenses. The Task Force identified this as another barrier to attracting new providers into the waiver, as well as keeping the providers who currently participate.

Lead and Senior Therapists

Lead and senior therapists are the professionals who are responsible for developing and monitoring the child's treatment plan. A lead therapist must have specific credentials such as a doctoral degree in psychology and must have a specific amount of experience. Similarly, a senior therapist must have a master's degree or a bachelor's degree and meet specific experience requirements.

When billing for services changed from the Medicaid card to the waiver, the reimbursement rate was changed from a 8 tiered rate schedule with rates for lead, certified senior, non-certified senior, and line staff face-to-face treatment, plus lead, certified senior, non-certified senior and line staff travel time, to a blended rate. The blended rate was based upon a typical blend of time for children receiving 28 hours of service, which was the average amount of time billed under the Medicaid fee-for-service system. The blended rate was adopted in an effort to streamline billing and make administration of the waiver easier for providers and county administrators of the waiver.

However, the Task Force expressed concern that the blended rate has led to families receiving less professional staff time. For example, the blended rate encourages providers to hire senior staff with bachelor degrees instead of master's degrees. Senior therapists with bachelor degrees can presumably be paid less per hour than senior therapists with master's degrees, thereby stretching the available treatment dollars. Task Force members expressed concern about what they perceive to be a dilution of the strength of the treatment team in light of the blended rate. In addition, the Task Force also expressed concern that the blended rate represents a significant reduction in overall provider reimbursement from the card service to the waiver, thereby further discouraging provider participation and jeopardizing the sustainability of participation by current providers.

The Task Force also discussed other barriers to recruiting and retaining qualified lead and senior therapists. Although DHFS requires that treatment provided in the intensive phase be behaviorally based, the Task Force noted that the state does not recognize certified behavioral analysts through licensure or other designation. This relatively new field is producing more and more graduates. By not recognizing this certification, Wisconsin may not be attracting this group of professionals to work in the state.

The Task Force recommended several ways to recruit and retain lead and senior therapists.

- 12. Recommendation:** Direct the same DHFS-provider workgroup recommended under staff training to examine provider reimbursement rates and make a specific rate recommendation with the goal of retaining a quality provider pool that delivers high quality, effective treatment.

Further direct the workgroup to develop a recommendation on provider rates by January 1, 2005. Direct DHFS to work with providers in immediate danger of discontinuing participation in the waiver to continue participation until recommendations are implemented. Include parents of children receiving treatment in the work group for purposes of this issue only.

13. **Recommendation:** Amend the waiver to allow certified behavioral analysts with a Ph.D. and experience with children with autism to be recognized as lead therapists.

Currently, certified behavioral analysts and certified associate behavioral analysts are not allowable providers under the waiver. Behavioral analysts who want to be lead therapists must apply for a variance in order to participate. The Task Force recommends removing this unnecessary hurdle to wavier participation by these specially trained professionals.

14. **Recommendation:** Create a state certification through DHFS, or a board certification through the Department of Regulation and Licensing, for certified behavioral analysts and certified associate behavioral analysts.

The Task Force recommends recognizing behavioral analysts in order to attract new providers to the state. The Task Force recommends that DHFS or the Department of Administration (DOA) investigate the two types of possible certification and that the Governor introduce legislation, if needed, to create one of the two types of certification.

15. **Recommendation:** Introduce legislation that would provide loan forgiveness to undergraduate and graduate students pursuing degrees in psychology with an emphasis in behavioral analysis if the student accepts a job in Wisconsin as a treatment provider for autistic children and remains in the state for at least 3 years.

Currently there are two programs in the University of Wisconsin System that offer a psychology degree with an emphasis in behavioral analysis, UW-Eau Claire and UW-Milwaukee.

Line Staff

Line staff work under the direction of the lead and senior therapists to implement the treatment plan. They receive their training from and are supervised by lead and senior staff, but they work one-on-one with the children. The line staff also sometimes accompany the child to community based activities that are intended to facilitate generalization of the principles being covered in the in-home sessions. There is high turnover among this group, leading to training costs for providers, interruption in services to families, and transition issues for children. The Task Force recommended several ways to recruit and retain line staff.

16. **Recommendation:** Give financial incentives to line staff to recruit them to the profession. Provide sign-on bonuses. Award scholarships to college students who work as line staff and pursue a related field of study.
17. **Recommendation:** Encourage providers to initiate outreach efforts to recruit parents to work as line-staff.

The Task Force noted that parents of children with autism could be an underutilized pool of potential staff.

18. **Recommendation:** Direct DHFS to create a guide for parents on how to recruit and screen line staff.

In many parts of the state, college students are a good source of potential line staff, but this is not the case in all areas, especially rural communities. In addition, other, less transient populations such as seniors and spouses that do not work outside of the home could be a more stable source of workers. Parents, particularly those with children in the post-intensive phase, are often heavily involved in helping to find line staff. The Task Force felt that technical assistance around recruiting, interviewing, and evaluating line staff applicants would be valuable to parents performing this function.

