Foster Despair

Improving Access to Education Services for Youth with Intellectual Disabilities in State Custody

November 2013

NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities

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A Letter from the Executive Director

I am shocked and saddened by what this report tells us about the plight of children with disabilities in our foster care system. While this report explores territory that is relatively uncharted for the outside world – not so for the P&As. When we researched this issue, we were struck by how little has been written about these children and how little data has been collected about their plight. However, the P&As have been serving these children in large numbers for years, advocating for their placement in less restrictive settings, for quality education, and appropriate mental health treatment.

Clearly our work is just beginning.

What we found when we prepared this report was far more than educational deprivation, as if that weren't concerning enough. In 2013 we are still hearing that children, who have been removed from the home due to no fault of their own, are being placed in settings designed for individuals with completely different needs, due to lack of placement/service options. For example, children with disabilities who have not broken any laws are placed in juvenile justice facilities because there are no other open beds. We learned that loving parents are still being required give up guardianship to the state in order to obtain publicly funded services for their children. Hundreds of youth from one state are being placed in out-of-state residential facilities, which makes it nearly impossible for their parents to visit them.

The findings of the report that are specific to education are equally concerning. By definition, these are children whose parents cannot move them to another school if they do not like the education provided -- they are trapped in a system with no other options but what the state provides.

In the course of our investigation, we learned that education deprivation is still used as punishment for disability related behaviors in some facilities, and of long term failure to provide access to educational credit to all children housed in state run residential facilities. This means that when the children return to public school, if they do, they have

lost credit for all of the work they did while in the facility. We heard of cases in which IEP/504 services are not individualized; that are capped, absent, or limited due to budget constraints. ("We just do not provide speech therapy here."). We learned of children removed from their homes because of specific service needs who were placed in settings that, as a rule, do not provide services required to meet those needs. The list goes on and on.

The 57 member P&A network is the Nation's largest provider of advocacy services for these children, and we serve hundreds each year. However, as this report shows, there are clearly still children who need our help. Like the other groups of individuals served in institutional settings, it is time for us to peel away the roof of each of these facilities and take a look inside.

Curt Decker

Executive Director

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Executive Summary

This report was commissioned by the Administration on Intellectual and Developmental Disabilities (AIDD) to examine why youth with intellectual disabilities (ID) in state custody receive lower test scores, are more likely to fail or repeat a grade, and experience lower graduation rates than their peers who are not in state custody. The youth in question are those who live in congregate care or other institution-type settings rather than with foster families or in juvenile detention facilities.

This report examines the following questions:

1. Nationally, is educational service deprivation a problem for youth with ID who are in state custody?
2. What are the most severe barriers to educational services?
3. What is needed to remove these barriers?

To get answers, the authors surveyed the nationwide system of Protection and Advocacy agencies (P&As). The P&As have extensive experience working with youth in state custody and representing children and families seeking access to educational services. The authors also reviewed academic research and legal research.

The results of our study were sobering and sweeping, reaching beyond school-based concerns. These were some of the most ***troubling findings***:

- Youth placed in settings that are not remotely designed for their needs, due to lack of placement/service options
    - Youth without psychiatric needs placed at psychiatric hospitals
    - Youth who are not alleged to have violated any laws placed in juvenile detention settings
    - Youth placed in nursing homes, due to lack of community supports
- Custody relinquishment: Parents regularly required to give guardianship to the state in order to obtain publicly funded services
- Education deprivation as punishment
- Routine placement in extremely restrictive settings, e.g. out of state residential facilities for hundreds of youth from one state
- Long term failure to provide access to credit bearing general education

- IEP/504 services that are not individualized; that are capped, absent, or limited due to budget constraints. ("We just do not provide speech therapy here.")

Education Barriers Identified For Youth with Disabilities in State Custody

- The unavailability of least restrictive placement options resulting in segregated schooling, residential treatment and/or out of state transfer. Intense segregation in both educational and residential settings.
- Student records that are not transferred timely or completely.
- Evaluations for special education eligibility are disrupted by out of home placement and lack of qualified providers.
- Educational services that are not individualized.
- Frequent system requirements conflicts leaving the youth caught in the middle.
- Removal from school is used as a form of discipline.
- Youth receive inadequate transition services, in programs that may feed them into the "School to Sheltered Workshop Pipeline," as well as the "School to Prison Pipeline"
- Services for dually diagnosed youth may not address all needs (e.g. may receive services limited to the needs related to behavior).
- General failure by states to provide educational programming sufficient to meet the needs of youth they house.
- The lack of an informed, caring adult to advocate on behalf of youth with disabilities to ensure they receive the services they need. (e.g. surrogate parents not appointed timely and/or insufficiently trained)

We developed the following **recommendations** as a result of this examination:

- Vigorously enforce current state and federal statutes related to the educational needs of these youth, such as the *Fostering Connections to Success and Increasing Adoptions Act of 2008*, *McKinney-Vento Homeless Assistance Act of 1987* and the *Individuals with Disabilities Education Act*, among others.
- Require data collection specific to the placements, educational outcomes, and service needs of these youth.
- Develop a pilot project to identify proven tactics, protocols, and advocacy strategies, and to develop technical assistance resources focused on ensuring quality education for this population of youth.

- Hold a roundtable or issues forum on the policy implications related to the most significant barriers identified and multiple facets of these issues.
- Enact policy change resulting in supports that will allow for increased placement of these youth in family based residential settings in the community.
- Require state level review of policies that cause conflict and confusion within state and county level services systems, resulting in service deprivation for these youth.
- Enact programs and policy changes that prevent academic disengagement, such as state wide programs that allow for swift and complete credit transfer when students change schools.

I. Introduction

A. Context

There are approximately 345,958 children in the state custody system nationwide.[1] These children and youth (hereinafter "youth,"[2]) are placed in a dizzying array of care arrangements and programs including, but not limited to juvenile detention, public or private residential programs, wilderness programs, boot camps, skilled nursing facilities, foster care, kinship (relative) care and group homes of various sizes, levels of formality and complexity. The degree of oversight, applicable rules/regulations, and identity of the overseeing agency(ies) that govern these placements vary dramatically from state to state and facility to facility.

