

# Siblings of Children with Autism Spectrum Disorder



Presented to:  
Autism Council of Utah

By  
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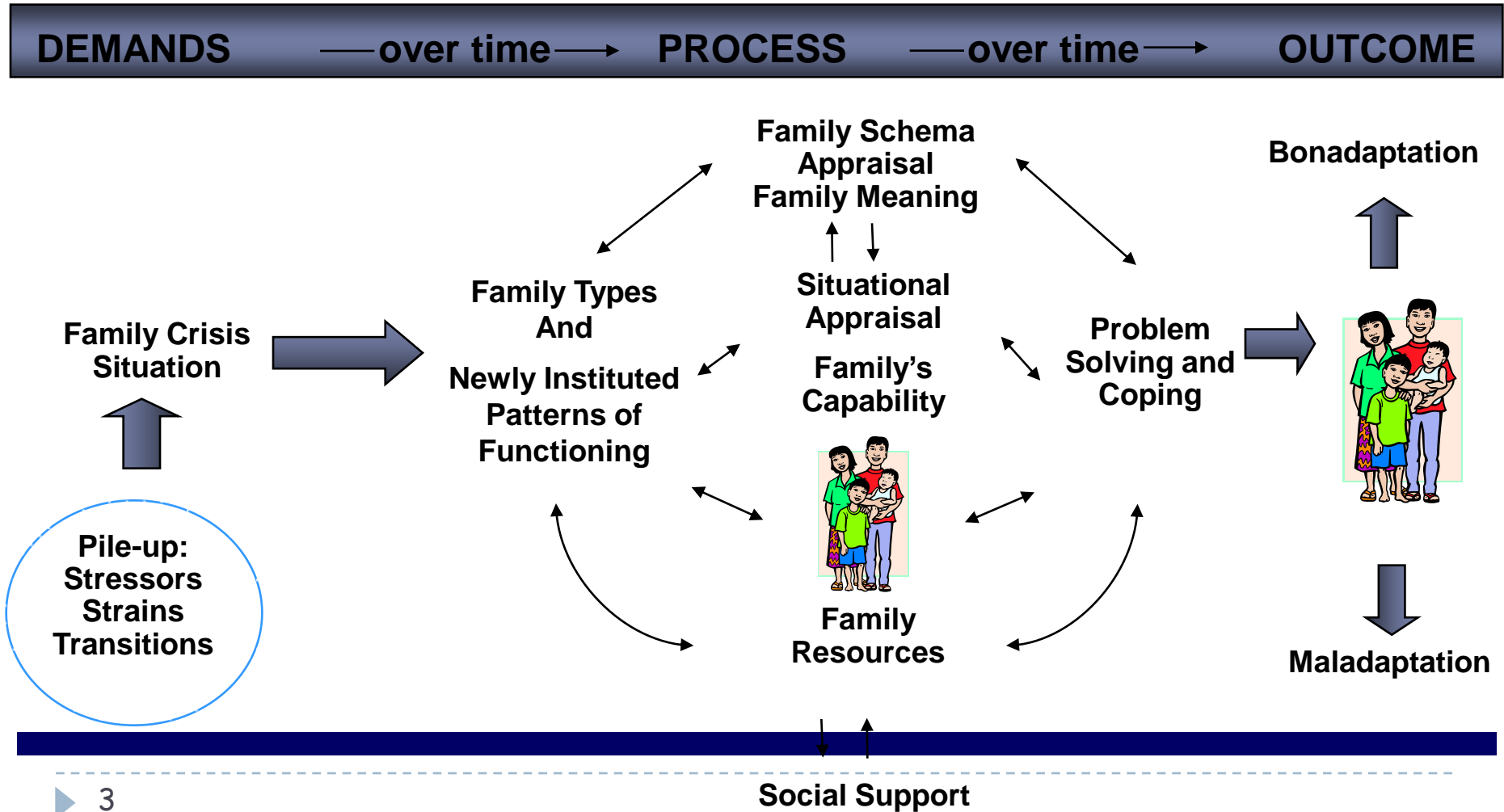
# Acknowledgements

