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## Creating Our Option By Sandy Ginther & Abbey Heines

June 2013

It was the middle of September in 1983. A middle child was born to a middle class family in the middle of Illinois, and an ordinary family began an extraordinary journey.

At that time when it came to children who were not 'normal' (in this case because of Down syndrome), the public mindset was one of common judgmental prejudice.

This prejudice was founded on noble pity, condescending rationalization and status quo rejection. It was 'okay' to rob such children of their birthright because there were special places with services for these children. These separate and special places were created to provide care and protection for those labeled 'disabled'.

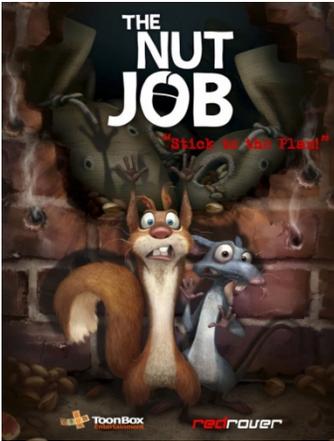
Such an approach was not seen to be malicious, but sympathetic. The public felt sorry for these children, these babies, who were thought to be without possibility, without value, without a life worth sharing among their family and the rest of us. These places made data collection, observation, study of anomalies and delivery of services and treatment easier because of their centralization. It was believed that only in these places could one get the best services. Families of these children were guided and advised to believe that these places were superior and better for everyone involved.

So on this baby's birth, Sandy and Greg Heins were told that instead of taking their 'Downs baby' home to that ordinary family and typical lifestyle, there were 'options'. Except that these parents knew this baby was, first and foremost, a 'Heins baby' – with or without Down syndrome. They wanted to find a way to give baby Abbey the best of both worlds... the best of those special places' services, and the best of being in her family.

They decided in that maternity ward that the best 'option' for Abbey and their family was to seek those 'special' services that happened in the separate places and have them brought to their own ordinary turf. The journey to include their daughter began on the car ride home from the hospital.

Immediately Sandy saw that she had lots to learn, and un-learn. The stereotypes that she held (like most everyone else) were either inaccurate or the result of misguided efforts. Reading, attending conferences and consulting with other families and organizations for those concerned with Down syndrome, took Sandy and the family from a missing and misinformed mode to an up-to-date knowledge base. From Sandy's own ignorance, she realized that the majority of the people would also have the same missing and misinformed status.

*Continued Page 2*



## Sensory Friendly Movie

Join us for **"The Nut Job"** on Saturday, February 8 2014 at 10:00 AM. This "sound down/lights up" movie is hosted by the Starplex Theater in Normal. The Starplex offers free child admission with one \$6 adult ticket purchase.

## Bowling is Back!

The Council for Exceptional Children is once again hosting Adult Bowling. Join them from 4-5 pm at the Bowling and Billiards Center on ISU's Campus. Bowling is scheduled for:

- February 9th
- February 23rd
- March 9th
- March 30th
- April 13th
- April 27th

Recognizing that prejudice can unfairly exclude and prevent the development of potential, lead Abbey's family to one of the first missions to give Abbey the best of both worlds. This mission was 'public awareness' about the potential of an individual with disability, and the need for everyone without a disability to be willing to accommodate environments and activities for inclusion, welcoming and participation. Transition planning and services can keep an individual from being dumped in a normal environment and activity versus being included with adequate thought and supportive design of adaptation and services. Indeed, 29 years later, this is still an active mission for this family.

The second prominent mission that Down syndrome brought to Abbey and her family's life was to battle health issues. From the discovery of a major heart defect at 6 weeks of age to the discovery of liver disease this year (and the multiple medical diagnoses and treatments, and 16 surgeries in between) fighting illness is still a way of life.

Yet along with missions, Abbey's story includes a wonderful worthy life, with some dreams coming true and surprising unimagined accomplishments. Some of those are:

Doing most of the same things as her typically developing sisters:

- Attending the same private preschools, the same childcare centers, the same grade school, the same middle school, the same high school, and a community college while her sisters went on to Universities.
- Enrollment in some of the same regular education classes and extracurricular activities across all school years.
- Attending the same activities and classes in gymnastics, horseback riding, ballet, Brownies, and soccer.
- Getting her driver's license.
- Working multiple jobs – video store, childcare center, insurance company.
- Volunteering – Nursing Home.

Public Speaking:

- Presentations to college classes at 4 different II. Universities.
- Presentations to Student CEC (Council for Exceptional Children) groups
- Breakout Session Presentations at Illinois Conferences
- Keynote Speaker at PEAK Annual Conference, Denver CO.
- Keynote Speaker for an Arc fundraiser.