19. **Recommendation:** Create co-ops and family networks to pool efforts such as interviewing and hiring line staff. Direct DHFS to create a web-based clearinghouse of line staff as a way to match parents and providers seeking line staff with interested candidates.

The Task Force noted that some providers may from time to time have more line staff candidates than they need, while others may be short. Such a clearinghouse could facilitate faster hires and minimize disruptions in childrens' treatment.

CASE MANAGEMENT

The Task Force was charged with identifying options for providing case management to participants in waiver programs. Under requirements established by CMS for Medicaid waivers, the state must meet minimum service coordination, or case management, requirements. For example, each child must have an initial assessment, eligibility determination, case plan development, and plan review every six months. Currently, these services are provided by case managers. In addition, case managers provide information to families, act as a liaison between families and providers, and provide quality assurance regarding the treatment and services families are receiving.

The Task Force identified several problems with the current case management system. Case management is viewed by some families as an administrative cost that takes funding away from treatment. The amount charged by each county varies between \$40 and \$125 per hour depending upon which allowable costs are included by the county. Some families, particularly those who were participating in the card service, feel they do not need case management as it is currently being administered by many counties. The most recent actuals show that families receive between 1 and 2 hours per month of case management per child. While families can apply to receive less than this amount, many families are not aware of this option or do not know how to apply. In addition, some Task Force members reported that not all counties are willing to reduce the amount of case management a family receives.

The Task Force also identified problems with the current administration of the waiver program, including administration of case management. Currently, counties and a few contracted private human services agencies administer the waiver. The Task Force expressed concern that administration by so many different entities leads to inconsistent interpretation and application of program requirements.

The Task Force described many administrative challenges that providers are currently experiencing with county administration. Providers enter into contracts with individual counties. Those contracts were reported by the Task Force not to be uniform from county to county. Some providers contract with multiple counties and therefore have several contracts with different requirements and timetables. Audits, civil rights compliance, and affirmative action reporting are state requirements that must be conducted by each county. In addition, there are counties that include unique, county-specific requirements in their contracts. Complying with nonconforming contracts can be expensive and time consuming for providers.

The Task Force noted that some aspects of the case management function as it is currently being administered are working well for families. The Task Force observed that the case managers themselves are usually dedicated, caring professionals who are doing their best for the children and families with whom they work. County administration of case management was felt to be particularly valuable in rural areas, given the relative lack of other resources for families in those areas. The Task Force also acknowledged the superior knowledge of local resources that county human services agencies have in all parts of the state. They noted that some families participating in the waiver participate in other human services programs and get continuity of support through one case manager. Finally, the Task Force acknowledged that some families need more case management services than others.

The Task Force formed its recommendations regarding case management with the following goals in mind: high quality, minimal administrative costs, flexibility in the level of case management services, and administrative consistency statewide.

20. Recommendation: Direct DHFS to submit a waiver amendment request to CMS to change the waiver to a state administered program, including state administration of the case management function. Simultaneously work with counties to resolve other issues such as inconsistent contracts and additional requirements.

State level operation of the waiver—an approach that would involve DHFS assuming management of the existing waivers on a statewide basis using a contracted agency or group of contracted agencies—would require DHFS to establish statewide standards that govern how vendors interact with families. In addition, state level operation of the waiver would require the development of a consistent set of business process, audit, and compliance standards for service providers.

State level operation of the waiver would likely take between 1 to 3 years to fully implement. DHFS would need to develop and issue a Request for Proposal (RFP) to identify a contract agency to complete the assessment, eligibility, plan development and plan review work that is required under the federal waiver.

When the Task Force made this recommendation, it requested a cost estimate comparing the costs of case management as currently administered with the costs of case management if it were to be administered by the state. Preliminary DOA estimates found state level operation of the waiver to be about \$497,000 more costly on an annual basis than the current county administered system. Although this preliminary estimate was based on a number of assumptions rather than direct experience, the Task Force recognized that it is at best uncertain whether state administration and operation of the waiver would be more cost effective compared to the current county administered system. However, the Task Force based its recommendation on a firm belief that the quality of the program would be enhanced by a state run system, and thought that the costs in the DOA estimate could be reduced in a variety of ways. Furthermore, the Task Force thought that some problems with county administration could not be solved and that any cost increases in state management would be offset by a decrease in case management services chosen by families.

Dissenting View: Retain the current administration of the waiver with the following revisions. Work with the counties to improve the administration of the current system by: improving collaboration and communication between county administration, county case managers, the state, parents, and providers; scheduling uniform training for county case management to be monitored by community integration specialists; and simplifying billing and payment schedules for providers and county case managers. In addition, develop a packet in Spanish and English for parents that would explain the waiver, give contact information, and explain the funding allocation developed for the program.