It is though time has stood still for these youth -- experiencing legal and practical barriers to education that have largely been eradicated for the population of children with disabilities with involved parents.

Youth in state custody[3] frequently demonstrate poor educational outcomes. Research has shown that these youth tend to obtain lower test scores and grades, and are more likely to fail a grade or perform below grade level than their peers who are not in state care. They are almost twice as likely to repeat a grade as a child not in care and to experience truancy, discipline, and absenteeism disproportionately. They are less likely to be involved in extracurricular activities. Thirty to fifty percent are eligible for special education, as opposed to fifteen percent or less on average for children not in care. Within special education, these youth tend to have disabilities that are different from those of youth who are not in state custody. Given these cumulative factors, it is not surprising that high school graduation and post-secondary enrollment rates are low.[4]

1 Annie. E. Casey, Kidscount Data Center (2011) http://datacenter.aecf.org/data/tables/6242-children-0-to-17-in-foster-care?loc=1&loct=2#detailed/1/any/false/867,133,38,35,18/any/12985,12986. Definitional variations make it difficult to match data counts involving this group.

2 In the P&As' experience, a great many of those placed are very young children.

3 As "state custody" is the term most frequently used, it will be used here although in some states the county actually has custody rather than the state.

4 Kele Stewart, The Connection Between Permanency and Education in Child Welfare Policy, 9 Hastings Race & Poverty L.J. 511 (2012).

Youth may be placed in state custody, commonly known as the "foster care system," due to an alleged violation of the law, parental abuse and neglect, or being found "in need of services" by a court. It is not uncommon for a single youth to be in state custody for multiple reasons. In addition, in some cases, families are required to relinquish custody of their children with disabilities in order to obtain publicly funded services for them. While the term "foster care" is often used generally, of specific concern to the P&A network are those youth who are not placed in a family foster home and are placed instead in a congregate care facility and/or institutional setting.

The Protection and Advocacy System (P&A) knows that youth with disabilities in government custody do not always receive needed special education and regular education services. For example, a recent investigation by Disability Rights Iowa found that youth who had not been arrested, but who were wards of the state for other reasons, were being deprived of special education services, and, in fact, any educational services at all. This occurred while they were being held in seclusion at a "juvenile home," an isolation that occurred for months at a time.[5] As a result of a complaint filed by the P&A with the state department of education, the State of Iowa is now investigating the matter. However, as this report explains, while it is clear that the State Education Agency is ultimately responsible for the provision of special education services, it is not always easy to determine which legal authority governs the placement of these youth and which agency is responsible for providing educational services at the local level. Legal authority and oversight of the residential setting in which a given youth is placed can be very unclear and overlapping, resulting in a seemingly intractable situation.

A significant percentage of youth in the juvenile justice and child welfare systems have disabilities, including intellectual disabilities. As a result, quite literally, thousands[6] of youth with intellectual disabilities are placed in a system that does not always meet their educational needs.

[5] For a news article about this case, see http://www.desmoinesregister.com/article/20130724/NEWS/307240049/Register-Investigation-Denial-of-schooling-is-alleged?News&nclick_check=1

[6] According to the U.S. Department of Education (https://www.ideadata.org/arc_toc13.asp#partbCC; Table B1-17), youth with intellectual disabilities who are eligible for special education made up 0.63 percent of the total population at last count. The rate in the child welfare population (youth in state custody), is probably much higher, given the higher rate of ID anticipated within that system, the fact that individuals tend not to self-identify and are not identified for services by these systems. Using that very conservative calculation, 63% of 345,958 (total youth in care in 2011) is 2179. Therefore the number of youth with intellectual disabilities in the child welfare system totals at least is 2179 nationwide.

B. Who We Are

National Disability Rights Network (NDRN) was commissioned by the Administration on Intellectual and Developmental Disabilities (AIDD) to determine the characteristics and depth of the problem of educational service deprivation for youth with intellectual disabilities in state custody. This report presents the findings from this evaluation and offers recommendations for training and technical assistance to the P&As to support advocacy on this issue, as well as policy recommendations. Data about the problem was obtained from the P&As from a variety of sources, including case dockets, technical assistance requests, and information requests, among others.

NDRN is the non-profit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP), the nationwide network of congressionally-mandated agencies that advocate on behalf of persons with disabilities in every state, the District of Columbia, Puerto Rico, and the U.S. Territories (American Samoa, Guam, U.S. Virgin Islands, and the Northern Mariana Islands). There also is a P&A affiliated with the Native American Consortium which includes the Hopi, Navajo and Piute Nations in the Four Corners region of the Southwest. Collectively, the P&A agencies are the largest provider of legally-based advocacy services for persons with disabilities in the United States, and the largest provider of education advocacy for children and youth with disabilities.

C. Specific Focus

Our original investigation addressed barriers to the appropriate education of youth with intellectual disabilities who are in state custody. The population it covered was specifically limited to minors in state/county custody with intellectual disabilities (ID), who were not currently placed in a foster home, and who were not adjudicated delinquent. In other words, youth with ID whose residential placement was anywhere other than: 1) juvenile or correctional facilities, or 2) family foster homes.[7]

However, the resulting report found barriers broader and deeper than these.

D. Defining the Problem

[7] We have discovered that youth who are not delinquent, are sometimes placed in juvenile detention facilities and other settings operated by a state's juvenile justice system due to a lack of space in other settings.

This report examines the following questions:

1. Nationally, is educational service deprivation a problem for this population and if so, which subgroups are most severely affected?
2. What are the most severe barriers to educational services?
3. What is needed to remove these barriers?

Sources of Information

We answer these questions using three separate sources:

- The considerable experience of the 57 Protection and Advocacy Systems.
- A review of the academic research.
- A legal research review.

II. Input from the Protection and Advocacy Systems

A. Methodology

In addition to reviewing P&A technical assistance requests and relevant dockets, NDRN also requested information from our members and received responses from 35 individual P&As.