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  - ▶ Division on Developmental Disabilities
    - ▶ Dolly Gray Children's Literature Award
  
- ▶ **Families of individuals with ASD**



# McCubbin's Model of Family Adaptation



# Sibling Relationships

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- ▶ Longest familial relationship
- ▶ Sibling bonds
  - ▶ Age, gender, shared experiences
- ▶ Overall quality of family life impacts sibling relationships



# Research on Siblings of Children with Autism

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## ▶ Challenges

- ▶ Forming healthy bond with child with autism
- ▶ Vulnerable to behavior problems, speech and language disabilities, anxiety, depression, and other mood disorders
- ▶ Higher risk for ASD
- ▶ More difficulties than siblings of children with Down syndrome and non-disabled

## ▶ Strengths

- ▶ Pride in teaching their sibling
- ▶ Higher self-esteem, empathy, maturity
- ▶ Take lead role in relationship
- ▶ Less quarreling and competition than families without disability
- ▶ Positive adjustment, particularly for sisters



# Other Concerns

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- ▶ Overidentification
- ▶ Embarrassment
- ▶ Guilt
- ▶ Isolation, Loneliness, and Loss
- ▶ Resentment
- ▶ Pressure to Achieve



(Meyer & Vadasy, *Sibshops*, 1994)



# Recommendations

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- ▶ Explain autism to siblings
  - ▶ Developmentally appropriate explanation
- ▶ Help siblings accept the child's role in the family
- ▶ Help siblings share thoughts and feelings, acknowledge their concerns
  - ▶ Model appropriate communication
  - ▶ Label own emotions
  - ▶ Family meetings
- ▶ Spend individual time with each child in the family
- ▶ Help siblings know they have right to their own life
- ▶ Set realistic expectations for siblings



- ▶ Avoid parental favoritism
- ▶ Provide sibling with private space/time
- ▶ Demonstrate positive interactions with child with autism
- ▶ Discuss options for the future with siblings
- ▶ Solicit help from family, friends, support groups
- ▶ Teach siblings to play with each other
- ▶ Provide opportunities to meet other siblings





# Resources - Books

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- ▶ Feiges, L. S., & Weiss, M. J. (2004). *Sibling stories: Reflections on life with a brother or sister on the autism spectrum.*
- ▶ Hale, N., & Sternberg, K. (2004). *Oh brother!: Growing up with a special needs sibling.*
- ▶ Hames, A., McCaffrey, M., & McCaffrey, B. (2005). *Special brothers and sisters: Stories and tips for siblings of children with special needs, disability, or serious illness.*
- ▶ Harris, S.L. (1994). *Siblings of children with autism: A guide for families.*
- ▶ McHugh, M. (2002). *Special siblings: Growing up with someone with a disability.*
- ▶ Meyer, D. (Ed.). (1997). *Views from our shoes: Growing up with a brother or sister with special needs.*
- ▶ Meyer, D., & Gallagher, D. (2005). *The sibling slam book: What it's really like to have a brother or sister with special needs.*
- ▶ Meyer, D. J., & Vadasay, P. F. (2007). *Sibshops: Workshops for siblings of children with special needs.*
- ▶ Meyer, D., & Vadasy, P. (1996). *Living with a brother or sister with special needs: A book for sibs.*

# Internet Resources

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## **Sibling Support Project**

- ▶ <http://www.siblingsupport.org/>
- ▶ The Sibling Support Project has published curricula and children's books that assist agencies in starting Sibshops and let young sibs know that they are not alone with their unique joys and concerns. They sponsor the Internet's first and largest listservs for young and adult siblings where participants share their issues with others who truly understand.
- ▶ Sibshops help brothers and sisters that have a sibling with a special need have opportunities to get support in a recreational and educational context. The Sibshops involve playing games that are different and unique, making new friends, and other activities. Sibshops are for a wide range of ages because the activities are easily adaptable.

## **SibNet**

- ▶ <http://www.siblingsupport.org/connect/the-sibnet-listserv>
- ▶ SibNet is an on line discussion group for young adult and adult brothers and sisters of people with disabilities and other health needs where you are able to post and view pictures as well as ask about how they can receive local service. SibNet helps brothers and sisters from around the world have many opportunities to discuss issues of common interest and concern and share information with one another.