A state run system would take several years to implement and would have start up problems just as the county system does. Families and providers have experienced a great deal of change in autism services in the last year, and the advantages of a state-run system do not seem to outweigh the costs and stress associated with another transition. In addition, counties

would have no incentive to improve the existing system in the interim and could exercise their right to stop managing the program as is allowed by the 60-day clause in their contracts. This would be a hardship for the families that rely on case management services. Many families have ongoing, strong relationships with their case managers that would be disrupted by a transition away from the current model.

21. **Recommendation:** Direct DHFS to send parents and providers specific instructions on how to request minimal case management services. Direct DHFS to use existing authority to require counties to honor qualified requests by parents for reduced case management services. Create an easy to use form and provide examples for families that illustrate the information required on the form.

Currently a family may request an exception to receive the minimum ongoing service coordination contacts. In order to qualify for an exception, the family must provide a rationale for the request and submit a plan that describes how the health, safety and welfare of the child will be assured without the required contacts. This recommendation would make it easier for families to make a request and receive a reduced level of case management services, conserving resources that could instead support other recommendations of the Task Force.

22. **Recommendation:** Increase case manager training. Conduct uniform training of case managers so that information is disseminated accurately.

23. **Recommendation:** Direct DHFS to give parents and providers the same written information on program requirements and administration that is given to counties.

EXCEPTIONS POLICY

The Task Force was charged with discussing and making recommendations on the newly developed exceptions policy.

Currently, intensive in-home autism treatment services are available to children who first enroll in the waiver when they are under 8 years of age for a period not to exceed 3 years of service. In addition, children must be prescribed a minimum of 20 hours per week of treatment in the intensive phase. An extension beyond 3 years of service may be granted in some exceptional circumstances, but there must have been a complete lapse in services of at least 90 days, there must be clinical justification to support the extension, and the child must have received 6 months of continuous service at some point within the original 3-year timeframe. For example, an extended illness may qualify a child for an exception.

24. **Recommendation:** Eliminate the exceptions policy. Instead, allocate the same number of total hours to families as they currently receive under the 3 year plan; however, allow families to use the hours over a 4 year period.

Under this recommendation, 20 hours per week of treatment would still be required in the in-home intensive treatment phase under normal circumstances; however, with agreement between the provider and the family, the child could go below that level without needing to apply for an exception. Families would not be entitled to use the total number of hours if the hours were not used during the 4-year period.

The Task Force reached this recommendation after considering the wide variety of circumstances that may cause a child's treatment to be interrupted. Ultimately, the Task Force concluded that this approach was fair to families and also respected the limits of the current waiver design.

25. **Recommendation:** Direct DHFS to develop alternative approaches to the current age restriction policy in the intensive phase. Include providers, parents, the Department of Public Instruction (DPI), and other stakeholders on a work group.

While the Task Force recognized that the policy restricting children from starting intensive in-home treatment after age 8 was developed based on a widely, if not universally, held view that that intensive services are most effective for very young children, the Task Force felt that some children could benefit from starting services after age 8. The Task Force expressed particular concern about children with Asperger's Syndrome, who tend to be diagnosed when they are older, or children who are diagnosed after age 8 because the family has had limited access to qualified diagnostic professionals. The Task Force also noted that many children with autism will need some amount of government-sponsored support or assistance throughout their whole lives, and the Task Force encourages DHFS to consider the most effective ways of providing needed services to these children.

SERVICES AVAILABLE TO ALL CHILDREN WITH AUTISM

The Task Force was charged with identifying services available to all children with autism. The Governor was interested in recommendations regarding services that could be available in the post-intensive phase.

There are 2 phases of the autism waiver program, the intensive and the on-going phase. As explained in the previous section, intensive in-home autism treatment services are currently available to children for 3 years. A child in the intensive in-home treatment phase is eligible to receive up to 20-35 hours of face-to-face treatment per week. After 3 years, a child is moved to the on-going phase. In the on-going phase, a child has an allocated budget and families can choose among all services available on the waiver. Those services include treatment but also include non-treatment services such as respite and adaptive aids.

The Task Force discussed the treatment that, in its view, should be provided in either the intensive or post-intensive phases, as well as the nature of services that should be provided in the post-intensive phase.

Intensive Services

26. Recommendation: Only reimburse evidence-based treatment that is shown to be beneficial based on clinical trials or single subject design experiments published in peer-reviewed journals.

Case notes and surveys would not be sufficient to document effectiveness. Children currently receiving treatments without support in published, clinical research would be able to continue those treatments for 5 years. Other treatment approaches would be eligible to be covered after 5 years provided that research supports the effectiveness of the approach. New participants in the waiver would receive coverage only for evidence-based treatment. Simultaneously work on increasing provider supply.

A majority of the Task Force expressed the view that only treatment that has been demonstrated to be effective through peer-reviewed research should be authorized under the waiver. The rationale of those expressing this view was that limited state funds should be used for those treatments that are most likely to be effective, so as to provide the best care for children and maximize their progress and potential. Although DHFS currently requires treatment provided in the intensive phase to be behaviorally based, the Task Force expressed concern that providers are receiving reimbursement for treatment approaches that are not behaviorally based or whose effectiveness is not adequately supported by research.