The strong and speedy response received from the P&As demonstrates to us that the P&A input is valid and the advocacy issue is of high interest to the network. A summary of the major questions and responses from the P&As follow.

B. P&A Feedback

General Conclusions

Several important conclusions may be drawn from the P&As' responses. What is most striking, however, are the types of barriers presented. It is as though time has stood still for these youth -- experiencing legal and practical barriers to education that have largely been resolved for the population of children with disabilities who have involved parents. In short, youth in government custody may be dealing with problems that were ubiquitous in the 1970s, before the enactment of IDEA, but are now, thankfully, exceptions in many public schools.

Level of Need

P&A agencies receive a substantial number of intake calls regarding the educational needs of youth in state custody. More than 90% of the responding P&As reported that they receive such calls. These calls are placed by a number of different sources, including foster parents, case workers, surrogate parents, and the youth themselves.

Responding to the first issues, "Which agency(ies) in your state has primary responsibility for making decisions on behalf of youth with Intellectual Disabilities (ID) in state custody?," it is telling that many P&As listed as many as seven state and county agencies having "primary responsibility" for these youth. This redundancy may be due in part to the varying needs of subpopulations within this group, but that cannot

provide a complete explanation. Confusion regarding which agency has responsibility for these youth is a common theme among the survey responses.

Many P&As responded to this question with the actual title of the agency(ies) having primary responsibility for youth in state custody. A list of the reported agencies grouped, by typical category follows. However, agency jurisdiction does vary from state to state.

Agencies listed included (not in rank order):

- State child welfare agency
- State education agency
- State department of mental health
- County child welfare agency
- State developmental disabilities sub – agency
- Local education agency
- County education agency
- Regional center
- State juvenile justice system
- Guardians *Ad Litem*
- State department of corrections

For the second inquiry, the P&As responded by identifying the residential settings that youth in state custody, *with and without disabilities* who are not adjudicated delinquent, are placed. The settings identified, in order by rank, are listed below, categorized as formal/government sanctioned settings and informal settings.

Formal/Government Sanctioned Settings[8]

- Foster home/care (100%)
- Kinship/relative care (formalized legal relationship including but not limited to guardianship) (91.4%)
- Group home (88.6%)
- Private residential facilities (82.9%)

[8] The number in parentheses is the percentage of responding P&A who listed this placement setting.

- Psychiatric hospital (82.9%)
- Juvenile detention facilities (74.3%)
- ICFs- MR (42.9%)
- Wilderness programs/boot camps (34.3%)
- Nursing homes (22.9%s)

Informal Settings

Youth in government custody *with and without disabilities* who are not adjudicated delinquent, are placed in the following informal residential settings:

- Placement with individuals who are not parent or guardian, e.g. couch surfing, staying with friends or relatives. (60.6%)
- Homeless but not living in a shelter (54.6%)
- Homeless shelter (51.5%)
- Programs that serve runaway youth (45.5%)
- Illegal settings/employment, such as the illicit sex and drug industry (30.3%)
- Unknown (30.3%)
- Migrant work/housing (21.2%)

Barriers Identified

Following are the barriers P&As identified in rank order, when asked to list the **most significant barriers** to an appropriate education for these students.

- Inadequate educational programming offered (e.g. placed in a setting that does not provide education sufficient to graduate on time or does not provide all of the services on IEP/504 plan.
- Insufficient support to access educational services (e.g. related services).
- Time delays in the provision of service that obviate the service (e.g., by the time service is provided, student has moved on).
- Lack of educational programming offered (e.g. placed in a setting that does not provide education, programming offered does not grant transferrable credit).
- Lack of qualified staff to provide educational services.
- Lack of adult support necessary to negotiate the system to obtain credit (e.g. surrogate parents, case managers).

- Migratory or transient nature of placement (not present long enough to make progress).
- Confusion about which agency/entity is responsible for providing educational services.
- Lack of transportation to educational services.

For those P&As who noted the **migratory or transient nature of the placement,** as a barrier, a number provided additional detail about the problems these youth face. It is important to note here that most of the issues identified below are addressed by currently valid federal legal authority, e.g. timely record transfer, transportation, service planning etc. Simple compliance with existing law is a significant issue.

- Placements being disrupted.
- Administrators who do not get moving on services fast enough.
- Local school districts that deny attendance due to temporary nature of placement.
- Time limited placements and failure to change transportation routes which results from moving from one school or school district to another.
- Detention Centers which on average only keep youth for 30 days, and so provide very limited, or no, educational services.
- The transition out of the placement to return home or to the home community does not always align with education and service needs of the youth.
- Untimely transfer of student records causes delays in delivery of services.

Additional barriers identified by the P&As:

- Lack of assistive technology.
- Lack of qualified professionals and remoteness of state institutions in a primarily rural state.
- State and local barriers to Least Restrictive Environment (LRE).
- Delay in getting records to support need for supports/services.
- Failing to take the role of the educational surrogate seriously.
- Criminal charges brought by a school district resulting in the youth being arrested before or without evaluation.

- Enrollment difficulties, including the school's refusal to enroll a youth due to lack of a birth certificate, lack of IEP, or other education records.).

Problems Unique To Youth with Disabilities Generally

In response to the question, "*Are there problems that are unique to, or more severe for, youth with disabilities?*" respondents reported that the lack of service and placement options for youth with disabilities that are truly responsive to their needs created problems unique to youth with disabilities.

Problems unique to youth with disabilities in government custody identified were:

- Youth in residential care who are required to attend a highly restrictive on-site school, because all students at the facility must attend the on-site school, even if they are able to attend a regular public school successfully with supports. One P&A reported. "Every youth I have met at the state residential treatment facility attends the facility's school rather than the other schools in the area."
- Out of State residential schools-- One small state reported having several hundred children in state custody housed out of state, for a period of years. In that state, parents are required to relinquish custody to the state in order to obtain residential services. (This was not an uncommon theme. Other states reported similar issues).

