

Iowa Juvenile Home: A Great Opportunity

Jane Hudson, Executive Director
Disability Rights Iowa
Senate Government Oversight Hearing
Sept. 17, 2013

Thank-you to...

All of you who are working together to make sure that:

- Young lowans are never confined in isolation cells again, and
- They are getting the treatment and services they need to have better futures

In particular, thank you

- Senate Government Oversight Committee
- Legislators from both sides of the aisle
- Governor
- Task Force itself – meeting tomorrow at the Juv. Home
- Director Palmer, Rick Shults and employees of the Department of Human Services,
- Mark Day, Interim Superintendent of the Juvenile Home, and his staff
- Other state agencies (DHS, ED, DPH and others)
- Attorney General's Office
- Iowa Juvenile Justice Task Force

...and many more

Introductions: Disability Rights Iowa (formerly Iowa Protection and Advocacy Serv.)

NEW EXECUTIVE DIRECTOR: Jane Hudson, J.D.

CHILDREN'S TEAM:

- Cyndy Miller, J.D., Senior Staff Attorney
- Nate Kirstein, J.D., Staff Attorney, DRI
- Beth Rydberg, Senior Advocate

Discuss

- 1) What Disability Rights Iowa is so you can better understand our role and our authority
- 2) How we became involved in the Juvenile Home last November
- 3) Our preliminary recommendations to the Legislature and the Task Force as they are working on solutions

What is Disability Rights Iowa?

- Not a federal or state agency
- But, non-profit law firm, 100% federally-funded to do two things:
 - 1) Investigate abuse and neglect of individuals with disabilities (INVESTIGATIVE AGENCY)
 - 2) Pursue legal, administrative and other remedies on behalf of individuals with disabilities

“AGENT OF FEDERAL GOVERNMENT”

Need to give you a little history

- Remember all of the civil rights movements in 1960's and 70's
- Disability Rights Movement – equal opportunities to get educated, work, access public services (crawling up court stairs)
- But, some individuals with disabilities had no voice at all b/c hidden away in institutions

Willowbrook State School (NY 1972)

- Psychiatrist trying to organize families to improve conditions
- Local reporter got keys from psychiatrist and went in
- Naked children doing nothing but moaning; stuffing food into their mouths, no education, no services, but smell was worst – filth, defecation
- Described as a “snake pit”

Willowbrook → Creation of Protection and Advocacy System for Ind. with Developmental Disabilities

- Created by bipartisan Congress in mid-1970's
- One P&A in every state and territory (57)
- Existed for more than 30 years
- Grown to serve all individuals with disabilities, including individuals with mental illness
- Network is largest provider of disability-related legal services in the country

Protection and Advocacy Systems for Individuals with Disabilities

- Funded by four federal agencies (formula grants)
 - U.S. Department of Health and Human Services
 - Health Resources Services Administration
 - Rehabilitation Services Administration
 - Social Security Administration
- Eligibility for services: Must have a disability

Protection and Advocacy Programs

- 1) Developmental Disabilities Assistance and Bill of Rights Act
- 2) Protection and Advocacy for Individuals with Mental Illness Act
- 3) Protection and Advocacy for Individual Rights
- 4) Protection and Advocacy for Individuals with Traumatic Brain Injuries
- 5) Protection and Advocacy for Beneficiaries of Social Security
- 6) Protection and Advocacy for Voting Access
- 7) Representative Payee Program
- 8) Client Assistance Program (advocacy re: vocational rehab)
- 9) Protection and Advocacy for Assistive Technology

Federal Law: Investigative Authority

Broad authority to conduct investigations:

- Access to all areas of public and private facilities where residents have access.
- Opportunity to interview employees, residents [even the victim(s)], and others who have knowledge
- Review records with consent of individual or guardian or other conditions met

Federal Law: Monitoring Authority

Monitor for safety and compliance issues:

- Reasonable unaccompanied access to residents
- Monitor all areas to which residents have access
- Inspect, view and photograph all areas

(Supersedes state and local laws which restrict access to minors and wards)