Dissenting View: Continue to allow all approaches currently allowed in the intensive phase. Focus on evaluating the effectiveness for each child and whether that child is making progress. Without an adequate supply of providers, a restriction to certain types of treatment may leave families without access to any services.

On-going Services

After a child has had 3 years of intensive services, the child is moved to the on-going phase of the waiver. Currently, each county receives a total amount based upon \$30.60 per day per child, but the actual amount received by an individual child is budgeted by the county. Counties are authorized to vary the amount a child receives based on the child's needs, although many families still receive about \$30.60 per day in services.

Some families continue the behavioral intervention therapies that they received in the intensive phase and, on average, these families are able to purchase 7 to 8 hours of services per week within their budget, although many families have problems finding providers who will take children with that number of hours. Families also have options to choose a variety of other services under the waiver, such as specialized child care and after school care, communication aids, respite care, consumer education, family directed services and supports, daily living skills, and supportive home care.

The Task Force expressed a strong and unanimous concern that the amount currently budgeted for families in the on-going phase is inadequate to provide the level of services that many of those children need, particularly those families still pursuing treatment. The Task Force discussed the "cliff effect" of the current program design, which may result in a child's treatment being greatly reduced at the exact point a child is beginning to make substantial progress. The Task Force also discussed the fact that even children who may be ready to transition to a reduced level of services after the intensive phase may at some point need a higher level of services, for example, as they go through puberty or make transitions in school. Task Force members also observed that behavioral treatment is not available in most Wisconsin Schools.

27. Recommendation: Increase the average daily rate to \$48 per child per day in the on-going phase. Base the actual amount received on the child's need. Base the need determination on a functional screen. Direct DHFS to add criteria to the functional screen for children with autism.

Currently, children in the on-going phase receive an average of \$30.60 per day. Although counties already have the authority to base the actual amount a child receives on the child's assessed needs, many families do receive about \$30.60 per day in services. The intent of this recommendation is to increase available services to children with higher need while decreasing services to children with lower need.

Dissenting View: Retain the structure of the program as it is currently administered. Do not fund high-need children more than low-need children in the on-going phase. Children who are considered low need still have as many needs as children considered high need.

28. Recommendation: Assuming recommendation #27 is adopted, establish a hold harmless provision so that no child shall receive a level of service lower than they are currently receiving in the on-going phase, as long as they are pursuing treatment in the on-going phase.

Dissenting View: Retain the structure of the program as it is currently administered. No child should receive less service than they are receiving now in the on-going phase regardless of what services they are currently receiving.

29. Recommendation: For treatment in the on-going phase, only reimburse evidence-based treatment that is shown to be beneficial based on clinical trials or a single subject design experiments published in peer-reviewed journals.

Case notes and surveys would not be sufficient to document effectiveness. Children currently receiving treatments that do not have support from published clinical research would be able to continue those treatments for 5 years. Other treatment approaches would be eligible to be covered after 5 years provided that research supports the effectiveness of the approach. New participants in the waiver would receive coverage only for evidence-based treatment. Simultaneously work on increasing provider supply. Do not exclude secondary treatments, such as brushing, that happen during the primary evidence-based therapy.

A majority of the Task Force expressed the view that only treatment that has been demonstrated to be effective through peer-reviewed research should be authorized under the waiver. The rationale of those expressing this view was that limited state funds should be used for those treatments that are most likely to be effective, so as to provide the best care for children and maximize their progress and potential.

Dissenting View: Retain the funding and structure of the program as it is currently administered. For treatment in the on-going phase, allow all treatments currently covered. Focus on evaluating the effectiveness for each child and whether that child is making progress. Without an adequate supply of providers, a restriction to certain types of treatment may leave families without access to any services.

30. Recommendation: Primarily fund evidence-based treatment in the on-going phase. In addition, allocate \$3,000 annually for families that choose non-treatment services.

Currently, children in the on-going phase receive an average of \$10,000 of services per year; however, the exact amount varies depending on the assessed needs of the child. The Task Force's recommendation would increase the annual average above \$10,000 for families that choose treatment and would limit families to \$3,000 if they choose non-treatment, such as supportive services. Under the recommendation, a family could receive coverage under the waiver for treatment or other services, but not both.

The majority of the Task Force expressed the view that treatment continues to be effective after the conclusion of the intensive phase and the state should, therefore, invest its limited resources in the manner most likely to benefit children, their families, and ultimately society. Task Force members related many examples of families who wish to continue to pursue treatment in the on-going phase but are unable to do so because of the sharp drop in available resources between the intensive and on-going phases under the current waiver design.

Dissenting View: Retain all of the current services available in the on-going phase and do not distinguish between treatment and other services.

