Autism doesn't discriminate....neither should we.

Many families are coping with autism these days. Consider the statistics; one in every 88 children is diagnosed with autism spectrum disorder (ASD). Even more startling, one in every 54 boys has autism. There is a child born every eight seconds in the United States, and according to the US Census Bureau, more of those births will be boys than girls.

One of the "gold standard" mental health treatment for kids on the spectrum is Applied Behavior Analysis or ABA.

Due to the passage of SB 946 the CA Autism Insurance Mandate, parents of children with autism who have state regulated health plans now have hope. Autism therapy should be covered through their plan. Regional Centers, the California agencies responsible for serving residents with developmental disabilities, can and should be responsible for the co-payment.

Although not all ASD kids qualify for regional center services.....only 20% qualify.

Also not all kids with ASD have private health insurance....Not by a long shot.

As a country we have made a vow that all children should receive timely access to medical treatment. Should we not also provide timely access to medically necessary behavioral health treatment.

ABA is scientifically proven to ameliorate the core deficits of autism, and kids that receive this Treatment make substantial, sustained gains in IQ, communication and socialization. Also ABA reduces mal-adaptive behaviors. All are necessary to become functioning members of society.

Children that do not receive this therapy may not be able to function in society, thereby costing us more money over their lifetime. As country we realized if we do not pay now we WILL pay later. This is why EPSDT coverage was set up in the first place.

With low income children the access to behavioral health specialist are high and if you have autism it's even worse. We cannot continue to allow the state/county mental health to continue to exclude low-income children with autistic spectrum disorders access ESPDT funds to obtain medically necessary treatment.

Autism doesn't discriminate, neither should we!

Allow low-income children with autistic spectrum disorders to access ESPDT to obtain medically necessary treatments.

ABA is an intensive, one-on-one outpatient therapy which has been successfully used to treat children at all levels on the autism spectrum for over five decades. It is an evidence based medical treatment which has been endorsed by the Office of Surgeon General, the Academy of Pediatrics, and many other esteemed agencies. The CA regional center system offers this treatment to children with autism prior to age three for those who qualify for Federal Early Start initiatives. After age three, however, many CA regional centers do not offer direct services to children with autism, and those that do, typically provide less than 10 hours a week of therapy, which is much less than what is medically necessary to be effective (25 hours a week is the standard).
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<td>Furthermore, low-income children who are on the high end of the autism spectrum still need ABA, but they do not qualify for regional center services and have no way to access this medically necessary treatment. Some school districts may provide very watered down versions of the treatment, but the most significant piece, the 1-on-1 intensity, is simply not available. School districts do not have a duty to alleviate disability and maximize functioning, as health plans do. They only have to provide an appropriate program. With the passage of SB 946, those with state regulated private health insurance will be able to obtain ABA services from their health plans, but those on MediCal are excluded from the law. Many states, including the District of Columbia and Virginia, are allowing low income children with autism to obtain ABA through ESPDT. ESPDT was created in part to screen for and treat mental health conditions in children on Medicaid. Autism is a severe mental health condition, but CA typically does not allow those with autism access to ESPDT services. Many low-income CA children with autism have no way to access this medically necessary treatment. The ESPDT program is a good way to make these services available.</td>
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<td>Allow those with special health needs to continue to buy in to Healthy Families due to lack of adequate networks.</td>
<td>While allowing those with incomes between 133 and 200% of the FPL to be eligible for MediCal is a great thing, many in this category with children had been able to buy in to the Healthy Families program for a very small amount of money. Due to recent budget cuts to Medi-Cal, specialist networks are often inadequate to meet the needs of children with special health needs, including autism. Healthy Families is a better option for many of these families, as it allows access to a more extensive network of providers, and also allows access to better mental health protection under the state mental health parity act. Please continue to allow families with special health care needs a choice between these two programs, regardless of income, by creating a waiver option.</td>
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<td>Medicare with lowest effective dose, disseminate safe tapering plan</td>
<td>Patient safety should be the paramount goal in any medication optimization plan. Dosages should be adjusted to the lowest effective dose for an individual, which may be much lower than those set by pharmaceutical companies in clinical trials. Every patient should be afforded the opportunity to safely discontinue medication upon remission, lack of efficacy, or should adverse effects outweigh benefits. Please consider this excellent plan developed by a coalition of patient advocates and adopted in Ashland, Ohio <a href="http://www.mentalhealthexcellence.org/Portals/2/Foundation%20Documents/Medication_optimization_in_the_service_of_recovery.pdf">http://www.mentalhealthexcellence.org/Portals/2/Foundation%20Documents/Medication_optimization_in_the_service_of_recovery.pdf</a> As “taper very gradually” is interpreted variously, I would add a recommendation of a 10% taper each month for 2 months, increase speed of taper if no withdrawal symptoms or if they last only a few days, lower the amount of decrement (e.g. 5%) if withdrawal symptoms appear at 10% decrements. (The 2-month trial taper is because sometimes it takes some weeks for withdrawal symptoms to show up, and if they do, slowing the taper will reduce neurological damage to the patient.)</td>
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To Whom It May Concern:

Our undersigned organizations have reviewed the documents submitted by the state to the Centers for Medicare and Medicaid Services (CMS) on October 30, 2012 requesting an amendment to the existing "Bridge to Reform" Section 1115 waiver. On November 9, 2012, we joined the National Health Law Program and other organizations in sending a letter to CMS expressing our concern that the state has submitted a request to amend an unrelated waiver, instead of applying for a new 1115 waiver specific to the Healthy Families transition and providing a meaningful opportunity for public comment and review. We also provided feedback to the state in a separate letter outlining additional concerns with their waiver amendment request and offering recommendations on how they may address some of those concerns.

