Survey results of proposed topics for the Policy Council for Children and Families (PCCF) 2018 legislative report

as conducted by

Texas Parent to Parent

August 2017
Q1 Help for families (please select 3):

Answered: 104    Skipped: 0

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better access to health care providers &amp; therapy services throughout the state</td>
<td>70.19%</td>
</tr>
<tr>
<td>Better access to support services throughout the state</td>
<td>61.54%</td>
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<tr>
<td>Provide support before a child with a disability goes to Child or Adult Protective Services</td>
<td>22.12%</td>
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<tr>
<td>Continuity of services during HHS transformation</td>
<td>25.00%</td>
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<tr>
<td>Provide behavior therapies, including ABA</td>
<td>39.42%</td>
</tr>
<tr>
<td>Require thorough background checks on anyone who works with children/youth with disabilities</td>
<td>25.96%</td>
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<tr>
<td>Access to medical marijuana for children it could help</td>
<td>34.62%</td>
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<tr>
<td>Allow families to provide input on how the state facilities are being used</td>
<td>20.19%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>26.92%</td>
</tr>
</tbody>
</table>

Total Respondents: 104
Q2 Mental Health Issues (please select 2):

Answered: 102  Skipped: 2

**ANSWER CHOICES** | **RESPONSES**
---|---
Implement Trauma Informed Care to provide appropriate client treatment | 36.27% 37
Statewide and uniform implementation of best practices in children’s mental health and suicide risk assessments | 61.76% 63
Provide safe and supportive environments in school for children with mental illness | 73.53% 75
Better coordination between families and Residential Treatment Centers | 18.63% 19
Provide a way to have "Host Families" so children will have more than one home and families will get a break | 27.45% 28
Other (please specify) | 6.86% 7

Total Respondents: 102
Q3 Transition to Adulthood (please select 3):

Answered: 104  Skipped: 0

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Guide for students before they leave school</td>
<td>27.88%</td>
</tr>
<tr>
<td>Training for students and families on services &amp; benefits at age 18 &amp; 21</td>
<td>65.38%</td>
</tr>
<tr>
<td>Require medical transition planning for students with medical conditions</td>
<td>29.81%</td>
</tr>
<tr>
<td>Promote employment &amp; work with companies in the community to find employment</td>
<td>69.23%</td>
</tr>
<tr>
<td>Promote independent living with community support &amp; transition services</td>
<td>74.04%</td>
</tr>
<tr>
<td>Certified family partner services and peer supports for families</td>
<td>34.62%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>5.77%</td>
</tr>
</tbody>
</table>

Total Respondents: 104
Q4 Education (please select 1):

Answered: 103      Skipped: 1

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully fund Special Education Services</td>
<td>59.22%</td>
</tr>
<tr>
<td>Provide equal education to children in Special Education</td>
<td>33.98%</td>
</tr>
<tr>
<td>Peer to peer support for children with disabilities</td>
<td>24.27%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>16.50%</td>
</tr>
</tbody>
</table>

Total Respondents: 103
Q5 Funding challenges - should the Legislature provide more funding for (please select 3):

Answered: 104  Skipped: 0

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Childhood Intervention Program</td>
<td>42.31%</td>
</tr>
<tr>
<td>Funding for Medicaid Waivers so children can grow up in a family</td>
<td>66.35%</td>
</tr>
<tr>
<td>Reimbursement cuts for therapy rates paid by Medicaid</td>
<td>27.88%</td>
</tr>
<tr>
<td>Respite Care</td>
<td>35.58%</td>
</tr>
<tr>
<td>Increase Attendant Care wages and rates</td>
<td>50.00%</td>
</tr>
<tr>
<td>Helping families of children with disabilities during a crisis</td>
<td>17.31%</td>
</tr>
<tr>
<td>Mental health services for children, including supports for their families</td>
<td>33.65%</td>
</tr>
<tr>
<td>Promoting Independence initiatives for children</td>
<td>29.81%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11.54%</td>
</tr>
</tbody>
</table>

Total Respondents: 104
Q6 STAR Kids, Medicaid Managed Care Program (please select 2):

Answered: 99  Skipped: 5

<table>
<thead>
<tr>
<th>ANSWER CHOICES</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Standardize the prior authorization process</td>
<td>66.67%</td>
</tr>
<tr>
<td>Nursing care provided at school to be directed by family, not Home Health Agencies</td>
<td>48.48%</td>
</tr>
<tr>
<td>Create a process to monitor problems &amp; report to state rather than the state monitoring</td>
<td>63.64%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>19.19%</td>
</tr>
</tbody>
</table>

