

# Accessing Residential Therapeutic Placement for Individuals with IDD

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# Disclosures

Karina Davis has no financial relationships with an ineligible company relevant to this presentation to disclose.

None of the planners have relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients

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# Objectives

Residential placement options for the IDD population – Who, What, When, Why?

Process for residential placement

What does this look like for Washington State residents?

Advocacy: Call to Action

Information and Resources

# Residential placement options for the IDD population

**Who:** Children and teens with IDD: those with less support needs and those with profound/high-needs autism w/IDD

**What:** Placement outside the family home, group home, or current residence into a short or long-term highly supported and structured, therapeutic and/or educational environment.

**When:** When the needs of the individual exceed what can be safely provided in the family home or current residence — the needs of the person exceed what the current residence can provide

**Where:**

- Residential treatment facility that serves youth with high-needs severe autism and/or IDD and aggression (e.g., Devereaux).
- Therapeutic boarding school that serves youth with this combination of issues and problems (e.g., HeartSprings)
- State Operated Living Arrangement (SOLA) with behavior supports (e.g. SOLAs in WA funded by DDA)
- Residential Habilitation Center (RHC) or called Intermediate Care Facility (ICF) with behavior supports (e.g. Fircrest in Shoreline WA, Lakeland, Rainier, and Yakima)
- Long-term therapeutic setting (e.g., Kennedy Krieger),
- Skilled Nursing/Assisted Living/Continuing Care—24/7 short and long term, personal care, medically fragile
- Intermediate care facility (ICF) to protect his/her health and safety. See 42 U.S.C. § 1396d(a)(15). He/she is entitled to this service with “reasonable promptness.” 42 U.S.C. §1396a(a)(8)

# Process for residential placement

Parent/caregiver request

Deemed medically necessary or recommended by provider

Identified by school district

Boarding in Emergency Departments or Psychiatric Inpatient facilities

Current DDA residential placement(s) fails

# Process for residential placement - *continued*

## Process and placement options vary depending on:

Level 1 (less support need) autistic population can generally participate in the same inpatient, educational, and therapeutic residential settings as typically developing peers, focusing on treatment needed for anxiety, depression, OCD, ADHD, etc. If that is not a good fit, there residential placement options that seek to accommodate the level 1 population—both in WA State and within the US.

Profound autism and IDD population (high support needs) can not be served successfully/denied placement at inpatient, educational, and therapeutic residential settings that serve the general or level 1 autistic population. Highly individualized programming, accommodating individuals with lower cognitive and adaptive abilities, and often needing specialization in treating significant challenging behaviors in the form of aggression, tissue damaging self-harm, property destruction, and unsafe bolting.

List of residential options—Katrina has started draft list for both tracks. Work in Progress.

# Process for residential placement - *continued*

## Getting started

Different pathways but most often include Care Coordination meetings initiated by parent or case manager and include the following systems of care:

- Parents/Caregivers
- Developmental Disabilities Administration (DDA) Case Resource Manager and a Supervisor with voluntary out-of-home request experience
- Medicaid Behavior Health Case Manager
- Private Insurance Behavioral Health Case Manager
- School and OSPI
- WISE Wraparound Coordinator and WISE staff who have experience with out-of-home placement
- Medical Providers and Therapists: SLP, OT, Med Prescriber, PCP, Specialists
- Applied Behavior Analysis (ABA) and/or Behavior Consultant
- Dept of Children, Youth, and Families (DCYF) and/or Child Protective Services (CPS) if involved
- Representation from any service, support, or therapy provider who can speak to the needs



# Who Pays?

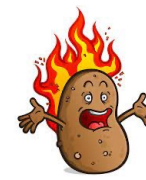
Depends on what type of placement is recommended or necessary:

- Medicaid
- Private Insurance
- School District
- DDA
- Private Pay

# The Current Situation



# A tool to help avoid the game of



Sample STATEMENT provided by the MD or PhD when asked to make a medically-necessary recommendation when the individual meets criteria for out-of-home care. This can be used at any time the provider deems placement necessary and/or when the patient is being discharged from the Emergency Department or Hospital setting:

This patient meets medical necessity for out of home care. For longer term care, the following options are recommended:

1. **Residential treatment** facility that serves youth with high-needs severe autism and/or IDD and aggression (e.g., Devereaux).
2. **Therapeutic boarding school** that serves youth with this combination of issues and problems (e.g., HeartSprings)
3. **State Operated Living Arrangement (SOLA)** with behavior supports (e.g., SOLAs in WA are funded by DDA)
4. **Residential Habilitation Center (RHC)** aka: Intermediate Care Facility (ICF) with behavior supports (e.g., Fircrest in Shoreline WA)
5. **Long-term therapeutic setting** (e.g., Kennedy Krieger),
6. **Intermediate care facility (ICF)** immediate placement to protect his/her health and safety.