In addition, we have thoroughly reviewed the Healthy Families Program (HFP) Transition Network Adequacy Assessment and Updated Strategic Plan released on November 1, 2012. As we indicated in our comments to the state, we continue to have outstanding concerns and questions about children’s access to care as part of the proposed Healthy Families transition – particularly around network adequacy for serving new applicant children, access to dental providers, and the adequacy of networks in non-Phase 1 transition areas. We strongly urge CMS to withhold approval of the transition until CMS determines that network adequacy requirements are met, without concern for issuing approval by January 1, 2013, which is not a statutorily required start date.

We believe that an ongoing monitoring process and overall performance standards must be in place before the Healthy Families transition begins, in order to ensure that the state and health plans can be held accountable for assuring access to care for children. In the initial approval of the "Bridge to Reform" Section 1115 waiver, the Special Terms and Conditions (STC) included explicit requirements for progress reporting and an independent evaluation of the transition to managed care for other populations under the waiver (e.g., Seniors and Persons with Disabilities and the Community-Based Adult Services).

We, therefore, request that as negotiations with the state on the Healthy Families transition move forward, that CMS insist the terms include:

1. monthly progress reporting requirements that pull from a variety of data sources (e.g., monthly enrollment data, quarterly utilization and encounter data, child-only HEDIS and CAHPS metrics, provider network change reports, plan grievances or appeals, help line calls and complaints, etc.) in order to identify new and monitor ongoing issues with access to care;

2. an independent evaluation component with a pre- and post-transition comparison analysis based on specific performance measures, such as whether children successfully transitioned from HFP to Medi-Cal with no interruption in care or loss of coverage and wait times for scheduling an appointment, that are determined before the transition begins;

3. a requirement that notices to transitioning families reflect only federally agreed upon policies. For example, the state is currently on track to send out a 30-day notice to the children transitioning in Phase 1A on December 1, and that notice includes a policy for determining premiums that has not yet been negotiated and

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<td>Comments from Children's Health Advocates</td>
<td>To Whom It May Concern: Our undersigned organizations have reviewed the documents submitted by the state to the Centers for Medicare and Medicaid Services (CMS) on October 30, 2012 requesting an amendment to the existing &quot;Bridge to Reform&quot; Section 1115 waiver. On November 9, 2012, we joined the National Health Law Program and other organizations in sending a letter to CMS expressing our concern that the state has submitted a request to amend an unrelated waiver, instead of applying for a new 1115 waiver specific to the Healthy Families transition and providing a meaningful opportunity for public comment and review. We also provided feedback to the state in a separate letter outlining additional concerns with their waiver amendment request and offering recommendations on how they may address some of those concerns. In addition, we have thoroughly reviewed the Healthy Families Program (HFP) Transition Network Adequacy Assessment and Updated Strategic Plan released on November 1, 2012. As we indicated in our comments to the state, we continue to have outstanding concerns and questions about children’s access to care as part of the proposed Healthy Families transition – particularly around network adequacy for serving new applicant children, access to dental providers, and the adequacy of networks in non-Phase 1 transition areas. We strongly urge CMS to withhold approval of the transition until CMS determines that network adequacy requirements are met, without concern for issuing approval by January 1, 2013, which is not a statutorily required start date. We believe that an ongoing monitoring process and overall performance standards must be in place before the Healthy Families transition begins, in order to ensure that the state and health plans can be held accountable for assuring access to care for children. In the initial approval of the &quot;Bridge to Reform&quot; Section 1115 waiver, the Special Terms and Conditions (STC) included explicit requirements for progress reporting and an independent evaluation of the transition to managed care for other populations under the waiver (e.g., Seniors and Persons with Disabilities and the Community-Based Adult Services). We, therefore, request that as negotiations with the state on the Healthy Families transition move forward, that CMS insist the terms include: (1) monthly progress reporting requirements that pull from a variety of data sources (e.g., monthly enrollment data, quarterly utilization and encounter data, child-only HEDIS and CAHPS metrics, provider network change reports, plan grievances or appeals, help line calls and complaints, etc.) in order to identify new and monitor ongoing issues with access to care; (2) an independent evaluation component with a pre- and post-transition comparison analysis based on specific performance measures, such as whether children successfully transitioned from HFP to Medi-Cal with no interruption in care or loss of coverage and wait times for scheduling an appointment, that are determined before the transition begins; (3) a requirement that notices to transitioning families reflect only federally agreed upon policies. For example, the state is currently on track to send out a 30-day notice to the children transitioning in Phase 1A on December 1, and that notice includes a policy for determining premiums that has not yet been negotiated and</td>
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agreed upon with CMS. If the agreed upon policy differs from what is now included in the notice, sending out a corrected notice will further confuse families; and

(4) a requirement that the state identify how it will comply with ACA Maintenance of Effort protections for children previously eligible for Healthy Families that will be transitioned into Medi-Cal. The STCs should require a plan for what Medi-Cal policies will need to be modified in order to ensure that children previously eligible for Healthy Families will not be at risk of losing coverage as a result of any difference between Healthy Families' and Medi-Cal's eligibility procedures.

Thank you for your consideration, and we look forward to our continued discussion about these issues.

Sincerely,

California Coverage & Health Initiatives
Children Now
Children’s Defense Fund-California
The Children’s Partnership
United Ways of California