

Supports Intensity Scales: The Latest in Research, Policy, and Practice

An AAIDD Webinar: June 17, 2020

Using the SIS with People with ASD: Let the Data Speak!

James R. Thompson & Karrie A. Shogren (University of KS)

Problem-Solving Supports with the SIS-C

Virginia L. Walker, Megan E. Carpenter (Univ. of NC-Charlotte),

& Melinda R. Snodgrass (Illinois State University)

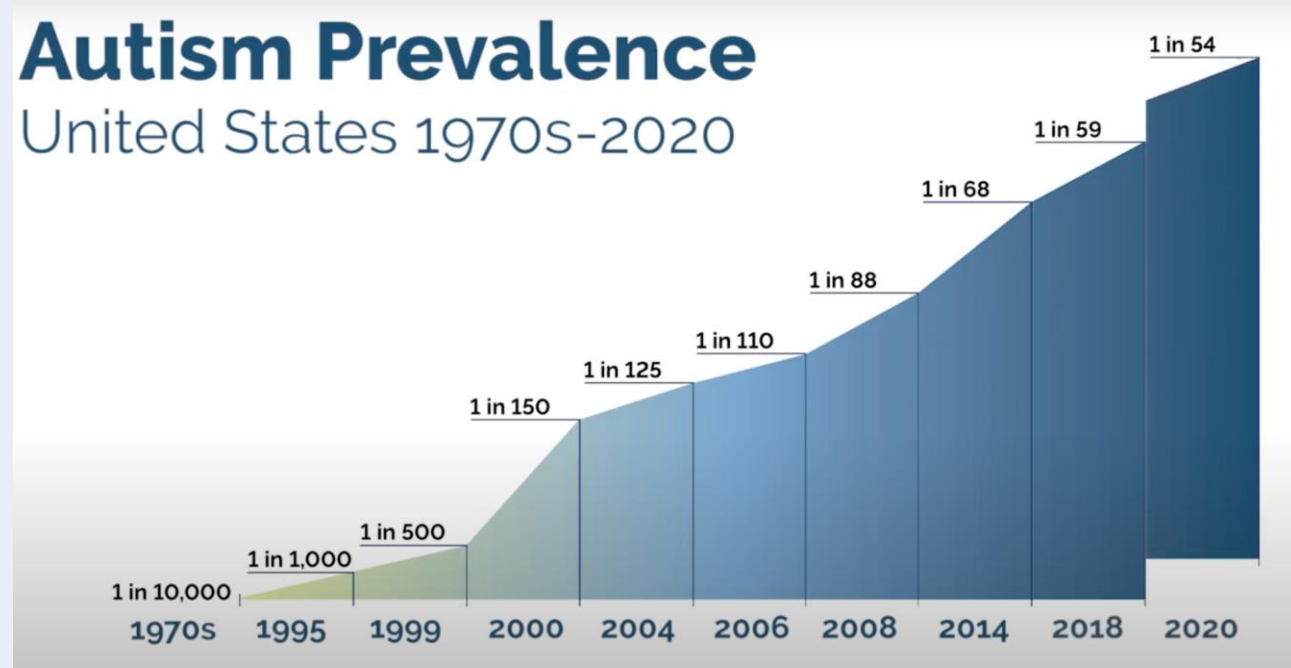
Telling Your State's Story with the SIS

Colleen Kidney & Megan Vilwock (Human Services Research Institute)



Rationale underlying SIS - ASD Studies

- The incidence and prevalence of ASD has been increasing over the past 50 years
- In the early 2000s SIS-A data were collected for the initial standardization sample – only 6% of the sample reported a diagnosis of ASD
- In 2014 SIS-C data were collected for the initial standardization sample – 52% reported a diagnosis of ASD



- The SIS-A and SIS-C are being used to inform supports budgets/funding for people receiving Medicaid Waiver Services.
- Finding from studies investigating the reliability and validity of the SIS scales for people with ASD are of interest, especially to the ASD community.