Children benefit from different approaches and some families do not have access to treatment services. Limiting services would hurt these children. Families should be allowed to choose the services that they think are most essential and beneficial in light of their individual circumstances. In addition, limiting reimbursement for other services disproportionately affects lower income families. For example, a YMCA membership, which is cost prohibitive for lower income families, provides a tremendous benefit to families with a child with autism for little cost. Without an adequate supply of providers, restricting families to treatment-only may leave families without access to any services.

31. **Recommendation:** Direct DHFS to use existing authority to require all counties to allow families to carry over dollars from month to month to use later in the year.

Currently, families are allowed to carry over dollars from month to month, but some counties will not allow this, and most counties will not allow families to do so for an entire year as unexpended funds lapse at the end of each year.

32. **Recommendation:** Direct DHFS to develop a specific SPC code for on-going treatment. Define on-going treatment as anything previously available on the Medicaid card or available now in the intensive phase.

The Task Force observed that the lack of a specific SPC code for autism treatment prevents DHFS from tracking families' choices to spend their allotted budgets in the on-going phase on this specific type of treatment. The Task Force also expressed the view that the purchase of treatment materials should be part of this code.

Dissenting View: Retain the structure of the program as it is currently administered. It is unnecessary to create a new SPC code because, as the waiver is currently written, appropriate definitions are in place or are monitored by DHFS.

Both Intensive and On-going Services

33. **Recommendation:** Direct DHFS to examine the problem of counties not putting people on Family Support waiting lists.

34. **Recommendation:** Direct DHFS to submit an application for a separate autism waiver and remove autism services from the children's long-term support waiver.

The Task Force expressed the position that it did not want its recommendations to affect or apply to children with other disabilities, as families of those children were not represented on the Task Force. The Task Force felt that a separate autism waiver would assure that their recommendations only apply to children with autism.

Dissenting View: Retain the structure of the program as it is currently administered.

PARENTAL FEE SHARING

Act 33 directed DHFS to implement a parental fee for children's long-term care services. The Department must develop a formula to assess the fee, which requires decisions regarding family income and service levels. Since the new policy will affect all children in the children's long-term support waiver, and not just children with autism, DHFS is gathering feedback from many groups on how to implement the new policy. This is the Autism Task Force's recommendation to the Governor and DHFS.

35. **Recommendation:** Keep fees as low as possible by keeping collection costs low. Implement a progressive fee scale or a flat fee, whichever is less expensive to administer.

If a flat fee is less expensive to administer, the fee would be flat only for families within a specific income range; however, the Task Force did not recommend the specific range. The Task Force recommends considering \$50,000-\$150,000 but notes that the beginning of the range may be too low. They recommend no parental fee for those families with incomes below the low end of the range. After the high end of the range, the Task Force recommends a progressive fee. The Task Force did not specify the dollar amount of the fee.

The Task Force recommends that families with more than one child in the children's waiver pay only one parental fee and that co-payments be returned to the program in which the child participates, such as autism services.

When calculating household income, the Task Force recommends deducting \$3,300 per child in the waiver program (up to 1 child) or the federally reportable medical expenses, including health insurance premiums and deductions, whichever is greater. All of a family's medical expenses would be eligible to be deducted under this recommendation, regardless of whether the family meets the applicable federal threshold for deducting medical expenses. The Task Force also recommends that household income and size be calculated in the same manner as under the Birth-to-Three Program. Finally, the Task Force recommends that the parental fee share in the on-going phase be less than in the intensive program.

Dissenting View: A progressive fee scale should be implemented regardless of administrative cost. There is a large difference between a family earning \$50,000 per year and a family earning \$150,000 per year. A progressive fee scale is more equitable and linked to ability to pay.

OTHER FUNDING OPTIONS

The Task Force looked at other funding sources for children with autism. Insurance mandates were one of the sources examined.

Wisconsin law does not currently require that private health insurance companies cover or provide treatment for individuals with a diagnosis of autism or a pervasive developmental disorder. At least 11 other states have laws, most often passed under the umbrella of mental health parity legislation, that require some form of coverage for autism treatment. Five more states identified by the National Association of Insurance Commissioners (NAIC) have specific laws that mandate some form private insurance coverage for autism treatment.

Rights to any state mandated insurance benefit depend on whether a covered individual's health plan is fully insured or self-insured. Self-insured plans, also frequently referred to as self-funded plans, are not subject to state regulation. Wisconsin's Office of the Commissioner of Insurance (OCI) estimates that approximately 50% of covered Wisconsin residents are in self-insured plans.

36. Recommendation: Support legislation that would require insurance companies to cover 4 hours per month of consultation with a certified behavioral analyst or psychologist for autism treatment in any setting.

37. Recommendation: Direct DHFS to create an on-going committee to examine other funding sources such as insurance mandates, surcharges on moving violations, excise taxes on the purchase of specific goods, or a surcharge on nurse or doctor licensing fees.

The Task Force recommends including parents of children with all disabilities, legislators, and providers on the committee. The Task Force recommends that the committee specifically examine insurance plans that do cover autism services in other states, and consult with the Office of the Commissioner on Insurance on the current law in Wisconsin with the goal of identifying other viable funding sources.