Total Respondents: 99
Q7 Awareness programs (please select 3):

Answered: 101  Skipped: 3

**Answer Choices**

<table>
<thead>
<tr>
<th>Answer</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidance from a family perspective for ECI versus private insurance services</td>
<td>32.67% 33</td>
</tr>
<tr>
<td>Including grandparents into the systems for support services</td>
<td>32.67% 33</td>
</tr>
<tr>
<td>Children Mental Health Awareness</td>
<td>48.51% 49</td>
</tr>
<tr>
<td>Support and strategies for suicide prevention</td>
<td>26.73% 27</td>
</tr>
<tr>
<td>Support and strategies to prevent substance abuse, including opioids</td>
<td>14.85% 15</td>
</tr>
<tr>
<td>Zika, nutrition, food allergies awareness</td>
<td>9.90% 10</td>
</tr>
<tr>
<td>Pilot program to fund family restrooms, providing large changing table so youth don't have to be changed on the floor</td>
<td>51.49% 52</td>
</tr>
<tr>
<td>Create a dictionary on the terms used around children with disabilities</td>
<td>24.75% 25</td>
</tr>
<tr>
<td>Description of the difference in referrals to Children’s Protective Services and Adult Protective Services</td>
<td>17.82% 18</td>
</tr>
<tr>
<td>Description of how the Foster Care Redesign will affect children with disabilities</td>
<td>40.59% 41</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11.88%</td>
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<tr>
<td>Total Respondents: 101</td>
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Open-Ended Responses for PCCF Topic Survey

Q1 Help for Families

1. Don't allow companies to serve as both a local service provider and as a supervisory state liaison for HCS.
2. ABA therapy should be REQUIRED to be covered by all insurance companies.
3. Get more people off the waiting list and on Medicaid Waivers. Consolidate the SSLCs so there is more money for community supports.
4. Better access to unique therapies/ provide access/ provide training -- executive function therapies; social skills for special needs who don't have "autism" but have other neurological disease; screenings for vision therapy/ convergence insufficiency-eye teaming issues for children with neurological issues/ epilepsy.
5. Affordable respite places with nurses trained for medical issues for special needs children.
6. Support for adult children with disabilities after high school - finding a job, keeping a job, job training, and companionship.
7. Provide a week paid vacation to the attendants that work for individuals with disabilities. They don't typically get time paid time off.
8. Focus on mental healthcare for children and youth.
9. The legislature stopped funding SSLC diversion. This is a major blow to the IDD safety net and WILL cause the SSLC census to increase.
10. We need more mental health services available 24-7. Our children are falling through the cracks due to long appointment waiting times.
11. Respite available to all families who have a family member with special needs.
12. Support Service Provider program for the state of Texas.
13. Help those children with severe disabilities and medical issues keep their support as they transition at age 21.
14. Allow parents to maintain choice of DME supplier. Many families have DME suppliers that go above and beyond to provide quality products.
15. Trimming unnecessary processes that may lead to excess cost or loss of services for children. Examples of this range from requiring too frequent evaluations for service authorization with repetitive information for children with chronic/congenital health issues (lapse of service between reauthorization is all too common) to sending all information in English AND Spanish without regard for the primary language of the family. These two examples are detailed below:
1) It is a phenomenal waste of resources to request the entire initial evaluation package information for reauthorization for every child needing therapy services. Rather than complete medical histories, etc., each and every time reauthorization is required, this process should be audited and rewritten to include only necessary updated information on a reasonable schedule that is based on the child undergoing evaluation. In this day and age of technology, a complete medical history should be required once and only once per child, with updates to each therapy as required. 2) Fostering good communication is critical in maintaining appropriate health care for special needs children. Families who do not speak English as their primary language should be able to request information in their primary language. Despite multiple forms indicating English as our primary language, and multiple communications to those in the state health system, we still continue to receive all of our information in both English and Spanish. How many more children could be helped with services they need if cost were cut in sending families information in their primary language only? A quick Google search indicates that this is easily tens of thousands of dollars for one multi-page color glossy mail out.