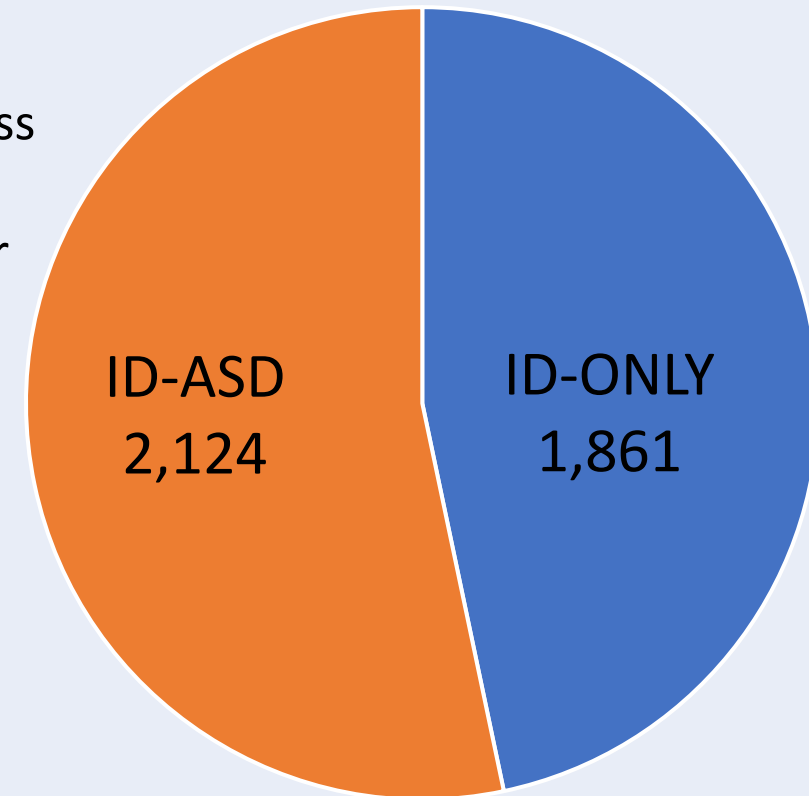
Thompson, J. R., Anderson, M. H., & Shogren, K.A. (in press). Measuring the support needs of people with intellectual disability and autism spectrum disorder with the Supports Intensity Scale – Adult Version. *Education and Training in Autism and Developmental Disabilities*. (to appear in the March, 2021 issue)

- Data from 19 jurisdictions in U.S.
- SIS-A scores for people with an ID diagnosis (no secondary diagnosis) and people with an ASD diagnosis (no secondary diagnosis) did not meaningfully differ.
- SIS-A scores for people with an ID diagnosis (with and without a secondary diagnosis, except no cases with a secondary diagnosis of ASD) and people with an ASD diagnosis (with and without a secondary diagnosis, except no cases with a secondary diagnosis of ID) did not meaningfully differ.
- Conclusion: The SIS-A is not operating differently when measuring the intensity of support needed by people with ID and ASD **receiving HCBS waivers**, and therefore it can be used with confidence with both populations.



Shogren, K. A., Wehmeyer, M. L., Seo., H., Thompson, J. R., Schalock, R. L., Hughes, C., Little, T. D., & Palmer, S. B. (2016). Examining the reliability and validity of the Supports Intensity Scale – Children’s version in children with autism and intellectual disability. *Focus on Autism and Other Developmental Disabilities*, 32, 293-304. DOI: 10.1177/1088357615625060