38. Recommendation: Create a committee to examine the role of the schools and other early childhood programs in providing services to children with autism. Include representation from DHFS, DPI, parents, providers and other stakeholders.

Although the Task Force was not charged with the role of schools in providing services, they agree that the role of schools could be strengthened. The Task Force noted that there is a bright line in Wisconsin between treatment of children with autism, provided through programs like the wavier, and education of children with autism, provided by schools. Although outside of its charge, the Task Force observed that this bright line is artificial and is not in the best interest of many children whose education often must be combined with treatment approaches in order to be successful.

SUMMARY OF THE RECOMMENDATIONS

The following recommendations are presented in the order of the Charge to the Task Force and are in no priority order.

- 1. Recommendation:** Direct DHFS to identify alternative funding sources for travel, especially funds that could be targeted to assist rural families and children in medically underserved areas.
- 2. Recommendation:** Direct DHFS to investigate options for locating treatment programs more centrally when distance to a provider is a problem.
- 3. Recommendation:** Allow flexibility in treatment delivery locations and modalities, with parent and provider consent, in order to reduce need for travel.
- 4. Recommendation:** Direct DHFS to reinforce travel billing guidelines with counties.
- 5. Recommendation:** Direct DHFS to create an ombudsman position, independent of the waiver program, to mediate travel and other administrative issues.
- 6. Recommendation:** Allocate any new travel funds made available first to all children in the on-going phase and then to new children in the intensive phase.
- 7. Recommendation:** Cap billing for collateral contact at no more than 20 percent of the child's calculated 6 month average allotted hours.
- 8. Recommendation:** Direct DHFS to further clarify billing for collateral contacts to counties, providers, and parents. Develop additional policies to clarify.
- 9. Recommendation:** Start the intensive phase clock when the child begins receiving 20 hours of face-to-face treatment per week.
- 10. Recommendation:** Direct DHFS to form a workgroup consisting of providers and DHFS staff to further analyze the impact of various staff training proposals on cost, provider supply, and other issues. Direct the workgroup to recommend high quality training approaches.
- 11. Recommendation:** Reimburse the first 30 hours of initial line staff training with waiver funding. The first 15 hours of training would be general training and therefore would not count against the child's total hours. The second 15 hours would be child specific training and would be credited against the child's hours.
- 12. Recommendation:** Direct the same DHFS-provider workgroup recommended under staff training to examine provider reimbursement rates and make a specific rate recommendation with the goal of retaining a quality provider pool that delivers high quality, effective treatment.

- 13. Recommendation:** Amend the waiver to allow certified behavioral analysts with a Ph.D. and experience with children with autism to be recognized as lead therapists.
 - 14. Recommendation:** Create a state certification through DHFS, or a board certification through the Department of Regulation and Licensing, for certified behavioral analysts and certified associate behavioral analysts.
 - 15. Recommendation:** Introduce legislation that would provide loan forgiveness to undergraduate and graduate students pursuing degrees in psychology with an emphasis in behavioral analysis if the student accepts a job in Wisconsin as a treatment provider for autistic children and remains in the state for at least 3 years.
 - 16. Recommendation:** Give financial incentives to line staff to recruit them to the profession. Provide sign-on bonuses. Award scholarships to college students who work as line staff and pursue a related field of study.
 - 17. Recommendation:** Encourage providers to initiate outreach efforts to recruit parents to work as line-staff.
 - 18. Recommendation:** Direct DHFS to create a guide for parents on how to recruit and screen line staff.
 - 19. Recommendation:** Create co-ops and family networks to pool efforts such as interviewing and hiring line staff. Direct DHFS to create a web-based clearinghouse of line staff as a way to match parents and providers seeking line staff with interested candidates.
 - 20. Recommendation:** Direct DHFS to submit a waiver amendment request to CMS to change the waiver to a state administered program, including state administration of the case management function. Simultaneously work with counties to resolve other issues such as inconsistent contracts and additional requirements.
- Dissenting View:** Retain the current administration of the waiver with the following revisions. Work with the counties to improve the administration of the current system by: improving collaboration and communication between county administration, county case managers, the state, parents, and providers; scheduling uniform training for county case management to be monitored by community integration specialists; and simplifying billing and payment schedules for providers and county case managers.
- 21. Recommendation:** Direct DHFS to send parents and providers specific instructions on how to request minimal case management services. Direct DHFS to use existing authority to require counties to honor qualified requests by parents for reduced case management services. Create an easy to use form and provide examples for families that illustrate the information required on the form.
 - 22. Recommendation:** Increase case manager training. Conduct uniform training of case managers so that information is disseminated accurately.