See 42 U.S.C. § 1396d(a)(15). He/she is entitled to this service with “reasonable promptness.” 42 U.S.C. §1396a(a)(8)

# Facing a Difficult Truth

While the goal for individuals with IDD is to keep them in a community and home environment, at times this isn't possible due to significant behavior challenges, and safety concerns, or the intensity of their needs exceed what can be safely provided in the family home. This can be due to their primary diagnosis or due to a secondary diagnosis such as a mental health issue. Some individuals with IDD also have medical issues that need to be addressed.

# Shut them Down

Advocates have been calling for the closure of institutions for many years after repeated failure of these institutions to meet minimum regulatory standards and to keep residents safe from harm.

The move to deinstitutionalize services for people with developmental disabilities in Washington State has resulted in reduced funding and closures.

The focus has shifted to creating services that are home and community based—viewed as equity, inclusion, and dignity.

# The Big Questions

- What are we doing to backfill or replace the intensity of services and supports necessary for our highest need individuals?

**Home and Community Based Services (HCBS) have been made the answer, but they are limited or nonexistent for our most profoundly impacted.**

- Result: They end up in serious behavior crisis; boarding in Emergency Departments, stuck in hospitals, or sent home unsafe, overmedicated, traumatized, and cycle repeats.
- Why?  
Because HCBS service providers are not trained, incentivized, or reimbursed more to serve this population, especially those who experience significant challenging behaviors.

# The Crisis in Crisis Services for IDD population in WA

## Recent Media Coverage

**Seattle Times:** Institutionalizing Her Son Was the Only Option

<https://www.seattletimes.com/seattle-news/mental-health/institutionalizing-her-son-was-the-only-option-a-mother-thought-now-shes-fighting-to-bring-him-home/>

**Reporter:** Hannah Furfaro Email: [hfurfaro@seattletimes.com](mailto:hfurfaro@seattletimes.com)

**Seattle Times:** Abandoned in the ER: When kids are left at hospitals, the state is no longer taking charge of their care <https://www.seattletimes.com/seattle-news/mental-health/abandoned-in-the-er-when-kids-are-left-at-hospitals-the-state-is-no-longer-taking-charge-of-their-care/>

**Reporter:** Hannah Furfaro Email: [hfurfaro@seattletimes.com](mailto:hfurfaro@seattletimes.com)

**KUOW/NPR:** <https://www.nwpb.org/2021/12/16/hes-13-years-old-autistic-and-stuck-in-the-hospital-for-the-holidays-hes-not-the-only-one/>

**Reporter:** Austin Jenkins Email: [austin@nwnewsnetwork.org](mailto:austin@nwnewsnetwork.org)

**Seattle Times:** 33 days without sunlight: Why hundreds of Washington kids with IDD are living in windowless emergency rooms <https://www.seattletimes.com/seattle-news/mental-health/33-days-without-sunlight-why-hundreds-of-washington-kids-in-mental-health-crisis-are-living-inside-windowless-emergency-departments/>

**Reporter:** Hannah Furfaro Email: [hfurfaro@seattletimes.com](mailto:hfurfaro@seattletimes.com);

**OPB News** Washington is sending youth in crisis to out-of-state boarding schools; taxpayers pick up the tab <https://www.opb.org/article/2022/05/23/washington-is-sending-youth-in-crisis-to-out-of-state-boarding-schools-taxpayers-pick-up-the-tab/>

**Reporter:** Austin Jenkins Email: [austin@nwnewsnetwork.org](mailto:austin@nwnewsnetwork.org)

**CROSS CUT:** This article features a young man who was placed outside WA state after several months boarding in SC PBMU. [Washington is shipping more disabled students out of state | Crosscut](#)

**Reporter:** Wilson Criscione, writes for InvestigateWest. His email is not listed but you can go to CrossCut webpage [Contact Us | Crosscut](#) and submit your story or share concerns.

