SECTION 5

Supporting Families with Children who Experience Disability



Collaboration with families to support inclusion and reflection of services practices

Inclusive mealtimes recognise the many ways of participating and being part of the community. The goal is not sameness. The goal is dignity, belonging, safety, relationship, and participation.

This means helping staff ask the right questions early, document what matters, share information respectfully across the team, and revisit arrangements with families rather than assuming one plan will remain right over time.

The importance of orientation time

Asking "how staff and families can work together before these moments arise, so inclusion is not improvised under pressure."

Understanding/acknowledging the impact of past experiences

For families, this can be intensely emotional. What families might be carrying from past negative experiences and the impact of this (not neutral space, often starts from experience induced anxiety).

For example, families might think – will they:

- judge me?
- think I have caused this?
- understand my child?
- keep my child safe?
- call me every time something is hard?/not call me when my child needs me?
- exclude my child from food learning?
- pressure my child?
- listen to us?
- see my child as a whole person?

Families experience the impacts of ableist views, stigma, lack of respect, lack of communication, assumptions, rigidity, failure to build relationships, seeing the label rather than the child.[6] Families also identify that misunderstanding inclusion is a major barrier.[6] Families describe the exhaustion of continually having to fight for inclusion and being reminded of the "extra" effort required for their child to participate.[5] That exhaustion matters for staff and family engagement.

Why families might disengage/cancel/don't want to talk

Sometimes, when a family disengages, cancels therapy, avoids meetings, does not return forms, or seems reluctant to talk, services may understandably wonder what is happening. But one risk is that this gets interpreted too quickly as denial, non-compliance, lack of commitment, or poor engagement.

Families may stop therapy or disengage from services for many reasons. For example:

- The goals do not feel like their goals.
- Every session feels like a report card on their parenting.
- Child is distressed and they feel that no one is listening.
- 'Support' is focused on making the child appear more 'typical', rather than supporting the child to flourish.
- Emotional labour is too much.
- Tired of being asked intimate questions that do not seem connected to meaningful support.
- Don't feel safe.
- Child doesn't feel safe.

Building trust with families

Shift from "How do we get families to engage?" to "How do we make engagement feel safe, worthwhile and trustworthy?" Trust is not built by saying we are inclusive. Trust is built when families experience us as respectful, careful, competent, humble, curious in the right ways, and accountable.

Consider what is asked and why[6]

It is important to carefully consider what we ask families and why. Families should not have to hand over every detail of their child's body, diagnosis, feeding history, trauma history, family life, culture, finances, routines, or struggles simply because professionals are curious.

It is essential to be really clear about what information we actually need, so we need to consider the precise purpose of each aspect of the information we are gathering. We need to consider what we need to understand so this child is safe, respected, and included.

We need to ensure that we don't inadvertently make families feel exposed, instead make families feel supported. Gather only what information is needed, then act on it. Before asking a family for information, we might pause and ask ourselves:

- Why do I need to know this?
- How will this information improve the child's safety, participation, dignity, or belonging?
- Who will have access to it?
- Have I explained why I am asking?
- Could I ask this in a less intrusive way?
- What will I do with what the family tells me?
- How will it change what we do?

This is especially important in food environments because food is personal. Food connects to culture, poverty, body image, medical histories, disability, parenting judgement, family stress, sensory experience, religion, trauma, and identity.

Responding

Listening requires response. The important question is not only how staff gather information, but how that information changes practice. Menu planning requires us to ask: "does this meet dietary guidelines?" but also:

- Who can safely eat this?
- Who is left out?
- Whose culture is represented?
- Whose family food knowledge is respected?
- Whose sensory needs have we considered?
- Whose medical needs have we planned for without making them feel separate?
- How will children participate if they do not eat this food?
- How will we communicate with families without judgement?
- How will we notice whether children feel included?

Instead of asking, "What special arrangement do we need for this child?" we might ask, "How do we design a setting where many ways of eating, feeding, communicating, and participating are expected?"

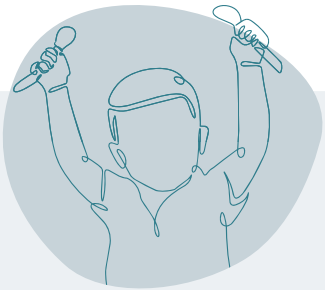
NATIONAL QUALITY STANDARD
QA2, QA6

Inclusion in practice – experiences and family engagement

Children have very strong views about inclusion and exclusion.[9,10] Children describe inclusion as being part of something, being able to play, being together, and helping others understand that difference is not bad.[9] Children also describe exclusion as feeling left out, not belonging, and being deeply affected by these experiences.[9]

As we think about food environments, we might ask what does inclusion feel like:

- At the lunch table?
- When a child has food allergies?
- When a child is tube fed?
- When a child has sensory aversions?
- When a child has diabetes and coeliac disease and the birthday cake arrives?
- When the menu is safe but the child is still sitting apart?
- When everyone else is praised for "trying new foods," but one child is doing extraordinary work just tolerating the smell, the sound, or the proximity of food?



