

Promoting Neurodiversity in Early Childhood Services



This pamphlet is intended for early childhood care providers who want to learn more about how to promote neurodiversity in early childhood. This could include early interventionists, developmental specialists, speech and language pathologists, occupational therapists, behavior analysts, preschool teachers, and anyone else who provides services to young autistic children and children with developmental disabilities.

Identity-first language is used throughout this pamphlet. For more information, please visit: triad.vumc.org/identity-language.

What Is Neurodiversity?

Neurodiversity is a perspective that views differences in brain structure and functioning as a normal human variation. These variations should not only be acknowledged, but also celebrated.

Neurodiversity is not a new concept, but its impact on approaching intervention with young children has more recently come into greater focus. The concept, developed as a response to contrasting medical and social models, includes components of both models to best capture the feedback and lived experiences of individuals with disabilities.

| Medical Model | Social Model |
|--|---|
| The first, and most common, way that autism was classified | Contrasts the medical model |
| Focuses on the disabilities, weaknesses, or deficits of individuals | States that society is not accommodating to individuals with differences |
| Assumes these deficits can be "fixed" to fit societal norms through intervention practices | Believes society should be the focus of change rather than the individual |

Neurodiversity embraces the identity of an individual that is inclusive of their disability(ies). Neurodiversity emphasizes that cognitive differences should be viewed as different ways of thinking and understanding the world, none of which is better than another.

Some differences for autistic individuals can include things like variations in experiencing the sensory environment, literal ways of thinking, and intense attention to detail and interests. Disabilities and differences are not minimized or ignored. They are important when considering adaptations that should be made while supporting meaningful areas of growth for neurodivergent individuals. Most importantly, having various perspectives can provide more creativity, productivity, and diversity in society. These differences should also be celebrated as part of what makes our world a richer place.



A more detailed review of this material and additional resources can be found in the interactive online toolkit. Register for a free account at triad.vkclearning.org and access the information in either the Early Childhood or Early Intervention folder.



Why Is Neurodiversity Important From a Young Age?

- As early childhood care providers, it is important that principles of human rights and dignity guide what we do across all the ages we serve.
- Some autistic adults report "masking" or "camouflaging" their autistic traits in order to conform to society's views, which can require a large amount of continued effort.
- Respecting neurodiversity should guide approaches at young ages so that autistic children can
 grow up learning about themselves and don't need to feel like they must change or hide who
 they are.
- Early identification of autism is increasing nationally, so it is important to promote these practices with families and service providers of young autistic children.

Commonly misunderstood ideas about

| neurodiversity and early childhood | | |
|--|--|--|
| Misconception: | Reality: | |
| Embracing neurodiversity means opposing all types of intervention. | Neurodiversity values intervention practices, so long as the intervention is "provided in a respectful manner; focused on teaching useful skills; and improves subjective quality of life" (Shuck et al., 2021). | |
| It is okay to make the intervention goals focus on making the lives of others easier to work with the child or attempts to "normalize" the child (e.g., creating goals around hand-flapping that is not harmful to the child because others view it as "annoying" or "strange"). | Neurodiversity focuses on intervention goals that teach functional skills that will help the child with day-to-day functioning (e.g., waiting in line/ waiting turn, requesting help or a break). | |
| The neurodiversity perspective is against any "labels" or pursuing diagnoses when concerns are noted. | Diagnostic information can be used to learn more about how someone experiences the world, and what supports they need. The purpose of this is to help neurodivergent people succeed while also respecting their neurological differences. | |

We must always continue learning from people with disabilities and remember to listen to their perspectives when making decisions or policies intended to support and benefit them. As the common saying within the disability community goes, "nothing about us without us."



Learn more about the history of neurodiversity, why it's important, and practical examples in the interactive online toolkit referred to on Page 2.



How to Consider Neurodiversity at Eligibility and Diagnosis

During first contact and initial eligibility:

Starting the Conversation

» Be sure to ask the caregiver about the child's strengths and skills and, if you have interacted with the child, highlight any strengths you have noticed.

Supporting Meaningful Child Goals

» During goal development, help the family understand that the focus will be on how to support the child to be meaningfully included throughout their daily activities rather than focusing on "fixing" or "curing" characteristics associated with the child's disability or diagnosis.

Focusing on Child Behaviors

» Assure caregivers that you do not want to change who their child is and what is unique to them, but instead want to help them use their strengths to meet their full potential.

Respecting Family Perspective

» Work with the family to understand and appreciate their perspective so that you can build an effective partnership moving forward.

Explaining common phrases used when discussing eligibility with caregivers

There are many terms used when pursuing services that may result in a more deficit-based conversation if they are not clarified with a caregiver.

| Term | Definition | How to Discuss with Caregiver |
|-----------------------|---|--|
| Educational Impact | The impact that a child's characteristics have on their ability to participate in a general education setting without additional support. | Explain that if there is identified educational impact, this does not mean the child cannot and will not continue to learn and progress in an educational setting. It is simply that they may need specific types of support to be most successful. |
| Severity Level | Many insurance companies require this for specific diagnoses to provide coverage for services. | Explain that severity level is not fixed and can change over time as the child's needs change. It does not necessarily predict the child's future abilities or needs. |
| Red Flags | Term often used to describe early signs associated with a particular delay or diagnosis, which may sound concerning to a caregiver. | Explain that these are certain behaviors that may lead us into exploring whether their child has certain needs related to a diagnosis. |
| Percent Delay | At times, service eligibility is based on the amount of delay a child shows relative to their peers. | Explain that this helps understand how much support will be needed in a particular area. |
| Areas of Deficit | Describes a child's development in relation to typically developing peers and may be viewed as a negative characteristic of the child. | Explain that this term means their child's performance in a certain area may need more support compared to either their child's performance in other areas or in comparison to what we would expect for that age, and that this will continue to be assessed and may change over time. |