Reasons for Monitoring

- Federal funding agencies expect protection and advocacy systems to monitor facilities
- P&As learn more about issues in facilities by visiting them, rather than just getting calls through intake
- P&As are able to conduct outreach to individuals with disabilities
- P&As use information gained in monitoring to identify issues and conduct more in depth advocacy and investigations

Federal Law: Training Authority

Provide information and training on:

- 1) Programs serving individuals with disabilities,
and
- 2) Individual rights
- 3) Protection and Advocacy System itself

Federal law: Authority to provide legal representation and advocacy

- Pursue remedies on behalf of individuals with disabilities to protect their rights
 - Legal (individual and classes of individuals)
 - Administrative
 - Advocacy
 - Negotiations
- Use alternative dispute resolution where possible

Federal laws P&As rely on to protect and advocate for individuals with disabilities

- U.S. and State Constitution
- Section 504 of the Rehabilitation Act
- Americans with Disabilities Act
 - no discrimination based on disability
 - right to live in the most integrated environment
- Individuals with Disabilities in Education Act
- Others

Iowa Authorizing Law:

The Protection and Advocacy agency is recognized as an agency legally authorized and constituted to ensure the implementation of Iowa law which:

- promotes and encourages adequate and safe care and housing
- for individuals who are aged or who, regardless of age, are infirm, convalescent, or mentally or physically dependent,
- by both public and private agencies

Disability Rights Iowa

- Formerly Iowa Protection and Advocacy Services
- Incorporated in 1984
- Designated by then governor as P&A
- Current Staff: 6 attorneys, 3 advocates, 1 paralegal, 2 benefit planners and administrative staff
- Location: 400 East Court Ave. Suite 500

As new P&A Director, I increased DRI's monitoring activities.

- 1) Understand issues in different types of facilities
- 2) Have greater presence across state
- 3) Outreach to individuals with disabilities
- 4) Monitored
 - nursing facilities
 - Mental health institutes
 - Residential and intermediate care facilities
 - State resource centers
 - and Eldora Training School for Boys and Iowa Juvenile Home for Girls/State Training School once a month

First Monitoring Visit by DRI in November 2012

- Met with then superintendent Deb Hanus and clinical director Ilona Avery
- Toured facility and school, including control room under classrooms
- Stunned to find three girls who had been living in the isolation cells for months
- Story that got me personally:
“Sorry, honey, we have to close the door....”

DRI'S Record Review as of April 3, 2013

47 youth: -10 boys; 37 girls

- 34 CINA, 7 delinquent, 6 dual

- 85% of youth had poly-trauma histories
- 98% of youth had mental health diagnoses
- 51% had post-traumatic stress disorder
- 68% were in Special Education
- 43% had previously been in Psychiatric Medical Institutions for Children (PMICs) or mental health institutes (MHIs)

Some describe as “worst of the worst,” but should we be more careful before we label these youth?

Other Problems That DRI Identified as Monitoring Continued

- Excessive and illegal use of restraints and seclusion
- Girls not receiving education while in long-term isolation
- Individual Education Plans for all Residents Inadequate
- Inadequate transition plans for girls aging out at 18 (education, vocational, living situation)
- Mix of populations: mostly foster girls, a few foster boys, a few delinquent girls
- Line residential staff, rather than treatment or educational staff, appeared to be running the show

Meetings to Discuss Possible Solutions

Numerous meetings between November 2012 and July 2013 to discuss how to solve problems:

- Disability Rights Iowa
- Department of Human Services (Rick Schults)
- Attorney General's Office

Disability Rights Iowa repeatedly suggested that the Iowa Department of Human Services take advantage of expertise from National Association of State Mental Health Program Directors, but never done.

But, kudos to the Department of Human Services for the changes that have occurred to date.