Leadership with Organizations:

- Recently appointed by the Governor to the Illinois Council for Developmental Disabilities.
- Founding member of the Illinois Self Advocacy Alliance for Change.
- Board member of Central Illinois Down Syndrome Organization, and newsletter contributor.

Church Activities:

- Acolyte
- Usher
- Communion Assistant
- Youth Minister Assistant
- Nursery Attendant

## Help Wanted

*The CIDSO Board is looking for a few good volunteers that would be willing to help us so we can continue to provide informational and social gatherings for our members. If you would be interested in coordinating any of the following, or have ideas for new event/activities, please contact us at [info@cidso.org](mailto:info@cidso.org):*

- *CornBelters Baseball Game*
- *Family Bowling*
- *Mom's Night Out/Coffee*
- *Dad's Hockey Game*
- *Play Group*



## Penguin Project Update

*The 2014 show is "Little Mermaid". Applications for artists ages 10 - 24 and mentors ages 12 - 21 are being accepted through February 20th. Call Bloomington Parks, Recreation & Cultural Arts at (309) 434-2260 or "like" them on Facebook, Penguin Project of McLean County for further information.*

Abbey's experiences replaced the 'special places mentality' of the early 80's, so she has NOT:

- Attended any special education building with only students with disabilities.
- Participated in only in Special Recreation programs and Special Olympics.
- Worked in any sheltered workshop.
- Lived in any congregate residential arrangement.

Abbey's ability to produce these accomplishments included ample challenges, planning and needed accommodations, adaptations, and modifications. That was taking the services from the special places and systems and bringing them with Abbey into the non-special places the rest of us inhabit. From Early Intervention services for infant and toddlers with delays to Adult services for individuals with disabilities... from the arenas of education to recreation... medical professionals to health insurance carriers, system to system has encountered the need to be enlighten and/or change the delivery of services and, almost always, the perspectives of people. Yet the quality of an included life, of not being removed, but belonging and contributing where one was intended to be, are worth any and all effort.... any and all changes to accommodate and modify.

It's the middle of the year 2013. And Abbey wants her story to share that while her father passed away, her grandparents passed away, and her sisters and best friend from kindergarten moved away, she still lives alongside her ordinary family (mom and stepfather) and in an ordinary community with her aunt, uncle, cousin, and friends and numerous acquaintances.

And, yes, she is still on an extraordinary journey as a middle child from a middle class family in the middle of Illinois.



*Sandy and Abbey  
December, 2011*

## About Our Organization

The Central Illinois Down Syndrome Organization (CIDSO) is a not-for-profit organization of families and interested persons working to increase public awareness, support families, and improve opportunities for those touched by Down syndrome. Established in 1974 to act as a support service, we serve Bloomington, Normal, and the McLean County area. Our organization is the oldest Down syndrome parent group in Illinois and the second oldest in the nation.

## New Parent Outreach

The process of acceptance begins as soon as Down syndrome is suspected. To support parents and extended family during this time, a parent outreach member will gladly make hospital or home visits. Informational packets are also available to new parents. Parent Outreach Members, *Brenda & Kevin Harms*, (309) 378-2388 and *Rick & Jennifer Bauersfeld*, (309) 874-2038, can be contacted any time.

## Enrichment/Participation Fund

This fund is designed to enrich the lives of those born with Down syndrome and promote community involvement/participation. It is available to any person with Down syndrome regardless of involvement/participation in CIDSO. Applications are reviewed at the quarterly board meetings and must be received by CIDSO at least 10 days prior to the board meeting. Additional details and applications can be found in the "Resource" section of the CIDSO website. <http://cidso.org/resources.asp>

## Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote or recommend any therapy, treatment, institution, political affiliation or professional system and any information contained herein shall not imply such. Please discuss specific concerns with a professional.

### Coming Soon!

Sensory Friendly Movie  
February 8<sup>th</sup>

CEC Adult Bowling  
February 9<sup>th</sup>

CEC Adult Bowling  
February 23<sup>rd</sup>

CEC Adult Bowling  
March 9<sup>th</sup>

Board Meeting  
April 7<sup>th</sup>

Board Meeting  
July 7<sup>th</sup>

Board Meeting  
October 6<sup>th</sup>

### We're on the Web!

See us at:

[www.cidso.org](http://www.cidso.org)

**Facebook Fan? Like Us!**  
**Central Illinois Down  
Syndrome Organization**