How to Talk With Caregivers About a Diagnosis Using a Neurodiversity Lens

Professionals can help ease caregivers' stress while promoting neurodiversity by following these guidelines:

- 1. Use appropriate language to identify autistic individuals and not terms such as "disease" or "special" to describe their functioning.
- 2. Remind caregivers not to focus on "recovery," but to focus on their child's quality of life.
- 3. Meet caregivers where they are emotionally and empower them to be part of the next steps in the process.
- 4. Set a positive and warm tone. Caregivers often have more confidence and feel more positively about a diagnosis when clinicians speak to them with positivity and respect.
- 5. Be honest and make expectations clear do not try to guess how the child will develop over time.
- 6. Encourage caregivers to keep the same expectations for their child as they did before the diagnosis, even if that means working on those skills in a way that may be different than they originally planned.
- 7. Be mindful about how to present intervention options to highlight bolstering their strengths rather than solely focusing on weaknesses.
- 8. Consider and respect the cultural background and attitudes of the family when giving feedback/ results, particularly as it relates to their culture's perceptions of disabilities.
- 9. Discuss caregivers' needs and be open to answering questions or working through feelings of distress or uncertainty.
- 10. Remember to amend intervention goals continually and reassess their purpose as they relate to an individual's well-being.

How to Consider Neurodiversity Within Goal-Setting and Implementation

| Who? | Clinicians, teachers/educators, and caregivers using a team-based approach. |
|-------|---|
| Why? | To ensure all the child's settings are included (e.g., school, therapy, and home) so that the child can experience consistency across contexts and ensure goals are relevant to the child's life. |
| What? | Set goals specific to the child that are functionally meaningful in their life and use their strengths to address areas of need. |
| When? | Start with a set of goals and update them over time to continue to focus on promoting independence and engagement. |
| How? | Start with small goals and then increase to bigger goals, making sure to continually assess if the current goals are realistic and relevant for the child. |

Goals should focus on a few primary areas initially, while recognizing that you may need to develop additional goals and regularly re-evaluate the appropriateness of the current goal. Early intervention often emphasizes routines-based intervention in natural settings. One of the benefits of that approach is being able to address a variety of skills in one routine (e.g., targeting communication, imitation, and joint attention all during bath time). The neurodiversity perspective is also helpful in making sure goals are always tied to meaningful outcomes in a child's day by using their strengths and interests to support areas of need.

Think about common goals you write for the children you serve. You likely already ensure goals are meaningful in the child's current life and take into consideration the child's strengths and preferences in order to promote success in meeting short-term goals. In addition to this short-term focus, you always want to make sure these components are infused in every goal you create as a means of respecting the child's dignity and voice in the services they receive, rather than solely as a means to successfully meet a goal. You also want to prioritize continually including goals that specifically focus on developing self-advocacy and self-determination to set the foundation for these important skills over time.

Goals do not have to be the same across settings and should be monitored over time as the child acquires new skills. Continue to check the child's progress so new goals can be set while keeping a focus on the meaning of that goal as it relates to the child's quality of life.

For case examples of goals and additional examples of wording with caregivers, see the interactive online toolkit referred to on Page 2.

How to Talk to Others About Neurodiversity

Other Family Members

MORE INFO

Other family members, such as siblings, aunts/uncles, or grandparents, may not understand what neurodivergent individuals need to succeed or how to shift from a more deficit-focused approach to a more strength-based approach. It can be helpful to empower caregivers to use the type of terminology that reflects this in their conversations and to model discussing their child's differences in respectful ways. In addition, you can practice with caregivers how they might respond when others make statements about their child that do not seem to respect neurodiversity in a way that can educate and model a shift in this thinking. For siblings, there are many books and videos that can be helpful in explaining a child's diagnosis in a strength-based way.

Other Health Providers or Educators

When other health providers or educators use deficit-focused language, you can reframe language in your responses as a model. This means using neurodiversity-friendly language while talking with them to model how certain concepts can be phrased. This way, the provider may ask why you are using words in a particular way and can start a conversation about neurodiversity.



For script examples on how to speak with others about neurodiversity, see the interactive online toolkit referred to on Page 2.

| | How Can You Advocate for Neurodiversity? |
|---------------|--|
| Stay informed | Stay up to date with the progressing neurodiversity movement. |
| Listen | Listen to the voices of neurodiversity advocates and autistic people. |
| Share | Share resources with colleagues, schools, family, and friends, etc., to spread awareness. |
| Check In | Monitor yourself so you continue to approach your work through a neurodiverse lens. |
| Ask | Keep asking questions about how you can improve your neurodiverse practices. |
| Act | Look for ways to be involved in the community to promote neurodiversity. Examples could include becoming involved in public policy and legislative initiatives, engaging in outreach activities to educate the broader population, serving on boards or committees, etc. |

References and Resources

Full references used for the development of this material can be found at triad.vkclearning.org.

The Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (VKC TRIAD) is dedicated to improving assessment and treatment services for children with autism spectrum disorders and their families while advancing knowledge and training. TRIAD offers free trainings and resources. triad.vumc.org

- □ Kapp, S. K. (Ed.). (2019). Autistic community and the neurodiversity movement: Stories from the frontline. Palgrave Macmillan.
- Des Roches Rosa, S., Byde Myers, J., Ditz, L., Willingham, E., & Greenburg, C. (2011). Thinking person's guide to autism: What you really need to know about autism, from autistics, parents, and professionals. Deadwood City Publishing.

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