

# Autism is Expensive!

## Navigating the Financial Maze from Private Insurance to Social Services and More.



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# Autism is a Journey.....



All journeys need to begin  
with a good road map....

# Start by being a wise traveler...

Put together smart, efficient, travel plans.....

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- Where do you want to see your family and child in 1 year, 5 years, 10 years, etc.?
- What are the skills your child and family need to meet those goals?
- Are the interventions you are currently spending time, money, and resources on helping your family and child develop those critical skills?
- If not, do you need to re-map your trip??

# Things to consider when developing your travel plans....

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1. How does the intervention fit with the current educational approaches being used?
2. How does the intervention fit with the profile of my child's strengths, needs, and learning style?
3. Is the intervention consistent with what we know about child development, development of children with ASD and effective treatments?

# Things to Consider, cont'd....

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4. How does the intervention fit with the long term goals for my child? For my family?
5. How will you measure if the intervention is successful?
6. What type of data will be collected and how will it be used to make decisions regarding the effectiveness of the intervention?
7. How long will you try the intervention before reviewing effectiveness and determining whether to continue?

# Things to Consider, cont'd....

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8. What, if any, are the negative effects of the intervention?
9. Is there any empirical research on the effectiveness?
10. What may the costs be in terms of time, emotionally & financially for my child, family, and educational community?

# And last but not least...

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11. Do those whom you trust and respect with regard to understanding the child support your belief that trying the intervention is the right thing for your child?

- Connecticut Guidelines for the Identification and Education of Children and Youth with Autism

# Dee's Final Questions

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- What does it cost? And who benefits from what I pay? Is this a money making scheme for somebody?
- What will be the long-term effects for my family if we adopt this treatment?
- Does it complement my desire to access my natural environment and supports?



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“A wise man makes his own decisions, an ignorant man follows public opinion.”

- Chinese Proverb

# Once you have your trip planned.....

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It's time to think about

“How are we going to pay for this?”

The costs of raising, educating, treating and caring for a child with autism can be \$10,000 to \$100,000 or **more** annually. Lifetime costs vary from \$3,000,000 to \$7,000,000 depending on the unique issues to the individual. That is a lot for any one family to shoulder.

# Resources to Think About:

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- Private Insurance
- State and Federal Programs
- Public Schools
- Private Funding/Local Scholarships
- Foundations

# Private Insurance

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Autism is known as “Pervasive Developmental Disorder.” Most medical books believe that the goals of treatment are to:

1. Increase socially acceptable and pro-social behavior.
2. To decrease odd behavioral symptoms.
3. AND to aid in the development of verbal and non-verbal communications.

[www.tacanow.com](http://www.tacanow.com)

# Private Insurance, cont'd...

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- Put simply, autism for medical billing purposes is treated as psychiatric disorder and for which there is no cure (Diagnosis 299.00-299.80). Payments will more likely be paid for specific types of communication or occupational therapy.
- The diagnosis codes 299.00-299.80 are RED FLAGS FOR INSURANCE COMPANIES!

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# Tips for Private Insurance....

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1. You need to make sure you have the PAYMENT FORM or SUPERBILL from your medical provider showing the CPT Codes, ICD-9 Codes, with procedures and treatments provided during the visit. IMPORTANT: this is needed to include correct diagnosis and miscellaneous codes when appropriate.
2. In your cover letter to the health insurance provider make sure to note that payment has been made and requested reimbursement to the health insurance carrier (i.e. your family) is requested. Be sure to send to the correct ACCOUNTS PAYABLE / REIMBURSEMENT ADDRESS.

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# Tips, cont'd...

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3. If you have ANY PRE-APPROVAL DOCUMENTS OR NOTES FROM A PHONE CALL, DOCTORS PRESCRIPTION & DOCTORS REFERRAL – please include this for your reimbursement purposes. (Note: THIS IS HIGHLY RECOMMENDED.)
4. Many health insurance companies need to see dates of services – especially for continuous treatment over time – for reimbursement review purposes.
5. Always make a copy of paperwork for your records. DO NOT SEND YOUR ORIGINALS. Always, always keep your originals and send copies. Be sure to document the claim process with who you spoke to, the date, and items discussed for future reference.