## **Sib Kids**

- ▶ [http://www.siblingsupport.org/connect/index\\_html](http://www.siblingsupport.org/connect/index_html)
- ▶ SibKids is similar to SibNet but is for younger brothers and sisters of people with mental, emotional, and physical needs.

## **Autism Siblings**

- ▶ [www.autismsiblings.org](http://www.autismsiblings.org)
- ▶ Shares stories and provides support for siblings of children with autism.

# Local Resources

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## **Autism Journeys Consulting**

- ▶ <http://www.autismjourneys.net>
- ▶ Opening in November at Thanksgiving Point. Contact Kate Anderson, (801)766-8681 or (801) 718-6441. Will hold sibling groups beginning next year.

## **Camp Kostopulos**

- ▶ [www.campk.org](http://www.campk.org)
- ▶ Contact Jared Allsop [jallsop@campk.org](mailto:jallsop@campk.org). They offer summer camps, family enrichment mini-workshops, sibling workshops, free parent planning workshops.

## **Clear Horizons Academy**

- ▶ <http://www.clearhorizonsacademy.org>
- ▶ Contact Sondra Hurst (801) 437-0490

## **Northern Utah Asperger/High-Functioning Autism Support Group**

- ▶ [eeekersleykin@networld.com](mailto:eeekersleykin@networld.com)
  - ▶ Contact Becky Eckersley (801) 773-2819. Available for phone support and will have group meetings again beginning Spring 2009.
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## **S.I.B.S. Day – A Workshop for Super Important Brothers and Sisters**

- ▶ Primary Children's Medical Center
- ▶ Contact Kevin Sutherland (801)588-3011

## **Sibshops of Utah County**

- ▶ [www.sibshopsfutihcounty.blogspot.com](http://www.sibshopsfutihcounty.blogspot.com)
- ▶ Contact Jessica Nix (801) 221-9930 x156 or [jnix@kotm.org](mailto:jnix@kotm.org) or Tina Dyches at [tina\\_dyches@byu.edu](mailto:tina_dyches@byu.edu)
- ▶ Second Saturday of every month (except November, when we have a Super Sibshop in conjunction with the Utah County Special Needs Conference, and December).

## **Sibshops Training**

- ▶ [www.autismaccess.com](http://www.autismaccess.com)
- ▶ Contact: Kim Moody (801) 661-9610
- ▶ November 13-14, Salt Lake City, Utah

## **Spectrum Academy**

- ▶ <http://www.spectrumcharter.org>.
- ▶ Contact [kimmooody@comcast.net](mailto:kimmooody@comcast.net). Sibshops will begin January 2009 on the third Tuesday of the month from 6-8 pm. Sibshops will be held in connection with the Parent Empowerment Nights.



# Other Resources

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## **Videos**

- ▶ *Understanding Brothers and Sisters on the Autism Spectrum &*
- ▶ *Understanding Brothers and Sisters with Asperger Syndrome*
  - ▶ [www.coultervideo.com/understandautas.htm](http://www.coultervideo.com/understandautas.htm)

## **National Sibling Day**

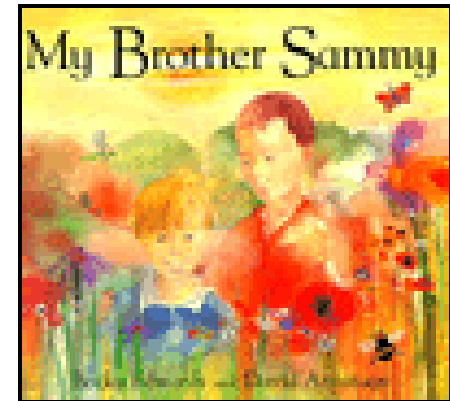
- ▶ When: Always April 10<sup>th</sup>
  - ▶ *National Sibling Day* is a day to appreciate and cherish your brothers and sisters. Siblings are truly a special blessing that we probably all too often take for granted. They are often our best friends and supporters through life.
  - ▶ *National Sibling Day* is similar to *Brothers and Sisters Day* which is celebrated on May 2<sup>nd</sup>.
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# Addressing Siblings' Concerns Through Literature