Troubling Findings

- Youth placed in settings that are not remotely designed for their needs, due to lack of placement/service options
  - Youth without psychiatric needs placed at psychiatric hospitals
  - Youth who are not alleged to have violated any laws placed in juvenile detention settings
  - Youth placed in nursing homes, due to lack of community supports
- Custody relinquishment: Parents regularly required to give guardianship to the state in order to obtain publicly funded services
- Education deprivation as punishment
- Routinize placement in extremely restrictive settings, e.g. out of state residential facilities for hundreds of youth from one state
- Long term failure to provide access to credit bearing general education.
- IEP/504 services that are not individualized; that are capped, absent, or limited due to budget constraints. ("We do not provide speech therapy here.")
- Intensely limited transition/vocational services; programs that feed the "School to Sheltered Workshop Pipeline"

- The IEPs that youth enter the facility with are often more robust than the IEPs at the facility. Education staffing at the facility is not based upon the individualized need of the youth but rather upon the number of youth in the facility. If the population is low (as is the case in some of the facilities for female youth) there are no direct special education services or supports. The decision to bring in a special educator is not based upon the need of the youth but based upon the budget allocation of the facility.
- Lack of community-based services for youth with intensive behavioral health needs.
- Conflicts between the state mental health division and the state education agency regarding who will pay for educational services, despite interagency memoranda of understanding and integrated treatment teams.
- Local treatment team recommendations for treatment/placement that are consistently rejected at the state review level.
- Evaluations are protracted and untimely for special education services, compared to the public schools, and the youth move before the process is completed and an IEP is developed. This requires the process to start again, sometimes multiple times.
- School attendance is denied as a disciplinary measure.
- Adequate behavior intervention plans and transition plans are not developed for youth.
- Youth are placed in overly segregated settings without access to meaningful special or general education curriculum, which is disengaging for youth.
- There is either a delay or a sharp reduction in services, including transition services, when youth are moved into a more restrictive setting, such as a juvenile detention facility or involuntary treatment.
- Programs are limited to a single disability category rather than being adaptable to students' individual needs. (In other words, services are only available to address one particular type of need, not all needs a youth may present.)
- Youth are not provided with meaningful transition services or are pushed out of school by age 18, even if they have not meaningfully reached their IEP goals.
- Youth who are homeless and eligible for special education services, but who lack appropriate records are denied enrollment by schools.

- School districts delay enrollment of youth placed in homeless shelters by scheduling enrollment appointments only on certain days, or trying to deny educational services until an IEP meeting can be scheduled at some future date.
- Attendance requirements pose large obstacles for transient youth to receive credit. Youth in state custody often lose several days of attendance between moves that cause them to lose credits and fall behind. This can be more significant for youth with disabilities because districts are not consistent in uploading special education plans to a state database, so there is often a lag time for incoming districts to be aware of educational needs for new students.
- Juvenile detention facilities do not employ all the types of related service providers necessary to provide a free and appropriate education (FAPE) e.g., speech language pathologists, occupational (OT) and physical (PT) therapists. (Youth are typically placed in juvenile detention facilities while they await adjudication. Thus the youth in detention usually have not been determined to be delinquent by the court and may not have violated any laws.)
- Specific learning disabilities are often undiagnosed. Despite behavior challenges with many court-involved youth with disabilities, they rarely receive functional behavior assessments or individually-tailored behavior plans." (It appears that the very facility that is intended to address the needs of children with severe behavioral problems may not have the programs and services to treat behavioral needs.)
- Staff in treatment facilities often are unaware of the nature of a student's disability and how the disability affects behavior. This results in children being punished for not meeting expectations rather than being given necessary accommodations. Staff needs training so they understand the needs of the population they serve.
- Educational staff is not trained to deal with trauma and emotional challenges faced by many youth in state custody.
- Youth who need evaluation are sent to the juvenile detention center for evaluation because it is the available option, even though they have not been accused of having violated any laws. (By way of analogy, it would likely not be deemed acceptable if an adult in psychiatric crisis was incarcerated because a prison employed the only evaluation provider available in the community.)

- Youth with both intellectual and developmental disabilities and mental health needs lack appropriate mental health care options and are sometimes placed out of state, making education questions more complicated.
- Youth in need of residential treatment (PRTF) for mental health needs face a distinctly insufficient education service delivery system with no clarity which state or local agency should fund, provide, or oversee the educational services in these facilities.
- Youth with disabilities in state custody are much more likely to be sent out of state to private residential treatment centers, instead of, for example, a local juvenile facility. This poses a problem in localities in which the local juvenile facility has a relatively strong school connection to the community. For example, provides mentors that stay with youth as they leave. Youth with disabilities who are sent to out-of-state PRTFs or RTCs do not benefit from the improved system.

Themes that emerge from these responses:

- Failures by states or localities to provide educational programming sufficient to meet the needs of youth they house.
- The importance of an informed, caring adult to advocate on behalf of youth with disabilities to ensure they receive the services they need.
- The unavailability of least restrictive placement options resulting in segregated schooling, residential treatment and/or out of state transfer.
- Student records that are not transferred timely or completely.
- Frequent moves impact educational success in a variety of ways.
- Evaluations for special education eligibility are disrupted by out of home placement and lack of qualified providers.
- Services are not individualized.
- Frequent system requirements conflicts leaving the youth caught in the middle.
- Removal from school is used as a form of discipline.

Problems Unique to Youth with Intellectual Disabilities

Many P&As responded specifically regarding youth with intellectual disabilities by noting that youth may have both intellectual and other types of disabilities (e.g. those with behavioral symptoms). Placements tend to address the behavioral needs first, often at the expense of services to assist with the intellectual disabilities. Many P&As

noted that children with all types of disabilities faced the same challenges in their state – that intellectual disability was not unique.

P&A Responses Regarding Unique or More Severe Problems for Youth with Intellectual Disabilities:

- Likely subject to protracted stays in restrictive settings.
- For youth living in State Supported Living Centers, there is memorandum of understanding between district and facility about responsibility for services, but confusion still remains in some cases.
- Youth with ID have no clear "lead agency." [State] Developmental Disability Administration claims to only serve individuals over 18--while [State] Department of Mental Health has an entire section geared towards children, so there are less community based supports for youth with ID.
- Although our state ICF-MR has some limited history of mixed success with teaching and training some youths with ID, it knows little about working with youths with autism or autism and ID.
- Youth who need Augmentative Communicative Devices (ACD) may or may not have access as the State institutions are very slow to repair them if they break. Nor will they buy them without pressure being applied. So if a

P&A Example

"As a particularly rural state, there is a **very limited pool of qualified people** in various educational and supportive services specialties.