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# Tips, cont'd.....

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6. Call on your health care reimbursements requests and make notes who you spoke to and items discussed. Payments from your health insurance provider should be processed in a timely fashion typically in 30-60 days or less. Each company has a different reimbursement policy and this would be explained in your Explanation of Benefits (EOB.)
7. If the insured has paid the vendor for services and seeking reimbursement for previous payment it is recommended to obtain a ZERO BALANCE due invoice. This demonstrates it has been paid and insurer is seeking reimbursement. If this is not provided sometimes insurance companies make the mistake of paying the doctor or treatment facility versus reimbursement the insurer. Please make this clear in your request.



# The Appeals Process

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Every health insurance provider has a process for appealing claims for reimbursements. It is estimated approximately 90% of the claims submitted to health insurance companies are rejected for some reason. Many insurers stop there and do not move forward on getting reimbursed. It is important to check with the appealing claim process and follow this all the way thru for proper reimbursement. Organization and complete documentation of this process is highly recommended.

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# The Appeals Process

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Families can appeal a claim if the claim is unpaid or partially paid (more than what the family was expecting.)

Bills and paperwork can be re-submitted for payment if CPT or ICD-9 Codes were accidentally omitted by the health care provider.

Ask your health care insurance company how the appeal process works and for assistance in this process. Each health insurance company should have an 800# with help available on the appealing process.

The insurer will have some responsibility of payment for procedures according to the policies of the health insurance provider. This varies by provider and can change regularly.

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# State and Federal Financial Resources

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- 💰 Medicaid
- 💰 TEFRA
- 💰 Developmental Disabilities Division – Community Services for Oklahomans
- 💰 Family Support Assistance Payments
- 💰 Supplemental Security Income (SSI)
- 💰 Supplemental Security Income –Disable Children’s Program (SSI-DCP)
- 💰 Respite Vouchers

# Medicaid

## \*For children under 19\*

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### What is it?

- Medical coverage for those who qualify.

### Who qualifies:

- Financial requirement must be met first.
- A person must have a physical or mental impairment, a disease or loss that appears reasonably certain to continue at least 12 months without significant improvement and that substantially impairs his/her ability to perform labor or services or to engage in a useful occupation.

### How do I get it?

- Apply at your local Department of Human Services county office.
- For more information: 1-800-987-7767

# TEFRA

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## What is it?

- Medicaid eligibility. People who are on TEFRA get all the services of Medicaid.

## Who qualifies?

- Children who meet an “institutional level of care” based on physical or mental disabilities.
- Children have to have an IQ less than 70.
- Parent income is not a factor.

## How do I get it?

- Apply at your local Department of Human Services county office.
- For more information: 1-800-987-7767

# Social Security Income (SSI)

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## What is it?

- Cash payment to a person with a disability (max payment is around \$600/month).
- Recipients also become Medicaid eligible.

## Who qualifies?

- Must have a developmental disability with an IQ less than 70.
- Met household income requirements.

## How do I get it?

- Apply at the Social Security Office.
- For more information: 1-800-772-1213

# Social Security Income – Disabled Children’s Program (SSI-DCP)

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## What is it?

- Can provide equipment/services not typically covered by Medicaid. Ex: therapeutic equipment, nutritional services, developmental child care, diapers.

## Who qualifies?

- Must have a developmental disability with an IQ less than 70.
- Met household income requirements.

## How do I get it?

- Apply at the Social Security Office.
- For more information: 1-800-772-1213

# Family Support Assistance Payments

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## What is it?

- Payments of \$250-400/month depending on the number of children with disabilities in the home.

## Who qualifies?

- Children with developmental disabilities under age 18.
- Children have to have an IQ less than 70.
- Household income less than 45,000/year.

