

RE: Notice Number: NOT-MH-08-003

Dear Sir or Madam,

Thanks for the opportunity to respond to this RFI. As parents of children with ASD and members of the Board of POAC (Parents of Autistic Children) of Central Maryland, we would like to provide input in the 4 areas you requested. POAC of Central Maryland's mission is to ensure local education agencies in our region provide quality research-based education to children with autism, and to provide training to parents, educators and other professionals regarding the use of research-based interventions.

Educational & Behavioral Treatment:

Since there is now a great number of children with ASD, and many more will certainly be born, diagnosed and treated before a prevention or cure is discovered, this area needs significant attention. Effective treatments will improve the quality of life of those affected and their families, and should reduce the public burden of long-term support of these individuals.

Recently much research has gone into diagnosis, with excellent results, but far too little has been done in the treatment that must follow diagnosis. There is no consensus on educational or behavioral treatments even though there has been some research and success in these areas. Insurance companies consider all methods "experimental". Public school systems, which are required to provide a Free and Appropriate Education, continue to provide inconsistent and highly variable education. To this end:

- New research is needed to fill in the gaps in current research, investigate the comparative effectiveness of treatments currently under research or debunk the spotty research that has been done.

In one of the few comparative treatment studies currently available, California State University researchers note this need, concluding:

Studies that further investigate the short-and long-term effects of "eclectic" intervention are also needed... The same can be said of early intervention that is based primarily or exclusively on models that have not yet been subjected to thorough scientific evaluations, such as TEACCH, "developmentally appropriate" programming, "floor time," Relationship Development Intervention, and sensorimotor techniques.¹

The results of such research would be of urgent interest to parents, schools and clinicians.

- Existing research-based treatment must be developed into a repeatable practice.

The great majority of existing treatment research has been conducted in university or clinic settings under conditions that are carefully controlled. While necessary to ensure the validity of the findings, this results in the dismissal of findings by local school systems as impractical to implement in an inclusive public education. A line of research that specifically targets translation and application of clinic-based treatments to inclusive education settings is critical.

- Existing research needs to be reviewed and as a result of such review, research based treatment standards acceptable to insurers and school systems (or courts) need to be established.



POAC of Central MD : Training... Support... Advocacy

A model for the review process that is needed already exists in the National Standards Project currently being directed by the National Autism Center. This project is proceeding slowly due to the voluntary role of the reviewers. Public funding for this project or one building on its model would greatly accelerate the results. HHS would be well positioned to engage the stakeholders who could then use the review to establish standards.

Medical Treatments:

Information from different institutions treating ASD is not disseminated effectively to other institutions or to private practice. In many parts of the country, there is little help available as the practice of treating ASD is limited to a few teaching hospitals where there is an emphasis on children. We are aware of efforts to establish national centers of autism research to address this issue, but this could be accelerated.

Diagnosis:

Research into diagnosis has been quite successful. This work needs to be developed to a maturity that private practice pediatricians are able and willing to perform this screening. As with treatment, standards need to be developed so that nonspecialty hospitals and private and school psychologists are equipped to address the referrals generated by private practice pediatricians and others.

Risk Factors and Biology:

Current research into the cause(s) of ASD is quite fragmented and incomplete. Understanding the biology of ASD will likely improve medical (pharmacological) treatments before a cause is determined or a cure developed. Targeted research into the subtypes of ASD and the biology of each will hopefully result in effective medical treatments while still accomplishing the goal of understanding the cause or cure. Definition of subtypes could also feed into targeting treatment research to determine whether certain interventions are more effective for individuals in certain subtypes.

In summary, much of the research that has been done has not been developed into routine practice. At a recent conference, the head of a state school system's autism program acknowledged the success of recent research, but responded: "I really can't do much until someone has written a manual". Closing the gap between research and practice could help many children soon.

Thanks for the opportunity to provide input. For the POAC of Central Maryland Board of Directors,

/s/
Pete Eisenreich

/s/
Wil Gehne

ⁱ Howard, Jane S., Coleen R. Sparkman, Howard G. Cohen, Gina Green and Harold Stanislaw (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, 26, 359-383.

