

Down Syndrome Advocates in *Action*



Waiver & SSI Assessment Preparation Checklist

For Families of Children with Disabilities

This checklist is designed to help families prepare for State Medicaid waiver assessments and Social Security (SSI) applications. It focuses on identifying current support needs, not potential, effort, or future progress.

Important: This tool is meant to help families organize information and describe needs clearly and consistently. It does not determine eligibility and does not replace official assessments.

How to Use This Checklist

- Check items that describe what your loved one currently needs.
- Think about your loved one on a challenging day, not their best day.
- Consider what would happen without a parent or caregiver stepping in.
- Describe needs as they exist today, even if skills are developing.

For State Medicaid Waivers: Focus on the level of supervision, assistance, or instruction required.

When preparing for a State Medicaid waiver assessment, use this checklist to describe:

- How much supervision, prompting, or hands-on assistance is required
- Whether needs are ongoing throughout the day
- What support is necessary to maintain health and safety

Assessments consider whether your child meets a level of care comparable to an Intermediate Care Facility (ICF) or, in some cases, a nursing facility. This does not mean your child belongs in an institution — it is the legal standard used to allow services in the

For SSI: Focus on how your loved ones functioning compares to same-age peers.

When applying for SSI, think about each checked item as a functional limitation.

SSI focuses on how your child's disability affects daily functioning compared to other children the same age.

Helpful SSI prompts:

- How often is support needed? (constantly, frequently, occasionally)
- What happens without support?
- Do these limitations occur across settings?

Sample SSI-style language:

- "My child requires constant adult supervision to remain safe, unlike other children their age."
- "Without support, my child is unable to complete age-appropriate tasks independently."
- "These limitations are present daily and across settings."

A Note for Families

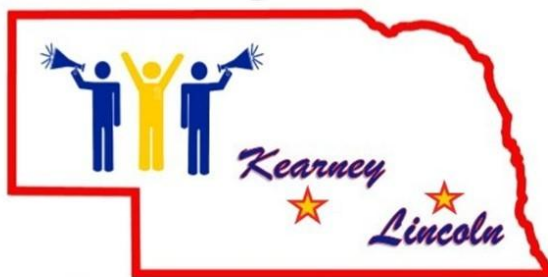
Describing support needs does not mean giving up on your child or overlooking their strengths. This process is about ensuring that the right supports are available — especially when families cannot be expected to fill every gap alone.

If you have questions or are unsure how to apply this information, please contact:

Down Syndrome Advocates in Action Nebraska (DSAANE)

 info@dsaane.org

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Supervision & Safety

- Requires constant adult supervision to remain safe
- Does not recognize common safety risks (traffic, water, strangers, stairs)
- Engages in unsafe behaviors without understanding consequences
- Cannot be left alone, even briefly
- Needs an adult to anticipate and prevent safety concerns

If support were not provided: _____

Communication

- Cannot consistently express wants or needs in an age-appropriate way
- Uses limited words, signs, or gestures to communicate
- Requires adult interpretation to be understood by others
- Becomes frustrated or dysregulated due to communication barriers
- Difficulty understanding directions or questions without repetition

If support were not provided: _____

Time Without School or Childcare or Day Services

- Requires full-time supervision or structured support
- Cannot access typical childcare or camps or community activities without added supports
- Parent or caregiver must adjust work due to supervision needs

If support were not provided: _____

Daily Living Skills (Self-Care & Routines)

- Needs hands-on help with dressing, toileting, or hygiene
- Requires frequent prompting to complete routines
- Cannot complete tasks independently from start to finish
- Skills vary significantly from day to day
- Needs direct instruction beyond what is typical for age

If support were not provided: _____

Behavior & Regulation

- Difficulty transitioning between activities or environments
- Requires adult intervention to regulate emotions or behavior
- Engages in behaviors that impact safety or learning
- Needs structured support to remain regulated
- Stress, fatigue, or changes increase support needs

If support were not provided: _____

Mobility & Physical Support (If Applicable)

- Needs assistance with balance, walking, or stairs
- Tires easily or requires physical support for endurance
- Uses adaptive equipment or requires hands-on physical support
- Needs assistance to access community spaces safely

If support were not provided: _____

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