## How do I get it?

- Apply at your local Department of Human Services county office.
- For more information: 1-800-521-3571

**No current waiting list!!!**



# Developmental Disabilities Services Division – Home and Community Based Services

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## What is it?

- Provides a wide array of community services. Ex: respite, in-home care, family training, architectural modifications, adaptive equipment.

## Who qualifies?

- Must have a developmental disability with an IQ less than 70.
- Financially eligible for Medicaid, based only on the individual's income, not the family's.

## How do I get it?

- For more information: 1-800-521-3571

# Respite Vouchers

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- Money for respite care.
- Child must have a developmental disability and family must meet the financial requirement.
- Providers must be over 18 and can be anyone except immediate family living in the home.
- Request an application through OASIS
  - (888) 771-4550

# Tips for Accessing State and Federal Financial Resources:

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- Learn the programs or talk to somebody who has used the programs before.
- Be persistent! Once you apply for a program, make sure you call and check in! Paperwork can easily get lost.....(once you apply they have 45 days to respond)
- Document everything you do (e.g. anytime you call, mail information, fax information). Keep copies of any information you send to anyone!
- When completing the application, have a developmental milestone chart with you and use the milestones to compare what your child and cannot do as compared to typical children.

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# OTHER FINANCIAL RESOURCES

# Donna Nigh Foundation

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- Pays up to \$2,000 for “therapeutic” type items that is not covered by insurance or other payer sources.
- Child must have “developmental disability with cognitive delays.”
- Complete the attached application, attach a “certificate of medical necessity,” from a therapist or doctor that justifies why you need the items.

# Consumer Involvement Fund

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- Money from Oklahoma Developmental Disabilities Council for advocates in the developmental disabilities field to participate in conferences and short-term educational programs.
- For person with disability, family member, service provider, graduate or member of Oklahoma Partners in Policy Making.
- 1-800-836-4470, or (405) 521-4984

# Nation-Wide Resources:

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## Travel:

- American Airlines, Miles for Kids in Need,
  - **1-800-421-0600** [www.ae.com](http://www.ae.com)
- [www.southwest.com](http://www.southwest.com)
- Don't forget to get a handicap parking decal!

## Assessment and Intervention Assistance:

- [www.act-now.org](http://www.act-now.org)
- [www.nationalautismassociation.org](http://www.nationalautismassociation.org) (too late for application this year, but look into it for next year!)
- United Health Care - <http://www.uhccf.org/apply.html>
  - For children 16 years and older.

# Local Trainings

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- Free monthly trainings (see attached)
  - “Life First Series”
- Statewide Training and Regional Supports (STARS)
  - [http://www.ah.ouhsc.edu/tolbert/courses\\_workshops/default.asp](http://www.ah.ouhsc.edu/tolbert/courses_workshops/default.asp)
  - Judie Grove, [stars@ouhsc.edu](mailto:stars@ouhsc.edu)



# School Resources

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- **Oklahoma State Department of Education, Angela Kelley** (405) 522-4513, or **Christa Knight**, (405) 521-4867
  
- **Child Study Center, School Support Services**, (405) 271-6824, **Dianne Mathis**
  - Performs trainings and consults in the public schools. There may be a cost to the schools.
  
- **Oklahoma State Department of Education, Assistive Technology Team**, (405) 271-3625, **Stefanie Olson**
  - Free trainings and consults to any student in the public schools regarding assistive technology.
  - Loan Program for Assistive Technology Items

# Other Resources

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- Disability Law Center

- <http://www.oklahomadisabilitylaw.org/>

- (405) 525-7755 (V/TDD)

- (800) 880-7755 (V/TDD)

- Association of University Centers on Disabilities

- <http://www.aucd.org/template/page.cfm?id=1>

# Summary

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- **Autism is a Journey!**
- **Plan your child's program as it is a trip!**
- **Make sure the key components in your program are all working together towards the same outcomes!**
- **Use your financial resources as effectively and efficiently as possible.**
- **Be organized and diligent with financial resources!**