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- 23. Recommendation:** Direct DHFS to give parents and providers the same written information on program requirements and administration that is given to counties.
- 24. Recommendation:** Eliminate the exceptions policy. Instead, allocate the same number of total hours to families as they currently receive under the 3 year plan; however, allow families to use the hours over a 4 year period.
- 25. Recommendation:** Direct DHFS to develop alternative approaches to the current age restriction policy in the intensive phase. Include providers, parents, DPI, and other stakeholders on a work group.
- 26. Recommendation:** In the intensive phase, only reimburse evidence-based treatment that is shown to be beneficial based on clinical trials or a single subject design experiments published in peer reviewed journals.

Dissenting View: Continue to allow all approaches currently allowed in the intensive phase. Focus on evaluating the effectiveness for each child and whether that child is making progress.

- 27. Recommendation:** Increase the average daily rate to \$48 per child per day in the on-going phase. Base the actual amount received in the on-going phase on the child's need. Base the need determination on a functional screen. Direct DHFS to add criteria to the functional screen for children with autism.

Dissenting View: Retain the structure of the program as it is currently administered. Do not fund high-need children more than low-need children in the on-going phase.

- 28. Recommendation:** Assuming recommendation #27 is adopted, establish a hold harmless provision so that no child shall receive a level of service lower than they are currently receiving in the on-going phase, as long as they are pursuing treatment in the on-going phase.

Dissenting View: Retain the structure of the program as it is currently administered. No child should receive less service than they are receiving now in the on-going phase regardless of what services they are currently receiving.

- 29. Recommendation:** For treatment in the on-going phase, only reimburse evidence-based treatment that is shown to be beneficial based on clinical trials or a single subject design experiments published in peer-reviewed journals.

Dissenting View: Retain the funding and structure of the program as it is currently administered. For treatment in the on-going phase, allow all treatments currently covered. Focus on evaluating the effectiveness for each child and whether that child is making progress.

- 30. Recommendation:** Primarily fund evidence-based treatment in the on-going phase. In addition, allocate \$3,000 annually for families that choose non-treatment services.

Dissenting View: Retain all of the current services available in the on-going phase and do not distinguish between treatment and other services.

31. Recommendation: Direct DHFS to use existing authority to require all counties to allow families to carry over dollars from month to month to use later in the year.

32. Recommendation: Direct DHFS to develop a specific SPC code for on-going treatment. Define on-going treatment as anything previously available on the Medicaid card or available now in the intensive phase.

Dissenting View: Retain the structure of the program as it is currently administered.

33. Recommendation: Direct DHFS to examine the problem of counties not putting people on Family Support waiting lists.

34. Recommendation: Direct DHFS to submit an application for a separate autism waiver and remove autism from the children's long-term support waiver.

Dissenting View: Retain the structure of the program as it is currently administered.

35. Recommendation: Keep parental fees as low as possible by keeping collection costs low. Implement a progressive fee scale or a flat fee, whichever is less expensive to administer.

Dissenting View: A progressive fee scale should be implemented regardless of administrative cost. A progressive fee scale is more equitable and linked to ability to pay.

36. Recommendation: Support legislation that would require insurance companies to cover 4 hours per month of consultation with a certified behavioral analyst or psychologist for autism treatment in any setting.

37. Recommendation: Direct DHFS to create an on-going committee to examine other funding sources such as insurance mandates, surcharges on moving violations, excise taxes on the purchase of specific goods and a surcharge on nurse or doctor fees.

38. Recommendation: Create a committee to examine the role of the schools in providing services to children with autism. Include representation from DHFS, DPI, parents, providers and other stakeholders.

APPENDIX

The Governor's Task Force on Autism received many letters and e-mails from parents, providers, and members of the public during the five months that it met. In addition, after the Task Force report was released to the public, comments on the recommendations were gathered through letters and a public hearing. Over 1,200 letters and testimony were received. Some of the comments responded to specific recommendations while others expressed more general concerns or offered unique suggestions of their own. The following is a summary of the comments received. The summary reflects the main points people made that had the strongest support.

Oppose recommendations #20, 34

Many people stated that the waiver is working well for them and that they appreciate the case management aspect of the waiver. They said that they contact their case managers to get answers to questions and help locate resources. In addition, some said that case managers know the unique services of each county and that after the children's waiver services are completed, it is helpful to be known by the county as the child will continue to receive other services. Similarly, some observed that changing the program would prevent counties from providing coordinated long-term care services.

Many people stated that after many initial start-up challenges, the waiver was working well now. Several individuals and organizations commented that while many of the issues with county management identified in the report were real, that as the county gained experience with administering the waiver many of the initial issues with the program had been addressed or were continually improving. Further, several people stated that there would be problems inherent in starting up a state administered system and that changing administration would be another upheaval for families.

The Counties Association stated that at the request of DHFS, many counties in Wisconsin agreed to participate in coordinating autism services for families in their counties. The transition was not without difficulty; however, the association felt that as time went on, counties got more experience coordinating services and that many of the initial issues were resolved.

Some people stated that the intent of the children's waivers was to create an integrated system for all children with disabilities. Many others said that a separate autism waiver would give preferential treatment to children with autism over children with other disabilities and would perpetuate a falsehood that children with autism have needs greater than children with other disabilities.