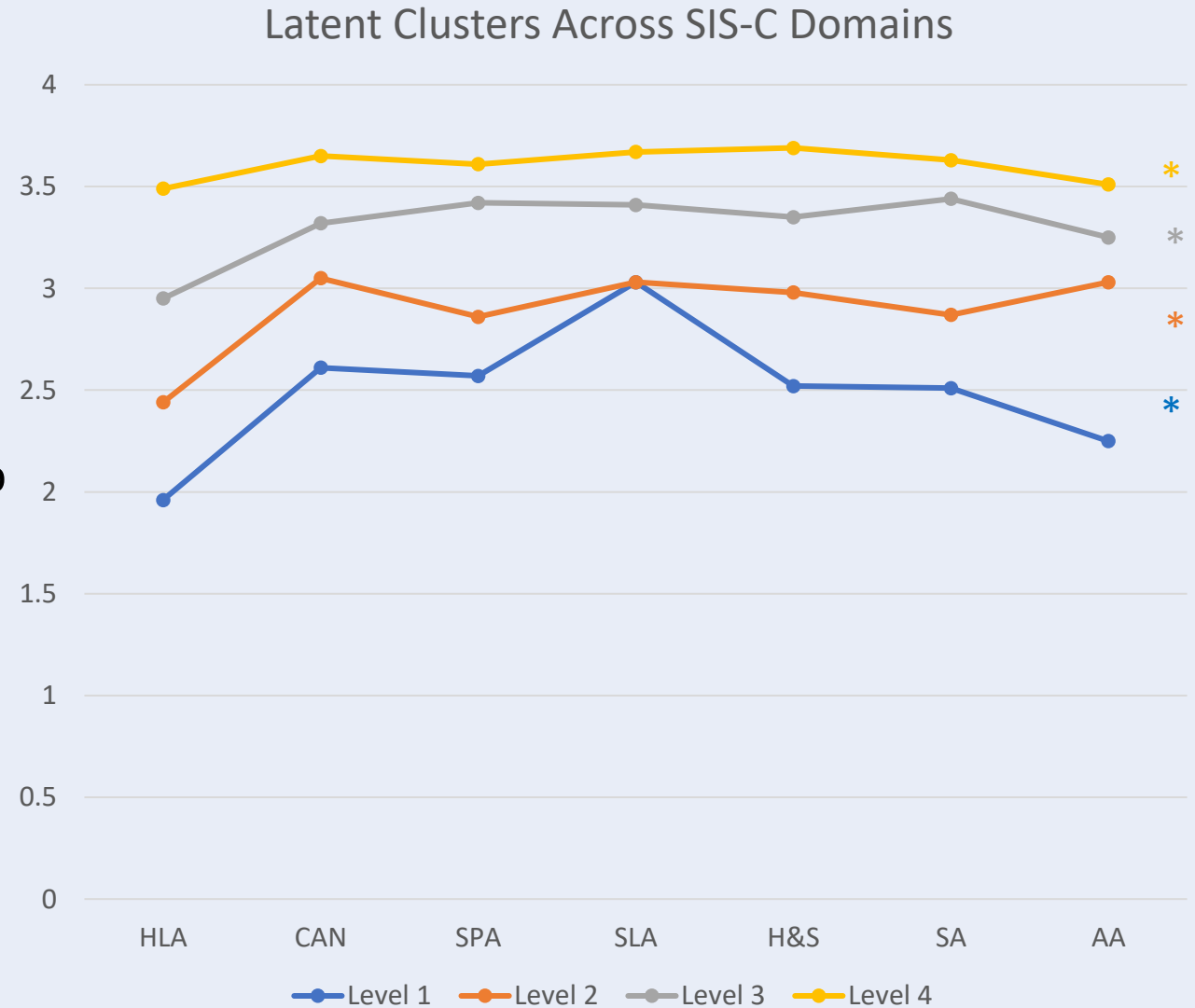
- Secondary analysis of subset of data from SIS-C standardization sample – 100% diagnosed with ID (with & without secondary disabilities) and 52% with dual diagnosis IDD-ASD (with & without additional disabilities)
- SIS-C scores for children with only an ID diagnosis (no secondary diagnosis) and children with an ID- ASD diagnosis. ID-ONLY compared with ID-ASD across 6 age groups
 - (a) ID-ONLY had higher exceptional medical scores and ID-ASD had higher behavioral support need scores
 - (b) Reliability (internal consistency) was very strong for both disability groups; Criterion related validity strong for both disability groups; Construct validity strong for both disability groups (scores were in the expected direction for IQ and AB)
 - (c) ID-ASD had more intense support needs in the social Domain and the Health & Safety Domain



Conclusion: The SIS-C is as reliable and valid measure of support needs for children with ID-ONLY and ID-ASD; children with dual diagnosis have more intense support needs in the Social and Health & Safety domains across age groups

Shogren, K. A., Shaw, L. A., Wehmeyer, M. L., Thompson, J. R., Lang, K. M., Tassé, M. J., & Schalock, R. L. (2017). The support needs of children nwith intellectual disability and autism: Implications for supports planning and subgroup classification. *Journal of Autism and Developmental Disorders*, 47, 865-877. DOI: 10.1007/s10803-016-2995-y

- Secondary analysis of subset of data from SIS-C standardization sample: IDD-ASD (n=2,124)
- Latent cluster analysis: Are the groups of children (across ages) whose pattern of scores mirror one another, sufficiently, to suggest that categories of children are evident? This is different from theoretical categorization and from categorization based on arbitrary cut-off scores. It involves examining the goodness-of-fit of data in relationship to hypothesized cluster models of support intensity.
- **Conclusion:** Findings provide more support for the construct validity of the SIS-C. The strongest evidence for was for a 4 support-intensity grouping of children, and contrast with the 3-level support intensity grouping in the DSM-5.
- Important to remember that the sample only included children with a dual diagnosis of ID and ASD; thus, entire range of children with ASD not represented.