Our state institutions generally are not located near larger population centers and as a consequence, the state institutions struggle to get qualified professionals to work there. … If the youth comes to the ICF-MR, for example, with an IEP, they may provide educational services ***for 1 hour or a couple of hours a week*** supposedly in keeping with the IEP.

Many services are not available, such as staff knowledgeable about teaching students with ***learning disabilities or autism.*** Even speech language supports may be hard to obtain at the state hospital, though they are available at the ICF-MR.

We had to file a State complaint to ensure that the state even asked youths if they had graduated, had an IEP, or wanted educational services once they were 18 or older. If the student arrives without an IEP, the state rarely evaluates the student to see if they need educational supports but were never identified."

student comes in with a device, it will work if the student already knows how to use it, but if it breaks it may be months before it is fixed.

- Staff is not trained to work with ACDs so depending on how it works, it may or may not be useful. ACDs that speak help, but ACDs that require pointing or things like picture boards are often simply put in a drawer and not used. Our ICF-MR has been cited for programmatic failures repeatedly by CMS and state quality assurance agencies for, among other things failure to provide appropriate programming and failure to keep residents safe.
- Youth with ID are easy targets who are victimized by staff and students in facilities.
- Youth with ID are misunderstood and/or mishandled by law enforcement.
- Vocational Rehabilitation Services counselors are often not at the table in IEP meetings for children who are in residential settings. VRS is loath to provide services until a child is out of a residential setting.
- Intellectual disabilities are often not accommodated for in the programming of residential treatment settings. Children with ID thus have a more difficult time meeting expectations for discharge.
- There is a lack of services and supports for youth with ID who are aging out of state custody, including youth who may pose a risk to themselves or public safety. This leads to increase risk of involvement with criminal justice system.
- Youth with ID are frequently placed in psychiatric residential treatment centers. These facilities are not designed for children with ID and they can get stuck in these facilities for years.
- ID students are placed in life skills programs that are essentially separate from the schools that may house them. Despite IEPs that may list activities that provide opportunities for interaction with peers, such interaction is usually quite limited, especially after grades K-5. Opportunities for these youth to pursue or expand those goals are usually dictated by whatever life skills work site (if any) is already available. These are predominantly janitorial and/or sheltered workshop feeder programs."
- General education programs are often geared toward attainment of a GED. Accommodations are not readily provided, so students whose intellectual disabilities may create barriers to success in these programs often do not qualify or are not supported to succeed.

- Youth with intellectual disabilities may lack the capacity to understand school "zero tolerance" policies. For example, one youth who enjoyed watching old Western movies used his fingers to indicate pointing and shooting a gun and was suspended from school. That started a process where the youth fell behind in school, had increased problems managing his behaviors, and ended up in the juvenile justice system. This slide into the school to prison pipeline is quite typical.
- Youth with intellectual disabilities are often placed in the most restrictive or undesirable transition programs. For example, a youth with intellectual disabilities in one school district was only offered a "hospitality" program where he only learned how to fold towels.

Themes that emerge from these responses regarding the problems unique to youth with intellectual disabilities:

- Youth receive inadequate transition services, in programs that may feed them into the "School to Sheltered Workshop Pipeline, as well as the "School to Prison Pipeline." Although it is beyond the scope of this report, the issues raised here are particularly concerning when one considers the very high rates at which children with disabilities are found in the juvenile justice system. Children and youth in state custody are also disproportionately placed in the juvenile justice system rendering those who fit into both subgroups particularly vulnerable to this outcome. Further study is needed on the specific relationship between the placement of youth with disabilities in state custody, the "School to Prison Pipeline" and proposed solutions to this problem.

The critical importance of knowledgeable, concerned adults and swift and effective legal advocacy is clear from the feedback we received.

- Services for dually diagnosed youth may not address all needs (e.g. may receive services limited to the needs related to behavior).
- Intense segregation in both educational and residential settings.
- Placement in settings not designed for them (e.g. placement of youth in juvenile detention or psychiatric facilities who have not violated any laws and do not have psychiatric needs.

The Most Concerning Results From the Survey -- Overall

- Youth placed in settings that are not remotely designed for their needs, due to lack of placement/service options.
    - Youth placed in nursing homes, due to lack of community supports.
    - Youth who are not alleged to have violated any laws placed in juvenile justice settings.
    - Youth without psychiatric needs placed at psychiatric hospitals.
- Custody relinquishment: Parents required to give guardianship to the state in order to obtain publicly funded services.
- Education deprivation as punishment.
- Routine placement in extremely restrictive settings, e.g. out of state residential facilities for hundreds of youth from one state.
- Long term failure to provide access to credit bearing general education.
- IEP/504 services that are not individualized; that are capped, absent, or limited due to budget constraints. ("We just do not provide speech therapy here.")
- Intensely limited transition/vocational services; programs that feed the "School to Sheltered Workshop Pipeline or the School to Prison Pipeline"

III. Legal Compliance

A. Representation of Individual Youth

Compliance with, and enforcement of, existing law would resolve many, if not most, of the educational barriers reported. There are at least three relevant federal statutes that apply to the issues raised in this report. In fact, most of the issues identified have been addressed by P&As advocacy previously -- through legal or policy work, or both. Unfortunately, P&As are unable to reach all of these youth, due to the scarcity of adult advocates and the migratory nature of their placements, among others. When P&As are involved, the cases often involve simple compliance issues that are quickly resolved.

What is clear from the findings is the importance of knowledgeable, concerned adults and swift and effective legal advocacy on behalf of youth in state custody.

