Key Takeaways

Navigating School

Facilitated by Jennifer Schaefer, CAPSW, and featuring HIE parent panelists Janina Easley, Tina Santos, Chris Melnyczenko, and Nicole Carrillo

This panel series features dedicated members of the HIE community who offer valuable insights into their experiences with the various impacts and outcomes of HIE.

HOPE for HIE

HIE Peer Perspective Series

1

THERE ARE SUPPORTS & STRATEGIES YOU CAN EMPLOY THAT MAKE A BIG DIFFERENCE FOR THE EARLY INTERVENTION-TO-SCHOOL TRANSITION.

Know that you can start **planning early.**

↳ Federal law requires a transition plan by age 3 (if a child is in EI), but parents can begin asking questions **6-12** months ahead of time.

Lean on early intervention specialists during transition conferences:

↳ Many states/districts offer a joint meeting between EI providers, the school district, and parents.

↳ Early intervention specialists can assist families in understanding timelines and sharing strategies with the new school team to smooth the handoff.

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- It's helpful to understand the **shift in therapy focus.**
  - Early Intervention services are usually frequent and play-based, supporting overall development.
  - In school, therapies are provided only if they help the child access and participate in learning.
    - Ask, for example, "How/will my child's PT, OT, or speech goals carry over once they enter school?" to help you determine if outside therapy is still needed.

- It's okay to consider your child's **overall health and readiness.**
  - Some families delay school entry if medical needs or family circumstances take priority.
    - That's okay—school districts typically allow flexibility when it's in the child's best interest.

2

CREATING AN IEP IS A PROCESS. GOALS AND SERVICES EVOLVE OVER TIME

and each meeting is an opportunity to refine supports.

You can **prepare ahead of time**

Some parents found it helpful to request a draft of the IEP in advance so they could review it carefully at home.

- While IDEA does not propose a timeline, two weeks before the meeting is generally considered reasonable in many districts.

You're allowed to **bring outside support**

Some families choose to bring a friend or an IEP advocate, while others opt to test the waters before they recruit that extra support.

- It is advisable to inform the school of this visitor for safety & protocol purposes.

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- It's okay to **ask clarifying questions**
  - This includes asking the difference between an IFSP (Individualized Family Service Plan) that's used in early intervention, and an IEP (Individualized Education Plan) used in school.

- Remember that **nothing is set in stone**
  - The first IEP rarely covers everything perfectly— and that's okay.
  - Goals may need to be revised, services may be added or changed, and supports can be fine-tuned as your child grows and their needs shift.

Viewing the IEP as a living document, rather than a one-time solution, can help families feel more confident and less pressured to get everything "perfect" on the first try.

3

AN IEP ADVOCATE ISN'T NECESSARY FOR EVERY FAMILY

but for some parents, their presence helped ensure their child's needs stayed at the center of planning.

Under IDEA **(Individuals with Disabilities Education Act)**, it is within your right to request an advocate to attend IEP meetings.

- Make sure you weigh costs and options. Some advocates are paid, while others offer free support through PTIs or nonprofit organizations.
  - PTI stands for Parent Training and Information Center — a federally funded program that helps families navigate the IEP process.

Advocates **bring expertise:** they know the law, how schools operate, and how to reframe requests.

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- You can use advocates for **some key moments and not for others:**
  - Some families only use an advocate occasionally — first IEP meetings, transitions to new schools, changes in services, or when disputes arise— while others rely on them more consistently.

- **Confidence can grow with backup.** Having an advocate at the table makes many parents feel less alone and more comfortable.

Advocates don't replace parents. Parents remain the decision-makers; advocates provide guidance, clarify options, and support communication, but the family's voice drives the process.

4

ADVOCACY ISN'T ONLY ABOUT IEP MEETINGS OR FORMAL REQUESTS

it's also about practical ways that help school staff understand and support your child's needs every day.

Many parents use an assortment of tools to help advocate for their child and inform staff of their needs:

- "One-pagers" with photos, strengths, and important medical notes
- A shared google doc that can be easily updated as the year progresses
- Short videos, photos, or in-person demonstrations of medical procedures, communication devices, or physical needs

Small actions—like sending notes about preferences or sharing tips for interactions—are all ways parents advocated for inclusion, safety, and understanding.

5

INCLUSION IS MORE THAN PLACEMENT—

it's about meaningful participation, respect, and preserving dignity in every aspect of the school day.

Dignity matters. There are ways for staff to help preserve it, whether that's...

- Encouraging genuine smiles for school photos, arranging accessible solutions for field trips, or respecting children's preferences during personal care and daily routines.

Inclusion means real participation, even if that looks different from their peers.

- This can look like taking on meaningful roles in classroom activities, specials (like music or art), and extracurriculars,

Ask about peer engagement or built-in buddy systems for forming friendships.

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- **It should be a shared responsibility among parents and staff** to anticipate challenges and advocate for solutions.
  - Parents can support by sharing insights about their child's needs, but a great goal is for school teams to proactively identify barriers and implement strategies.
- **Respect goes a long way.** Listening to children's preferences, honoring their routines, and treating them with dignity are central to feeling included.

6

BUILDING AWARENESS ISN'T A ONE-SIZE-FITS-ALL APPROACH.

When families shared their children's stories, they saw schools become more confident, peers more curious, and communities more supportive. And they did this in a multitude of ways:

- **Classroom presentations** about disabilities or differences, using visuals, props, or interactive discussions.
- **Awareness events or school-wide activities,** like Read Across America, disability awareness days, or assemblies.
- **Honest conversations with teachers, staff, and peers** to clarify needs, routines, and preferences.
- **Harnessing social media to highlight everyday experiences,** not just the "good" or "perfect" moments.

7

HERE ARE SOME TRIED AND TRUE PIECES OF ADVICE FROM OTHER PARENTS WHO JUST GET IT...

- **Don't be afraid to celebrate your child's voice in meetings** — this means making space for their thoughts, preferences, and feelings to be heard and considered.

- **Expect a learning curve.** School staff are learning about your child; mistakes or misunderstandings are part of the process, and patience helps.

- **Build your support network.** Other parents, advocacy groups, and former teachers can provide guidance, ideas, and reassurance.

- **Don't compare to others.** Every child's journey is unique—focus on your child's strengths, needs, and growth rather than measuring against peers.

8

HERE ARE SOME HELPFUL RESOURCES FOR RELIABLE INFORMATION & SUPPORT

- **Head Start – Transitions Resources for Families:** Has guides and information on the kindergarten transition process.

  >>> Headstart.gov/publication/transitions-resources-families

- **Parent Training & Information Centers:** PTIs provide free, state-specific guidance on IEPs, transitions, and parent advocacy.

  >>> ParentCenterHub.org/find-your-center

- **HIE.Support** can connect families to guidance and support for navigating a range of HIE impacts, outcomes, and experiences.