Support recommendations #20, 34

Some parents wrote to tell their individual stories about problems with county administration or case management. Many of these families wrote that case management was an unnecessary service that takes funding away from treatment. Some parents wrote to ask that the waiver policies be clarified stating that the policies were unclear from county to county.

In addition, some providers wrote to say that they supported the concept of having the state administer the program. They explained that from the provider perspective, there was a lack of continuity between the counties that they serve. For example, although working under the same waiver, some providers explained that they would often be told different and conflicting

information from one county to the next. Some providers said that this has led to confusion not only on their part, but on the part of the parents that they work with as well.

Many people wrote to ask for a separate autism only waiver. They said that autism is a unique disability and that the behaviors and learning deficits associated with autism tend to be more difficult and stressful on these families than the behaviors associated with other disabilities are on other families.

Support recommendation # 24

Many people wrote or testified in support of the elimination of the 3-year rule in the intensive phase. They said that all children should have access to the total number of therapy hours they are allocated, rather than using a defined 3-year period for therapy access. In addition, a number of people expressed the view that the state should not guarantee 3 years of intensive treatment to all children since some children will only need 1 year and some will need more than 3 years.

Oppose recommendations #26, 29

Many people stated that the treatment or services their children were using were effective for their child, yet those treatments would not fit the criteria specified in recommendation #26. They stressed that there are several ways to treat autism, each child is different, and that there can not be a one size fits all approach to therapy for children with autism. Many personal stories were submitted that explained how a specific treatment was tried and wasn't effective and then a different treatment was used and was effective for their child.

Support recommendations #26, 29

Many people also stated that they supported recommendation #26. These parents said that in times of limited funding, the state should only fund treatment that is effective and stated that evidence-based treatment that is shown to be beneficial based upon clinical trials or single subject design experiments published in peer reviewed journals was a useful way of identifying effective therapies. These parents stressed that the definition of evidence-based treatment would include many different therapies.

Oppose recommendation #30

The Task Force received many letters and heard testimony opposing giving more funding to families that choose evidence-based treatment in the on-going phase over families that choose other services in the on-going phase of the program. People who were opposed to this recommendation stated that an array and choice of services should be provided in the on-going phase. Some parents explained how services other than traditional treatment had benefited their child. Further, some stated that the distinction between treatment and other services seemed artificial since all of the treatment and services help families raise a child with a disability and help children thrive in the community. Some pointed out that the waiver spans birth to age 21, so there is great need for flexibility as the same services are not effective for every age. In addition, some said that the waiver was originally adopted to provide families with flexibility and choice of services most effective for their families while saving Medicaid funding.

Support recommendation #30

The Task Force also received many letters and heard testimony that supported funding evidence-based treatment more than other services in the on-going phase. Most of these people also supported limiting treatment in the intensive and on-going phases to evidence-based treatment.

Many of these families stated that their children were making progress in the intensive phase and that after transitioning to the on-going phase, their children were not making as much progress anymore due to the decreased hours. They argued that funds for other services were taking the already limited on-going phase dollars away from treatment. Some of the people who asked the Governor to primarily fund treatment stated that autism funds were restored specifically for treatment, not other services. Those expressing these views also observed that when budgets are tight, treatment should be funded before services.

Oppose recommendation #35

Many people wrote to say that they did not support the recommendation on parental fee sharing. Although the Autism Task Force is only one of many affected groups that DHFS is seeking feedback from on this policy, some people wanted it to be noted that a flat fee would be inequitable for families on the low end of the flat fee range.

Some recommended that a progressive family cost share be implemented that starts at an income level of \$60,000 and that families with more than one child on the autism spectrum be limited to one cost share. Others suggested focusing on fees as a percentage of income rather than as the percentage of care costs. Many people expressed concerns about the difficulties that middle-income families would have in paying the fees. They stressed that some children may go without treatment if the family could not or would not participate due to the parental fees.

General Comments and Other Proposals

Task Force recommendations would negatively impact children with other disabilities Some people and organizations commented that implementing many of the recommendations such as loan forgiveness to autism providers or staff bonuses would give preferential treatment to children with autism over children with other developmental disabilities.

Extend the waiting period for people who move to the state to receive treatment

Several people wrote to express concern that the waiting period is not long enough to discourage people from moving to the state for the purpose of receiving services for autism under the Medicaid waiver. They stated that some people move to the state so that their children can receive treatment, and then they leave once treatment is completed. This, they said, drains resources from other children with autism.

Intensive Phase Services

Some people suggested broadening services available in the intensive phase to include services that assist families with safety, care and parenting needs such as perimeter fences, therapeutic supplies, adaptive equipment and respite care.

Role of Schools

Several people wrote to support an increased role of schools in treating and supporting students with diverse needs, including autism. Some suggested reallocating funds to provide support for smaller class sizes and training teachers in educating children with autism. Others suggested allowing waiver funds to be used to allow professionals to consult with school staff and for other activities that would increase inclusion of children with autism into the classroom.