feeding matters

Addressing PFD in Neurodiverse Children in Schools: Success Stories and Lesson Learned

MARGARYTA KUZMIN, MA, CCC-SLP, TSSLD-BE
Lead SLP, BCSS-Candidate

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Non-Financial:

ASHA Member (Special Interest Groups SIG13 & SIG16)
Enrolled in ASHA BCSS program
Feeding Matters Alliance Member

Sections of this talk

Prevalence	Risks/Ethics	Case Studies	Lessons/Reflections
2 min	3 min	10 min	5 min

Prevalence

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- PFD among typical children has been on a rise
- PFD among children with developmental disorders has been also on a rise, estimated from 30% to 80%

(Vissoker et al., 2015; Arvedson, 2008; Lefton-Greif, 2008)

- Children with developmental disorders face a higher vulnerability to developing PFD compared to their typically developing peers, but the underlying causes of these disorders remain multifactorial

(Kovacic, K. & et al., 2020; Goday,S. et al., 2019; Linscheid et al., 2003)

PFD Risks in School

for children with developmental disorders

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- Inadequate nutrition
- Food avoidance
- Swallowing difficulties
- Inability to develop age appropriate feeding skill

(Goday et al., 2019)

PFD Heightened Risks

for children with developmental disorders

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- Choking on mealtimes
- Aspiration during meals
- Poor Nutrition during the school day
- Limited school participation (low energy, sickness, poor attention, poor attendance)
- Poor social interactions while in school (feeling left out/different)
- Extended school mealtimes

(Homer, 2016)

Ethics

when addressing PFD in children with developmental disorders in schools

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- SLP's scope of practice is to address feeding and swallowing (ASHA, 2016)
- The Individuals with Disabilities Education Improvement Act of 2004 safeguards the rights of students with disabilities, guarantees access to free appropriate public education, and requires the provision of services for students facing health-related disorders (e.g. PFD) that hinder their full participation in the educational curriculum (IDEA, 2004)
- School districts enrolled in the National School Lunch Program by the U.S. Department of Agriculture Food and Nutrition Service are obligated to adhere to regulations (refer to 7 C.F.R. § 210.10(m)(1)). These regulations mandate the provision of meal substitutions or modifications for children with disabilities that significantly limit their dietary options, as outlined in the Meal Requirements for Lunches and Requirements for Afterschool Snacks in 2021.

School PFD Case Studies

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- Case #1 M.A. (Autism)
- Case #2 A.C. (Cerebral Palsy)
- Case #3 J.E. (Multiple Diagnosis)

Case #1

M.A. 5 year old (Autism)

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- **History:** low weight (31lbs), food refusal, no feeding therapy during early intervention, frequently sick, dairy allergies
- **PFD Concerns within a school:**
  - not gaining weight for more than half a year
  - being sick often (congested, absent)
  - frequent vomiting after meals
  - eating small amounts
  - refusing any school food
  - limiting food choices (oatmeal, gummies, puffs, mashed potatoes)
  - dairy allergy
  - difficulty focusing on school activities
  - poor intake of liquids

Case #1

M.A. 5 year old (Autism)

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- **Evaluation:**
  - good bolus control
  - ability to manage soft solids safely
  - refusal of food
  - poor attention
  - frequently congested /sick
  - very skinny (30lbs for half a year)
  - eats small amounts (½ container of oatmeal for a day)
  - throws up frequently
- **Challenges:**
  - parents needed initial support to address M's feeding
  - extended time for HIPAA forms and follow up appointments with Pediatrician, GI, ENT, and Nutritionist
  - very skinny
  - vomits frequently

Case #1

M.A. 5 year old (Autism)

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- **Treatment:**
  - created school-based team (SLP, parent, nurse, teacher, paraprofessional, OT)
  - ongoing communication with the parent
  - food diary kept (amount of food he eats & his weight)
  - daily systematic desensitization, food exploration/play & increase food intake
  - collaboration with Pediatrician, GI & ENT
  - stopping on eating puffs (had dairy)
  - mealtime plan: food available during the day
  - PEP (Positive Eating Program)
  - appetite stimulant was recommended
  - nebulizer for in-school cough management
  - increasing amounts of breaks
  - adding small amounts of olive oil
  - added lactose-free formula

Case #1

M.A. 5 year old (Autism)

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- **Outcomes:**
  - ongoing collaboration between the team
  - taking few bites of new flavors and textures (rice cracker, kiwi, apple)
  - stopped vomiting
  - increased lactose free formula
  - increased amount of food (1 whole container)
  - slowly gaining weight (35.7 lbs)
  - happier and more attentive

Case #2

A.C. 8 year old (Cerebral Palsy & Multiple Disability)

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- **History:**
  - cerebral palsy, multiple disabilities
  - came to school on puree and soft solid diet
  - mom had no concerns with A.'s feeding
  - child is not ambulatory, severe gross/fine motor difficulties
  - frequently sick, congested
- **PFD Concerns within a school:**
  - low weight
  - frequent coughs during meals
  - frequent cough post feedings
  - visible signs of aspiration (watery eyes, flaring of nostrils, coughing during and post swallow, facial grimaces)
  - safety
  - fears (teachers, paraprofessional)

Case #2

A.C. 8 year old (Cerebral Palsy & Multiple Disability)

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- **Evaluation:**
  - poor management of both consistencies (puree and soft solids)
  - poor lip seal on a spoon
  - swallowed with an open mouth
  - tongue discoordination, pumping & thrusting
  - poor tongue control and long transport of the bolus
  - poor mastication skills on soft solids
  - delayed onset of pharyngeal swallow
  - multiple swallows
  - cough during and after meals
  - other sign of aspiration
- **Challenges:**
  - lead-SLP assigned to address this case
  - school staff shared liability and safety concerns
  - A. coughed during every mealtime (breakfast & lunch)
  - A. was refereed for MBSS (took time)
  - Parents were committed to feed A. and were afraid that a feeding-tube would be placed, which they did not want. Translation services were needed.