16. The HUGE need for facilities throughout the state to have handicap accessible restrooms BIG enough to fit with a teenager/adult in a wheelchair with their medical equipment/machines and that have changing tables BIG AND STRONG enough to carry a teenager/adult that cannot sit on their own nor hold their head up.

17. Improved access to long-term care services and supports. The current wait is too long.

18. Decrease time on Medicaid waiver lists.

19. More access to Mental Health Services for children. I had a terrible time trying to find for my daughter a counselor who is taking new patients with Medicaid. It took months.


21. Increase access to services for Spanish-speaking families

22. For sport facilities and programs, such as for Paralympics, all coaches, Board of Directors, and staff should be required to have background checks and Safe Sport training.
Q2 Mental Health Issues

1. Allow for use of medical marijuana as a treatment for autism.
2. Families should not be considered at fault if they have made documented efforts to help their loved ones with mental health issues. The legislature needs to provide an exception within cps language.
4. Provide safe and supportive environments in the community for children with mental illness.
5. Address options for individuals with IDD when residential placement may be appropriate at the time. Families are being denied when the child has an IQ below a certain threshold, even when recommended by a support team and long history of decompensating with other community supports in place.

Q3 Transition to Adulthood

1. Increase accountability for schools and the state.
2. Not all children grow into functioning job holding adults. The state must set standards for Adult DayHabs and provide higher wages for the gifted people who work there.
3. As it becomes more difficult to obtain guardianship over our young "adult" children, we need some way to have perhaps a temporary guardianship for a period of 3 years or 5 years at least.
4. Develop a Transition Guide for students, including contact information, frequently asked questions, guidance, and support.
5. Provide meaningful dayhab for adults with IDD.
6. Transition should begin at diagnosis. Promote transition planning at the earliest age possible. Linking what children learn to lifelong goals will improve outcomes.

Q4 Education

1. Children and teens who are high functioning shouldn't be mixed in mainstream classrooms with those who are low functioning.
3. Document accurate efforts to engage special ed students in regular classes.
4. Support people who choose to homeschool their children.
5. Children should have access to diagnosticians and speech and occupational therapy, etc.
6. Financial support or tax deduction for families of children with special needs so they may attend specialized private schools who can better serve the students' needs.

7. Require special ed & inclusion teachers specific training each year for the causation & manifestations of the student’s disability. For example: many children have "executive brain function" issues & teachers don't know what it is beyond "organization".

8. Support teachers to better understood their students & how to work for success with them. For example, perhaps a child’s private therapists could give short trainings to teachers on "expressive/ receptive language issues" and how that effects the students conversation/ understanding/ writing, etc. and what to do or say or how to approach teaching of children for success & progress in education.

9. It is imperative that Special Ed in the various school districts not be a home for teachers who want to do something else and are not fully qualified. SPED should not be an academic home for coaches who are minimally qualified to teach.

10. SPED should not have to "owe" funds to the rest of the school district and thus not be able to hire the best teachers for the most vulnerable students.

11. Have the State of Texas provide Education Saving Accounts for children who are disabled so better choices can be made for either private or public setting.


13. Set higher expectations and standards for outcomes for students with disabilities. Have IEP goals be measurable, accountable, written in plain language for parental understanding and tied to a specific graduation outcome.

14. All school employees should know the laws and be trained to deal with children with special needs.

15. Provide schools with funds to help children with disabilities have one on one assistance.

16. Ensure that skilled personnel are provided to meet a child's needs.

17. Provide equal services to children in public and private schools. If a child qualifies for service, he/she shouldn't be denied that service because the special education service funding is different for private versus public education.

18. ALL school staff should be properly trained to deal with students with disabilities! Including front desk, volunteers!

19. Provide equal education to children RECEIVING special education services. Special education services are just that - a service - not a place.
Bolster/ include therapeutic components in programming.

**Q5 Funding Challenges**

1. Implement pay for parent caregivers who cannot work outside the home due to caring for a child with disabilities or mental health issues.
2. Provide funding for respite in the family home.
3. Teach new mothers that brain stimulation must occur in the first two years of development and that just leaving babies in a crib or stroller isn't good enough for their development.
4. Eliminate interest lists.
5. Increase job training.
6. Provide stable employment opportunities.
7. Address the divide in state programming for students with visual impairments. Provide for continuity and better transition training.
8. Educate people on how promoting independence is different from waivers etc.
9. Services for disabled children should be funded adequately.
10. If a complete process audit is done across the board for the entire system, significant cost could be recovered to provide additional funding for direct services for special needs children without a bottom line budget change.
11. Funding more aids and support in school for kids with special needs and for programs educating peers.
12. Inclusive child care initiatives and grants to help fund programs that serve the child through the parent. Parental wellness is a strong indicator of child and family success and parents of children with disabilities experience lower parental self-esteem, higher levels of stress and financial instability, and isolation.
13. Provide funding for Paralympic Sport facilities whose goal is to coach Paralympians (youth and adult).

