



Improving Monitoring and Screening:

Case Study 3

A director of a community Part C program made the following statement: “We often don’t really see a reason to make an autism diagnosis. It won’t change the IFSP, which is based on need regardless of diagnosis, and it won’t change what services they have access to in their rural community. So, why even tell a family who lives in the middle of nowhere this really challenging news when it won’t change anything?” In a state where a diagnosis does not direct a child to specialized services, what are the reasons for encouraging this director to continue to make a diagnosis of ASD where appropriate? What ethical issues are involved in responding to this director? How do other states achieve specialized services for children with ASD and has that helped?

1. Read the case study. Outline and determine the problem that is presented.
 - Focuses on a Part C program that does not use a diagnosis to determine services, so they don't see the point of making the ASD diagnosis
 - Differences in access challenges: rural/urban
 - Do we identify children even if there are not services available?
 - Families are told that they need to "get" the diagnosis in order to get more services
 - Families are told to come back when they are 3 because Part C will not be doing an ASD evaluation until then
 - Important to know diagnosis because even if doesn't influence Part C services it may be needed for other services in other sectors
 - There is worry that if something is identified as a need then the agency will have to provide the service
 - Are agencies not diagnosing because they feel unsure prior to age 3, or because of feeling obligated to provide service?
 - Many feel that the diagnosis needs to come from a psychologist or physician and the early intervention program doesn't have the resources to provide that, so they recommend that the family see a specialist, but they may have to wait 6-9 months for that. Then it's covered by insurance or the family pays for it, not early intervention.
 - Need diagnosis in order to document the need
 - In rural areas, even if the assessment need is addressed, there may be nowhere for families to go to for intervention
 - Waiting list issues -- families that want and need more but there is no one available to provide the service
 - Director does not have the right to limit information for family

- A diagnosis is important concerning accessing benefits, accessing therapy, etc.
- A diagnosis directs to the known effective interventions
- It is good to understand why the early intervention director has reached this attitude/opinion and to understand needs in community
- Need to know prevalence of ASD to advocate for additional resources in community while avoiding evaluations that would make the diagnosis work against this
- We want to empower families not just because there are limited services – we don't want to withhold information from a family – the family can't access services they don't know about
- Need to look at the bigger picture
- It's more than a training issue – it is a choice by providers in the community
- Diagnosis for services misses the bigger picture there are other issues to address such as the social support, reasons to understand the disability, other medical issues, etc. If a pediatrician knows they have autism, they might look for other issues associated with ASD (e.g., toileting, sleep, seizures).

2. Brainstorm new or existing approaches that could be used to help address this problem. What avenues has your state or program pursued in similar situations? Is there something your state or program has wanted to implement, but hasn't yet due to lack of funding/resources? Are there innovative approaches that could be used?

- What are pieces of the problem that could be attacked in a more focused way?
 - Can't start with more funding. Circular challenges--training, documentation of diagnosis, funding, back to training
 - Maybe training is the place to start. If we have a better trained workforce of professionals from diverse skill sets, then they may be able to develop almost like a union approach, where they can command higher pay over time
- Training physicians and having guidelines from the professional organizations (e.g., AAP) does help move the field as they educate parents and encourage them (re: what to ask for) – although may need to think about moving beyond AAP so it reaches more diverse professionals
- When implementing screening plan, need to think through the steps in the process and referral pathways. Some physicians don't screen because they are worried about being too hard on families, or they have had bad experiences with referrals not panning out; or they refer to their own specialists but not to early intervention. These issues seem to come up across multiple states.
- Training needs to include physicians. Hard to maintain long-term. Need to go into the practice to help make change happen.
- Evaluate whether an increase in screening actually leads to an increase in early intervention, but tricky to study because you don't know which kids have been missed.

- State agencies could help by partnering with researchers to make the follow-up phase work. They could document the successes and the break downs in the referral pathway, although this would also add to the documentation of the problem.
- Need to understand why the number of kids identified with ASD is not being documented in the early intervention record--are we really poor at identification or are we poor at record-keeping?
- Need to know what the baseline is, and where the breakdown occurs.
- AUCD Six by Fifteen campaign: the early identification goal is re: the baseline.
- Identify programs to promote training
 - CAAI (mostly numbers trained, not what they do with that training)
 - "Learn the Signs. Act Early." (mostly perception, not outcome)
 - If we're doing these big training initiatives, we need to meaningfully measure the outcome. Some research indicates that "one off" trainings are not effective; there needs to be some ongoing consultation for it to stick.
- Need technology to support that ongoing consultation in rural areas.
 - UT is planning to implement something like this in coming years.
 - CA is trying a pilot with Guam to do telehealth consultation -- so far tried with parents, and plan to try consultation to professional using the ADOS next.
- Need to get beyond the process evaluation--what is the impact for actual families?
- Telehealth for parent training and training of professionals
 - OH - Kent State "Tele EI" Project is part of a HRSA Autism Implementation Grant
- Information can be disseminated to parents concerning their rights for evaluation and intervention
- Family-to-Family network is a good venue for providing information to families concerning rights and how to advocate for their children
- Family Support resources information important to families in this process
- MABHaccess.com: MA parents can go on line to get real time information about resources by zip code
- In AZ, a primarily rural & frontier landscape, there have been significant changes in the AZ early intervention program and how those services are distributed across the state. In the past, therapists have traveled to rural areas. However, a change in funding has resulted in a penalty to therapists who were traveling in hopes that local therapists would instead meet those families' needs. In face of that, they continue to encourage appropriate diagnoses and the recording of that information on the ISFP so a record is being kept for when the child moves from Part C to Part B services.
- Family advocacy groups
- A medical plan may provide a more informed context
- In OH, a Medtapp grant trains providers who want to work with Medicaid populations; focuses on cultural competency, ethics
- A phone conference to talk about needs of the child may help; making a relationship with the community provider can help as well

3. Engage in dialogue and discussion to explore and clarify the problem and talk about which approaches may be the most feasible and effective for addressing this problem.
 - Need for technology (telehealth)
 - Training is also needed
 - Family support/resources important