- Leadership of the Juvenile Home changed in January
- Use of long-term isolation cells stopped
- Significant reductions of restraint and seclusion use (side-by-side)
- Individual behavioral specialist trained (?) staff
- Recent restraint and seclusion policies are reflecting best practices
- Cottages remodeled and painted
- Establishment of transition room for in-school suspensions
- Behavioral and educational assessments and plans are occurring
- More off-campus activities

Also, lots of involvement from those who were concerned about conditions

- Governor issued Executive Order and created top-notch Task force (10/15/13 recommendations)
- Assessments of strengths and needs by Departments of Education and Public Health
- Legislators on both sides of the aisle, courts and others focusing on how to continue to improve the Juvenile Home

So, why is Disability Rights Iowa still involved?

- Monitor implementation of new policies and procedures.
- Advocate for individual residents whose rights are violated (excessive & illegal restraint)
- Help residents become better informed and skilled to assert their own rights (educational rights)
- DRI's state complaint with Dept. of Education to get compensatory education for girls in isolation cells
- System changes still needed...

DRI's Evolving Recommendations regarding system changes...

- DRI made preliminary suggestions in July
- Refined as DRI continued to monitor and get input from clinical experts
- DRI wants to see what Task Force and Legislative Committees recommend
- But, in the mean time, we wanted to share with you what our current thinking is:

#1 How can Juvenile Home transition from corrections-based system to system based on trauma-informed care, treatment and recovery?

Trauma-Informed Care

- Trauma-informed care is an approach to engaging people with histories of trauma that
 - recognizes the presence of trauma symptoms and
 - acknowledges the role that trauma has played in their lives.
- Paradigm shift: **"What's wrong with you?"** → **"What has happened to you?"**
- Trauma-Informed Care already recognized in Iowa as a best practice and evidence-based (redesign, suicide prevention laws)

Strategies to create this change...

- 1) Leadership toward Organizational Change**
- 2) Use of Data To Inform Practice**
- 3) Workforce Development**
- 4) Use of S/R Prevention Tools**
- 5) Consumer Roles in Inpatient Settings**
- 6) Debriefing Techniques**

Snapshot of Six Core Strategies for the Reduction of Restraint and Seclusion from the National Association of State Mental Health Program Direct

Implementation

- Hire leadership committed to culture of trauma-informed care, treatment and recovery.
- Strength and needs assessment before hiring new leadership?
- Workforce training and skills.
 - Current workforce → more training and oversight
 - Additional workforce experienced in trauma-informed care

#2 How could the Juvenile Home be a pilot program for improving the children's mental health system?

Only a few dozen youth there now:

- Questions

- What could have been done to prevent youth from being discharged from previous placements?
- Should an institution-based campus facility be maintained or should Iowa consider community-based alternatives used in other states (Missouri?)
- Could the juvenile home be one aspect of a continuum of care for youth with mental illnesses and histories of poly-trauma?

#3 What can Iowa do to ensure that youth aging out of the Juvenile Home have the education, skills and plans that they need to move into adulthood?

- Interdisciplinary and interagency teams needed to work on individualized transition plans and implementation.
 - Education
 - Vocational
 - Behavior management
 - Medication Management
- Efforts to give youth skills to live in the community before they age out.

#4 What type of oversight is needed to ensure that the Juvenile Home is keeping residents safe?

- Always a need for independent oversight
- Risk Management tool to correct issues before they happen
- Juvenile Home currently exempted from any oversight
- Department of Inspections and Appeals provides oversight of private facilities and some public facilities (Woodward and Glenwood State Resource centers. Why not the Juvenile Home?)

#5 Should the school and residential facility be managed separately?

- Educators in charge, rather than health care professionals.
- AEA 267 already operating special school programs (the Learning Center, Pinecrest Center, Bremwood)
- Tama School District not appropriate because:
 - might not have the resources to deal with youth with behavioral issues.
 - Youth need year round school because of transiency
- Independent school can ask questions and raise issues. Checks and balances.

Great Opportunity

- To work together to develop a comprehensive system for serving children with serious mental health issues and histories of trauma

When we lowans removed these children from their families, we promised that we could do better. Now is the time to do better.

Thank you for asking us to speak today.

- Questions?
- Comments?