Systemic Work

- Can Olmstead/ADA be used to ensure that children are being placed in the Least Restrictive Environment (LRE)? Reducing out of home placement will increase the possibility of placement in a quality neighborhood school that is LRE.
- Does sufficient community support exist for child welfare clients with disabilities to avoid institutional placement? e.g. Does a child have to be placed in a RTC or group home in order to get counseling?
- Does your state have an adequate network of sufficiently trained and funded therapeutic foster care homes?

Relevant Federal Statutes Include:

- *Fostering Connections to Success and Increasing Adoptions Act of 2008*: 42 U.S.C. § 675 et al. Supports educational stability of kids in foster care.
- *McKinney–Vento Homeless Assistance Act of 1987*, 42 U.S C §§ 11431-11435. See esp. 42 U.S.C. §11432(g)(3)(A)(i). Addresses the provision of transportation and school enrollment for migratory and unaccompanied youth, include youth in state custody.
- *Individuals With Disabilities Education Act (IDEA),* 20 U.S.C.1400 et seq. Key Provisions: Parent: Definition at 34 CFR 300.30(a)
- Surrogate Parent: 34 CFR 300.519
- Enrollment/Records Transfer: 34 CFR 300.323(e), (f) and (g)

The Americans with Disabilities Act and Section 504 of the Rehabilitation Act, as well as other state and federal statutes, may also be of use in addressing these issues. They are not included here simply because they do not mention foster youth specifically.

IV. Training and Technical Assistance Recommendations

Grouping the barriers discussed above by topic, it is possible to see how these statutes apply. Specific training and technical assistance on the application of each statute to the barriers identified can facilitate P&As' understanding and application to advocacy efforts regarding the provision of appropriate education services to youth with intellectual disabilities in state custody.

As examples, the *Fostering Connections to Success and Increasing Adoptions Act of 2008,* 42 U.S.C. § 675(5)(d) states: "…a child's health and education…is reviewed and updated, and a *copy of the record is supplied to the foster parent or foster care provider* with whom the child is placed, at the time of each placement of the child in foster care, and is supplied to the child at no cost at the time the child leaves foster care if the child is leaving foster care by reason of having attained the age of majority under State law." This provision may be of use in preventing some of the chaos that ensues when youth move from setting to setting. Similarly, moving from school to school when placement changes, and barriers to enrollment, are addressed by the *McKinney Vento Act.* [9]

The *Individuals With Disabilities Education Act (IDEA) provides the statutory authority to address barriers* related to:

- Educational records transfer/delay[10]

[9] 42 U.S.C. §11431-11435. Information about McKinney Vento can be found at http://www2.ed.gov/programs/homeless/index.html. See especially, USDOE guidance document (http://www2.ed.gov/programs/homeless/guidance.pdf) at G-8, G-10, H-1, H-5 and J-2. These provisions address enrollment barriers, transportation, application to foster children and unaccompanied youth (e.g. runaways).

[10] 34 CFR 300.323 (e), (f), (g) "…**(e) IEPs for children who transfer public agencies in the same State.**

If a child with a disability (who had an IEP that was in effect in a previous public agency in the same State) transfers to a new public agency in the same State, and enrolls in a new school within the same school year, the new public agency (in consultation with the parents) must provide FAPE to the child (including services comparable to those described in the child's IEP from the previous public agency), until the new public agency either—

(1) Adopts the child's IEP from the previous public agency; or **(2)** Develops, adopts, and implements a new IEP that meets the applicable requirements in §§ 300.320 through 300.324. **(f) IEPs for children who transfer from another State.** If a child with a disability (who had an IEP that was in effect in a previous public agency in another State) transfers to a public agency in a new State, and enrolls in a new school within the same school year, the new public agency (in consultation with the parents) must provide the child with FAPE (including services comparable to those described in the child's IEP from the previous public agency), until the new public agency—

- Transportation (Also addressed by *McKinney Vento*)
- IEP implementation (see FN 14)
- Least Restrictive Environment (primarily as applied to the school/educational setting)
- Access to the general curriculum
- Appropriate transition services
- Provision of a trained and qualified surrogate parent without conflicts of interest[11]
- Evaluation qualifications and timelines.

Due to entrenched policies and procedures it may not be simple to challenge these barriers when a child is in state custody. For some states, policy changes may be required.

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(1) Conducts an evaluation pursuant to §§ 300.304 through 300.306 (if determined to be necessary by the new public agency); and

(2) Develops, adopts, and implements a new IEP, if appropriate, that meets the applicable requirements in §§ 300.320 through 300.324.

(g) Transmittal of records. To facilitate the transition for a child described in paragraphs (e) and (f) of this section—

(1) The new public agency in which the child enrolls must take reasonable steps to promptly obtain the child's records, including the IEP and supporting documents and any other records relating to the provision of special education or related services to the child, from the previous public agency in which the child was enrolled, pursuant to 34 CFR 99.31(a)(2); and

(2) The previous public agency in which the child was enrolled must take reasonable steps to promptly respond to the request from the new public agency. "

[11] 34 CFR § 300.30: "…**(a)** *Parent* means—

(1) A biological or adoptive parent of a child;

(2) A *foster parent,* unless State law, regulations, or contractual obligations with a State or local entity prohibit a foster parent from acting as a parent;

(3) A guardian generally authorized to act as the child's parent, or authorized to make educational decisions for the child (but not the State if the child is a ward of the State);

(4) An individual acting in the place of a biological or adoptive parent (including a grandparent, stepparent, or other relative) with whom the child lives, or an individual who is legally responsible for the child's welfare; or

(5) *A surrogate parent who has been appointed in accordance with § 300.519 or section 639(a)(5) of the Act. (emphasis supplied)*

The surrogate parent provisions of the IDEA can be found at 34 CFR 300.519.

P&As and other disability rights advocates have successfully challenged many of these barriers, using a range of legal, administrative and other appropriate remedies, including the failure of states to provide integrated residential settings. Major litigation, such *as Rosie D. v. Romney*,[12] *Katie A. v. Douglas,*[13] *U. S. v. Florida,* [14] and *City of New York v. Maul*,[15] has challenged the very premise that certain children and youth need to be placed in residential and other highly restrictive settings. Similarly, P&As have been involved in policy efforts to bring youth home from out of state facilities (returned to in-state care), as well as the "School to Sheltered Workshop Pipeline" the "School To Prison Pipeline," and custody relinquishment.