VIGNETTE 5

Including a tube-fed child in mealtime as a social routine

Kai is two and gains his nutrition by being tube-fed. During orientation, Kai's family explains the feeding routine and shows staff how Kai communicates comfort, discomfort and interest. At lunch, staff initially plan for Kai to have his feed in a quieter corner while the group eats. Kai looks toward the lunch table, vocalises when the mealtime song begins and reaches toward the basket of cups. His family has shared that Kai enjoys being near peers during family meals and likes choosing between two spoons to hold while he has his tube-fed meal.

Response

Mealtime can still be meaningful when a child does not eat orally. Kai's participation may include social connection, rhythm, communication, choice, sensory engagement and belonging. The service should follow all health and feeding plans, while also designing the routine so Kai is not positioned outside the group.

Educators can seat Kai safely with peers, offer choices such as which cup to pass or which spoon to hold, and respond respectfully to other children's curiosity. For example: "Kai you have food in a different way, don't you. You like sitting with us while we all have our food and you are great at helping with the cups." Staff should speak with Kai, not only about him, and ensure equipment is treated as ordinary and respected rather than hidden or made to feel strange.

Family engagement is central. The team should document what supports Kai's safety and belonging, who needs to know the plan, and how arrangements will be reviewed as Kai's needs and preferences change.

Reflective questions

- *Does our service understand mealtime participation as more than oral eating?*
- *What meaningful roles and choices are available for children who do not eat the same food, or do not eat orally?*
- *How do we support other children's curiosity in ways that are respectful and matter-of-fact?*

An inclusive mealtime recognises many ways of participating socially and communicating preferences. One child may speak. Another may point. Another may gesture. Another may communicate through facial expression, body movement, stillness, or distress. One child may eat orally. One may be tube fed. One may use their hands. One may use cutlery. One may need specific textures. One may need distance from food. The goal is not sameness. The goal is dignity, belonging, safety, relationship, and participation.

NATIONAL QUALITY STANDARD
QA2, QA5

Seeking and respecting children's perspectives, input and feedback

This is where children's perspectives are essential. Children communicate in many ways: through words, signs, devices, drawing, movement, gesture, silence, facial expression, behaviour, touch, sound, proximity, refusal, repetition, and play. Communication is not only speech.

- If a child pushes food away, that is communication.
- If a child leaves the table, that is communication.
- If a child eats only when seated next to a trusted educator, that is communication.
- If a child watches but does not touch, that is communication.
- If a child becomes distressed during cooking experiences, that is communication.
- If a child beams when they can hand out cups, that is communication.
- If a tube-fed child reaches for the lunchbox, the pump, the spoon, sings the song, wants a friend beside them, that is communication.

The challenge is increasing guidance for the depth of listening that this takes.

EARLY YEARS LEARNING FRAMEWORK
Outcome 5

NATIONAL QUALITY STANDARD
QA2, QA5

Reflective questions

- *How do we ensure mealtimes promote dignity, belonging, safety, relationships and participation for all children, rather than focusing solely on food consumption?*
- *To what extent do our mealtime environments and routines accommodate different ways of eating, feeding, communicating and participating, rather than expecting all children to engage in the same way?*
- *How do educators listen to and interpret children's communication during mealtimes, including non-verbal communication such as gestures, behaviour, proximity, refusal, sensory responses and emotional regulation?*
- *Does our service definition of "participation" include children who are tube-fed, have sensory sensitivities, allergies, medical needs, or who engage with food in different ways?*



VIGNETTE 6

Refusal as communication, not non-compliance

Noah is three and often becomes distressed when foods with a strong aroma are served. He turns away, covers his nose and pushes the bowl away. During a busy lunch, an educator says, "Noah is being fussy again. He won't even try it." Noah slides under the table and begins to cry. Another educator notices that Noah had been calm before the food arrived and that the smell and mixed texture seemed overwhelming for him.

Response

An inclusive lens treats Noah's refusal and distress as communication. The question is not "How do we make him try it?" but "What is Noah experiencing, and what would safe participation look like today?" The educator can reduce pressure, acknowledge Noah's communication and offer a role that protects dignity and belonging.

A response might be: "Noah, we think your body is telling us this smell is too much right now. You can sit beside me with your familiar food, or you can sit over here by the door where the smell is less." Staff can work with the family to understand sensory preferences and what supports have helped elsewhere. They can also plan predictable, pressure-free exposure, such as a small lidded tasting bowl at a distance, a choice of seating, a gradually building exposure to different smells, or a role that lets Noah participate without needing to eat strong smelling food.

Feedback to the family can include participation and regulation, not only intake: "Noah didn't like the smell of the soup today. He moved away, then came back to help hand out spoons and sat with the group for the song. We are trialling a seat near the door where the smells are less strong and will keep watching what helps him feel safe. We would welcome any ideas you might have."

Reflective questions

- *What labels do we use when children decline, move away or become distressed around food?*
- *What might the child be communicating through behaviour, proximity, silence or refusal?*
- *How can day-to-day feedback describe participation, comfort and support strategies, rather than only what was eaten?*