**Seattle Times:** Settlement in foster youth with IDD hotel stays suit commit WA child welfare program to think 'outside the box' | [The Seattle Times](#)

**Reporter:** Nina Shapiro [nshapiro@seattletimes.com](mailto:nshapiro@seattletimes.com)

**New York Times:** Sabrina's Parents Love her but the Meltdowns are Too Much.

<https://www.nytimes.com/2022/06/01/nyregion/autism-child-violence.html>

**Reporter:** Joseph Goldstein Health writer for NY Times.

**Politico:** People will Die Waiting: America's system for intellectually disabled nearing collapse.

<https://www.politico.com/news/2022/08/10/americas-system-for-the-disabled-is-nearing-collapse-00050713>

**Reporter:** Dan Goldberg

**Seattle Times Opinion Page:** Stacy Dym, Director, Arc of WA, stating the importance of a bill that would mandate DDA forecast needs for IDD population, one of the only vulnerable groups in WA with no forecasting <https://www.seattletimes.com/author/stacy-dym/>

# Call to Action and Resources

**Consider reaching out to the reporters or media outlets covering these stories** who welcome your input, examples, lived experience, and advocacy priorities.

**Ask leadership at your agency, requesting the concerns and/or ideas are shared with systems of care responsible for serving our IDD population in Washington, including DDA, HCA-Medicaid, School Districts, and DCYF.**

**Share concerns directly with advocacy groups who represent the needs of our IDD population:**

- Education Ombuds: <https://oeo.wa.gov/>
- Developmental Disability Ombuds [www.ddombuds.net](http://www.ddombuds.net)
- Washington State Developmental Disabilities Council: <http://www.ddc.wa.gov/>
- Washington Autism Alliance: [www.washingtonautismalliance.org](http://www.washingtonautismalliance.org)
- The Arc or Washington [www.arcwa.org](http://www.arcwa.org)
- Northwest Justice Project: [www.nwjustice.org](http://www.nwjustice.org)
- Disability Rights WA [www.disabilityrightswa.org](http://www.disabilityrightswa.org)

**Contact elected officials in your legislative district:**

How to find **your** legislative district number, legislator's names, and contact info  
:<https://app.leg.wa.gov/districtfinder/>

Your voice matters more than you think!



# Information and Resources

**Washington Autism Alliance** [www.washingtonautismalliance.org](http://www.washingtonautismalliance.org)

**Informing Families** [www.informingfamilies.org](http://www.informingfamilies.org)

**Partners are Vital in Education PAVE** [www.wapave.org](http://www.wapave.org)

**DDA** [www.dshs.wa.gov/dda](http://www.dshs.wa.gov/dda)

**Arc of WA** [www.arcwa.org](http://www.arcwa.org)

**Parent 2 Parent Washington** [www.arcwa.org/parent-to-parent.org](http://www.arcwa.org/parent-to-parent.org)

**National Council on Severe Autism** [www.ncsAutism.org](http://www.ncsAutism.org)

**Voice of Reason:** Speaking out for people with IDD [www.vor.net](http://www.vor.net)

## **BIPOC community**

- Open Doors for Multicultural Families: <https://www.multiculturalfamilies.org/>
- Vietnamese Family Autism Advisory Board (VFAAB): <https://vfaab.org/>
- Somali Health Board: <https://somalihealthboard.org/>
- WA Multicultural Link [www.wmslink.org](http://www.wmslink.org)
- Families of Color Seattle: <https://www.focseattle.org/>

## **Self-Advocacy**

- People first Washington
- Alliance for people with disAbility
- Square Pegs Adult Autistic meetups
- Self Advocates in Leadership (SAIL)

**Autism Confidential:** The residential crisis for our those with severe autism and IDD  
<https://www.youtube.com/watch?v=c6uQG5Vcmrw> (30 minutes)

**Autism Confidential:** How do we create long-term options for our most severely impacted IDD population:  
<https://www.youtube.com/watch?v=c6uQG5Vcmrw> (30 Min)

**Shut Them Down: Institutions for IDD community in WA State:**  
<https://www.disabilityrightswa.org/shut-them-down-its-time-to-close-washingtons-dangerous-residential-habilitation-centers/#introduction>

**When Severe Autism Kicks your Child Out of State for 40 years:** <https://www.ncsautism.org/blog//kickedout-when-severe-autism-kicks-you-out-of-state-for-20-years>

**When You Have a Daughter like Mine, One Size Does Not Fit All:** <https://www.nytimes.com/2021/07/04/opinion/disability-funding-medicaid.html>

# THANK YOU

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