Information from the P&As' reflects emerging need and a ripe opportunity to provide training and technical assistance focused on enhancing P&As' understanding of issues, tools and strategies to address barriers to access to education services for these youth. The advocacy in which many of the P&As are already engaged, and the increasing numbers of youth in the state custody system nationwide converge to support a recommendation that, if funding were available, a pilot project could be designed with several P&As to identify proven tactics, protocols, and advocacy strategies, and develop technical assistance resources focused on ensuring quality advocacy. Moreover, the policy implications and multiple facets of these issues, and the impact on youth with intellectual disabilities in state custody receiving appropriate education services, lend themselves to a roundtable or issues forum. NDRN and the P&As, with their breadth of expertise and access authority, are uniquely situated to address these issues.

[12] *Rosie D. ex rel. John D. v. Romney,* 474 F.Supp.2d 238 (D.Mass. Feb 22, 2007)
[13] *Katie A. v. Douglas,* CV-02-05662AHM (SHX), (C.D. CA 2011)
[14] *U.S. v. State of Florida,* 1:13-cv-61576 (S.D. Fla. 2013)

[15] *City of New York v. Maul*, 929 N.E.2d 366, 903 N.Y.S.2d 304 (N.Y. May 06, 2010)

V. Policy and Other Recommendations

Data Collection

First and foremost, data collection is essential. This group of youth is little studied and it appears often overlooked. It is difficult to locate data about them, and there is a paucity of relevant academic research, especially with regard to children with disabilities and youth in state custody who are not placed in traditional, family based foster homes. [16] More information is required regarding demographics and positive policy solutions for youth in state custody. There are entities that have made this their mission and have provided critical information, such as the Annie E. Casey Foundation. More work like theirs is needed.

We appreciate the data collection challenges caused by the migratory nature of children in care. But, this creates a vicious cycle because the problems that cause children to be so migratory, and to be placed in highly restrictive settings cannot be addressed if little is known about them. Each state should be able to report where every youth in its care is placed and provide basic demographic information about each individual, including his or her educational needs. P&As can play a vital role in raising these questions and creating sound solutions.

Non-Litigation Projects

State law memo:

What are your specific state's rules re: records transfer, credit transfer, alternate routes to graduation, surrogate parents, rights of foster parents vis-à-vis surrogate parents? Are there any state interpretations of McKinney Vento (e.g. "awaiting foster care placement") or other relevant state laws that apply to foster children? What if anything is the foster child's right to counsel? There is a state law chart on the ABA website that can be used as a start.

The chart can be used as a training tool and a Bench card for juvenile court/ family court judges.

Assist in training surrogate parents.

Collect data on the number of child welfare clients served and types of cases they present. P&As may be doing more CW work than is formally recorded. This data alone is helpful.

Fight policy barriers that cause students to lose credit and partial credit earned when they transfer schools and settings, as allowed by state law. Some states now have good laws.

[16] Please see "Resources" section for some of the limited research available.

Reducing Out-of-Home Placements

Reducing out-of-home placement will greatly increase the possibility of placement in a quality neighborhood school that meets the individual's LRE. Agencies with primary responsibility for serving youth in state custody should reach out to the P&As to answer important questions such as: Does sufficient community support exist for child welfare clients with disabilities to avoid institutional placement? Does the state still use custody relinquishment as a method for obtaining services? Is a sufficient continuum of services provided so that youth are not placed in settings that are not remotely designed for their needs, due to lack of placement/service options? For example, are youth placed in skilled nursing facilities, due to lack of community supports? Are youth who are not alleged to have violated any laws placed in juvenile detention settings? Are youth placed at psychiatric hospitals within the state when they do not need psychiatric treatment and services? In order to do this additional work, P&As would benefit from additional funding.

Other

Some states have adopted state laws and policies regarding credit transfer and other methods to help prevent school disengagement. Dissemination of information about these models and about model statewide surrogate parent programs will be of use.

VI. Conclusion

As this report details, P&As recognize that youth with intellectual disabilities in state custody face barriers to accessing education services. In general, youth with disabilities in state custody face a number of other serious barriers as well. P&As have demonstrated that they are well qualified to challenge many of these barriers, using a range of legal, administrative, systemic, and other appropriate remedies. Yet, there is much left to be done and additional resources are needed to meet the expanded need.

Resources

Academic Articles - Education of Youth in the Child Welfare System

1) Kele Stewart, The Connection Between Permanency and Education in Child Welfare Policy, 9 Hastings L.J. 511 (2012). Addresses the role of permanency in educational success.
2) Rebekah Gleason Hope, Foster Children and the IDEA; The Fox No Longer Guarding the Henhouse? 69 La. L.Rev. 349 (2009). Addresses improvements to the surrogate parent system and barriers to education faced by foster children).
3) Gina Choe, Statewide Special Education Surrogate Parent Programs; Ensuring Quality Advocacy To All Foster Children With Special Needs, 50 Fam. Ct. Rev. 512 (2012). Proposes principles for administrative regulations establishing statewide special education surrogate parents programs.
4) Amy Reichback, Marlies Sanjaard, Guarding the Schoolhouse Gate; Protecting the Educational Rights of Children in Foster Care, 21 Temp.Pol.& Civ. Rts. L. Rev. 101 (2011). Addresses special education discipline rights in the context of foster care/child welfare placement.
5) Paul J. Soska III, Patrick D. Pauken, Surrogate Parents Under the Individuals With Disabilities Education Improvement Act of 2004; The Who, Why, When and How, 252 Ed. Law Rep. 551 (2010). Addresses reform of the surrogate parent system.
6) Janet Stotland, Janet Stocco, Kelly Darr and Kathleen McNaught, Special Education Decisions for Children in Foster Care: Everyone Has a Role, 26 No. 2 Child L.Practice 17 (2007. Reviews legal authority re: surrogate parents.