**Q6 STAR Kids, Medicaid Managed Care Program**

1. Increase payments to healthcare providers enabling more providers to accept Medicaid.
2. Get more providers and specialist to treat our children and adults. Especially in large established facilities close to their homes.
3. Improve STARKIDS MCO provider networks. The current PCP and specialty provider networks are inadequate. They are based on public clinics and FQHCs designed to serve the indigent, uninsured, & underinsured, which are overwhelmed & understaffed and unable to provide appropriate access to care and quality of care. These providers
are not able or willing to provide comprehensive care to members with complex disabilities - The PCPs only treat 1 medical issue per visit, which is inadequate for members with complex medical conditions. The MCO provider networks exclude private multi-specialty clinics and private specialists who can provide appropriate access to care and quality of care to members who are underserved by the current STARKIDS MCO provider networks.

4. Promote MCO accountability when wrongfully terminating or reducing services to medically fragile children.

5. Allow for increased funding for needed equipment, supplies and modifications to home/vehicle.

6. Need more providers and attendant care workers in rural areas.
   Durable Medical Equipment providers are very few in rural areas.

7. A better system to weed out abusers.

8. Better collaboration with agencies.

9. I'm not sure what the difference is between reporting to the state and state monitoring. I don't want families to be responsible for the system but I do want parent complaints to be taken seriously and addressed.

10. Increase reimbursement rates for providers.

11. Collaborate with all agencies providing services to the child in MDCP.

12. Standard processes & procedures across all MCOs; better oversight & management; more freedom and flexibility for families. Consider a study to compare services rendered under fee-for-service versus services rendered under managed care, and denials and appeals under each delivery model.

13. All health care for a special needs child should be family directed with outside support given as individual families request support.

14. Improve the authorization process.

15. Improve provider networks for STARPLUS and STARKIDS MCOs. The current networks are too narrow and restrict provider choice, access to care, quality of care, and continuity of care for children and adults with complex healthcare needs.

16. Provide easy access to Single Case Agreements to improve access to providers when the STARKIDS and STARPLUS MCO networks don't meet the member's needs. Please remember that you are dealing with people with documented disabilities here, and the MCOs are arbitrarily restricting their access to necessary medical care in order to improve profits, which puts the health of the member in jeopardy. There's something very wrong with this picture!!!
Q7 Awareness Programs

2. Epilepsy awareness-SUDEP-sudden epileptic death syndrome; status seizures (emergency medical situation); recognizing seizures & basic "what to do" is someone is seizing; ESETT-awareness of federal medical studies on epileptics with status seizures that don't stop.
3. Food allergies--basic info on how to use an Epi-pen; recognize when someone is having a food allergy episode; education on foods that cause allergies & the severity of allergy that can be life threatening.
4. Asthma--when asthma can be life threatening -how to recognize & what to do; what to do if medicine is not available for attack".
5. Involve employers/companies in hiring people with disabilities.
6. What would happen to a disabled individual when parents die and no one to care for that person? Can a caregiver foster them and get paid for that individual?
7. Anti-bullying
8. The need for skilled providers to meet a child's needs. Whether they are learning Braille, sign language, mobility, or such they should be taught by a skilled provider.
9. More assistance to families on how to navigate complex social service, financial assistance, and medical assistance programs. Most families have to figure it out for themselves, which makes it difficult to access the services they need.
11. Clear information is more helpful.
12. Guide or specialized training for school district staff to understand the typical day in the life of a family raising a child with a disability, emphasizing the unique family structure, time allocations, barriers, and stressors, and the role of district staff to support the family.
13. Initiative to open the conversation about individuals with disabilities and challenging behavior/aggression. Parents and families across the state quietly navigate ongoing physical aggression and are reluctant to discuss. It becomes a dirty little secret that nobody talks about. Not getting support and help can destroy relationships within the family, increase safety concerns, and damage outcomes for the individual.