Case #2

A.C. 8 year old (Cerebral Palsy & Multiple Disability)

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- **Treatment**

Before the MBSS:

- the lead school-based SLP created a team
- teacher and paraprofessionals were trained
  - smaller spoonfuls
  - time between each spoon
  - chin down position
  - positioning
  - longer breaks
- Food log
- Cough log
- Open communication with parents
- Parents agreed to take A. for a swallow study

After MBSS:

- MBSS indicated aspiration on all consistencies
- A. was placed on a g-tube feedings
- feeding therapy focused on oral food stimulation
- practice of her oral motor & chewing skills (w/flavor)
- practice swallowing skills via empty spoons

Case #2

A.C. 8 year old (Cerebral Palsy & Multiple Disability)

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- **Outcome**
  - ongoing collaboration within school-based team
  - A. gained weight
  - feeding therapy: practicing lip seal and tongue movement
  - practices chewing & swallowing
  - less sick
  - feeding protocol for the classroom
  - follow-up MBSS in the future
  - plan for feeding trials

Case #3

J.E. 9 year old (rare genetic disorder Nono, Autism, Multiple Disabilities)

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- **History:**
  - fed by bottle (Formula - slightly thickened with cereal)
  - refused all puree
  - feeding was not addressed during early intervention
  - never transitioned to purees or soft solids
  - 6-8 bottles a day
- **PFD Concerns within a school:**
  - low weight
  - cannot join his peers during mealtimes
  - has not developed age-appropriate feeding skills
  - no self feeding skills other than holding his own bottle
  - poor attention during class activities
  - low energy, frequently sleepy during class

Case #3

J.E. 9 year old (rare genetic disorder Nono, Autism, Multiple Disabilities)

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- **Evaluation:**
  - J has been on formula for 5 years
  - no issues with swallowing (big whole in the nipple)
  - presented with oral dysphagia
  - poor tongue control and coordination
  - good jaw control on a bottle
  - tongue thrust
  - good lip seal on bottle
  - J is nonambulatory, non-speaking (no sounds)
- **Challenges:**
  - creating a school-based team
  - J. behaviorally is attached to the bottle
  - J. presents with sensory-based issues with food
  - J.'s mom was not on board initially due to time constraints
  - creating a plan that is easy for everyone to follow

Case #3

J.E. 9 year old (rare genetic disorder Nono, Autism, Multiple Disabilities)

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- **Treatment:**
  - school-based team: SLP, mom, teacher, OT, para, nurse
  - J started with 1 spoonful of puree before his breakfast and lunch bottles.
  - Training was provided to the paraprofessional on how to help J.
    - tactile cues to seal his lips on the spoon
    - cues to allow his tongue to manage a spoonful of puree food at one time.
  - 1 spoonful was increased to 3, to 5 and to 10.
  - videos were sent to mom
  - mom started sending puree foods to school
  - mom also trained J's caregivers at home
  - worked with volume and different flavors of food
  - increase puree foods and decrease bottle feeds in school

Case #3

J.E. 9 year old (rare genetic disorder Nono, Autism, Multiple Disabilities)

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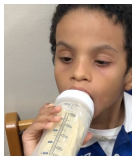
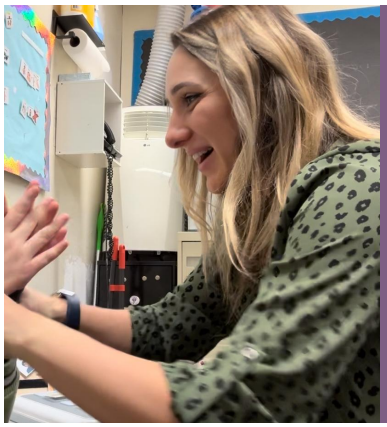
- **Outcomes:**
  - through the 2.5 years of work
  - J. was able to fully transition to pureed foods
  - He tried many new flavors of puree (hamburger, pizza, salads)
  - consumed 1-2 trays of purred lunch
  - ate lunch with his peers at the table
  - gained weight
  - started to walk with support
  - learned to self-feed with a spoon, drink with open cup with some spillage
  - started to babble
  - graduated, attending middle school and is learning to chew and eat soft solids (with ongoing support)





Lessons/Reflections

from a school-based SLP

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Lessons

when addressing PFD in specialized school settings

- Addressing PFD within Schools requires **A LOT** of effort
  - HIPPA forms, parent interviews, assessments, creating of School-based teams (caregivers, OT, PT, teachers, papa, nurse, ect.), creating the treatment plan, progress monitoring and ongoing positive collaboration between all members.
  - \+ Large Caseloads and other duties
  - Feeding concerns and goals must be on the IEP
  - Referrals and Collaboration with medical teams take a long time
  - Lack of training in assessment and treatment of PFD among other school SLPs and awareness of PFD within school staff
  - As prevalence of PFD is increasing, we need more skilled professionals to address feeding/swallowing disorders in schools (especially in specialized schools)

Reflections

when addressing PFD in specialized school settings

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- Helpful tips to target PFD in your school
  - Get administrative support (by advocating for your students)
  - Creating trainings for parents & staff members
  - Growing trust in your school (show your work!)
  - Building strong and positive relationships with school staff
  - Use research to your advantage
  - PFD can and should be addressed within the schools

THANK YOU

KuzminSLP@gmail.com

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