Academic Articles - Residential Placement

1) Lenore Behar, Robert Friedman, Allison Pinto, Judith Katx-Leavy, Hon. William G. Jones, Protecting Youth Placed in Unlicensed, Unregulated Residential "Treatment" Facilities, 45 Fam. Ct. Rev. 399 (2007) Provides recommendations re: regulatory consistency, state to state.
2) John A. Inglish, Preventing Custody Relinquishment For Youth With Mental Health Needs: Implications for the State of Utah, 12 L.J. & Fam. Stud. 237 (2010) Contains policy recommendations re: preventing custody relinquishment.

3) Yael Zakai Cannon, There's No Place Like Home: Realizing the Vision of Community – Based Mental Health Treatment for Children, 61 DePaul L.Rev. 1049 (2012)

Relevant Cases

1. **Nursing Facilities**

***U.S. v. State of Florida*,** 1:13-cv-61576 (S.D. Fla. 2013)

"On July 22, 2013, the United States filed a lawsuit against the State of Florida in federal district court to remedy ADA violations involving the State's failure to provide services and supports to children with disabilities in the most integrated setting appropriate to their needs. The lawsuit alleges that, as a result of the manner in which Florida administers its service system for children with significant medical needs, children with disabilities are unnecessarily segregated in nursing facilities when they could be served in their family homes or other community-based settings. The lawsuit further alleges that the State's policies and practices place other children with significant medical needs in the community at serious risk of institutionalization in nursing facilities.

Previously, in June 2012 and April 2013, the Department of Justice filed two Statements of Interest in private litigation that is related to the United States' lawsuit (*T.H. v. Dudek*, No. 12-cv-60460 (S.D. Fla. 2012)). "

From: http://www.ada.gov/olmstead/olmstead_cases_list2.htm#fla

2. **Foster Care**

***City of New York v. Maul*,** 929 N.E.2d 366, 903 N.Y.S.2d 304 (N.Y. May 06, 2010)

Class Action on behalf of individuals with developmental disabilities who are, or have been, in the New York City foster care system. The suit, brought by the New York Lawyers for the Public Interest (a subcontractor of the New York P&A) alleges that the Agency for Children's Services (ACS) and the state Office of Mental Retardation and Developmental Disabilities (OMRDD) is violating state law and the integration mandates of the ADA and Section 504 of the Rehabilitation Act for: 1) failing to coordinate with each other to find appropriate, least restrictive placements for individuals with developmental disabilities in the custody of ACS; 2) placing individuals with developmental disabilities in inappropriate facilities, such as adult nursing homes; 3)

failing to provide educational and other support services to individuals with developmental disabilities; and 4) leaving eligible individuals on waiting lists for appropriate community placement, in some cases for years. In April 2008, the Court rejected the defendants' argument against class certification that determining whether an individual is in the least restrictive placement must be done on an individual basis and is not appropriate for class certification. The Court held that it "can certainly consider as a general matter whether placing children in an adult nursing facility or leaving children on a waiting list for months and even years for permanent placement, constitutes violations of state and/or federal law."

On February 10, 2009 the NYS Appellate Division affirmed the certification of a class of plaintiffs. Both OMRDD and ACS agree that there are currently at least 150 kids in ACS custody who are waiting for residential placements with OMRD. The state appealed the certification and lost.

Katie A. v. Douglas, CV-02-05662 AHM (SHX)(C.D. CA 2011) (Formerly *Katie A. v. Bonta*)
On November 18, 2011, Comments of the United States in Support of Final Approval of the Proposed Settlement Agreement were filed in support of the parties' agreement to the manner in which the State will provide an array of intensive, community-based mental health services to Medi-Cal eligible foster children or children at-risk of entry into the foster-care system. The United States argued that the parties' Settlement Agreement, agreed upon after nine years of litigation, was "fair and reasonable" and advances the important public interest of compliance with title II of the Americans with Disabilities Act and the Early and Periodic Screening, Diagnostic and Treatment ("EPSDT") provisions of the Medicaid Act. '

From: http://www.ada.gov/olmstead/olmstead_cases_list2.htm#fla

3. Residential treatment centers

Rosie D. v. Romney (formerly Swift) (D.Mass. 2001).

Class action alleging that the state has violated the Medicaid EPSDT, reasonable promptness, method of administration, and managed care provisions by failing to ensure that class members received necessary, intensive home based services and

mental health assessments, resulting in a waiting list for case management services. The class includes children with mental illness who have been hospitalized or are at risk of hospitalization because of lack of home-based mental health services.

On January 27, 2006, the District Court in Massachusetts granted all of the injunctive relief plaintiffs sought and required the state to improve its system for assessing and providing adequate in home-behavioral supports to children with severe emotional disturbances under EPSDT. The Court found that the state had violated reasonable promptness and EPSDT provisions, but not equal access requirements. The Judge approved a remedial plan in February 2007 that restructured the children's mental health system by incorporating intensive home-based services, including behavioral health screenings, assessments, case management, crisis intervention and in-home therapeutic supports. For further information or resources go to: http://www.rosied.org.

Other Resources

1. NDRN has a number of materials on its website for P&A staff from its foster care legal backup, including "compilation of Child Welfare Facts of the Week" Patricia Julianelle (2009).
2. *Blueprint For Change, Second Edition, Legal Center for Foster Care and Education,* a collaboration between Casey Family Programs, ABA Center for Children and the Law, in conjunction with Education Law Center –PA, and the Juvenile Law Center , 2008
3. Demographic Data about the Child Welfare Population: http://www.acf.hhs.gov/sites/default/files/cb/afcarsreport20.pdf (Does not include disability).
4. *ABA Center on Children and the Law:* www.abanet.org/child/education/publications.
5. *National Association for the Education of Homeless Children and Youth*: www.naehcy.org.
6. *Children's' Defense Fund Materials on Fostering Connections:* http://www.childrensdefense.org/policy-priorities/child-welfare/fostering-connections/
7. GAO Report: Residential Treatment Programs: Concerns Regarding Abuse and Death in Certain Programs for Troubled Youth, GAO-08-146T (2007).

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