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## ▶ Siblings' Coping Strategies

- ▶ Autism Through a Sister's Eyes
- ▶ Ian's Walk
- ▶ My Brother Sammy
- ▶ Tacos Anyone?
- ▶ Talking to Angels

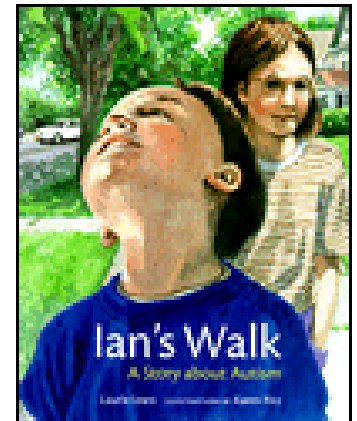


## ▶ Overidentification

- ▶ Are You Alone on Purpose?

## ▶ Embarrassment, Resentment, Isolation

- ▶ Rules
- ▶ Wishing on the Midnight Star



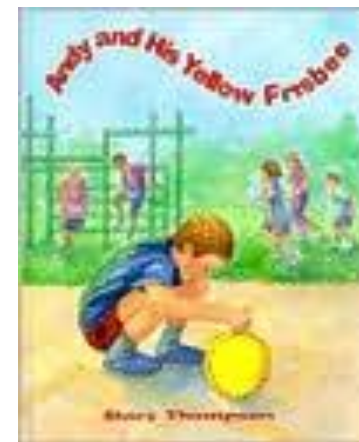
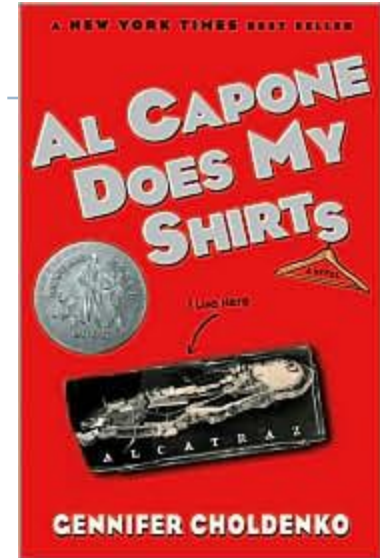
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▶ **Increased Responsibilities**

- ▶ Al Capone Does My Shirts
- ▶ Andy and His Yellow Frisbee
- ▶ Apart
- ▶ Keisha's Doors
- ▶ Ian's Walk

▶ **Pressure to Achieve**

- ▶ Are You Alone on Purpose?



# Acceptance and Inclusion by Peers

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- ▶ Adam's Alternative Sports Day
- ▶ Al Capone Does My Shirts
- ▶ Ann Drew Jackson
- ▶ Blue Bottle Mystery
- ▶ Buster and the Amazing Daisy
- ▶ Captain Tommy
- ▶ Crow Boy
- ▶ Jackson Whole Wyoming
- ▶ Lisa and the Lacemaker
- ▶ Looking After Louis
- ▶ Of Mice and Aliens
- ▶ My Best Friend Will
- ▶ Running on Dreams
- ▶ Sariah McDuff Will Walk With You
- ▶ To Be Me
- ▶ Trevor Trevor





# Understanding Autism Spectrum Disorders

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- ▶ To Be Me
- ▶ The Flight of a Dove
- ▶ Life With Gabriel
- ▶ Matthew's Box
- ▶ Holy Smoke
- ▶ I Have Autism
- ▶ Russell is Extra Special
- ▶ My Friend with Autism
- ▶ All About My Brother
- ▶ I Love My Brother
- ▶ This is Asperger Syndrome
- ▶ Asperger's Huh?
- ▶ Autism Through a Sister's Eyes
- ▶ The Curious Incident of the Dog in the Night-time
- ▶ The V.O.E. of Merilee Marvelous

# Research Opportunities

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- ▶ To be considered for research regarding siblings of children with ASD, contact Tina Dyches at (801) 422-5045 or [tina\\_dyches@byu.edu](mailto:tina_dyches@byu.edu)