Problem-Solving Supports with the SIS-C

Virginia L. Walker | Melinda R. Snodgrass | Megan E. Carpenter | James R. Thompson

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Background

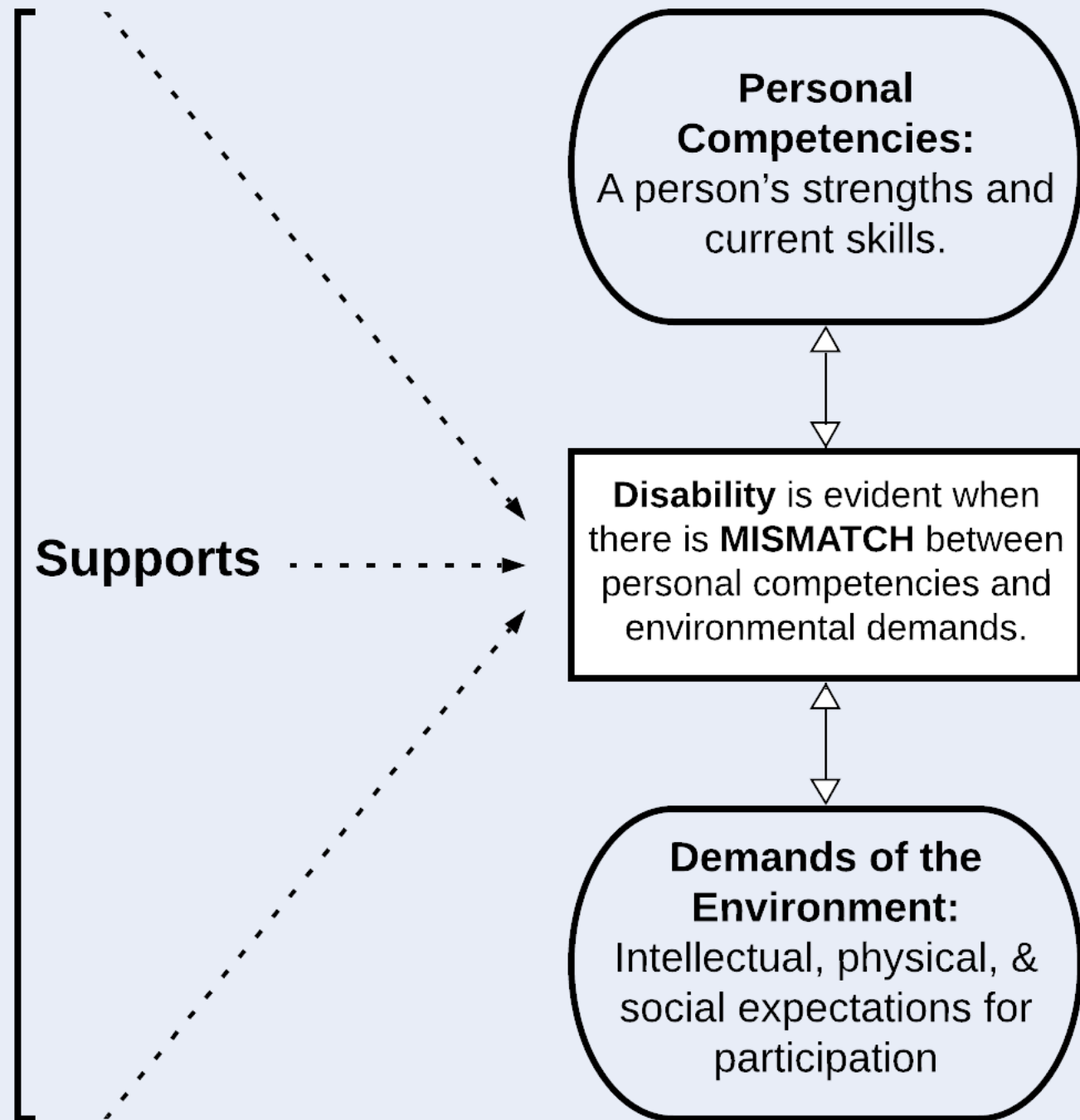
Benefits of participating in general education classrooms:

- Positive outcomes related to **academic and social skills** (e.g., Fisher & Meyer, 2002)
- Progress in the **general education curriculum** (e.g., Browder, Hudson, & Wood, 2013; Spooner, Saunders, Root, & Brosh, 2017).
- Greater **access to the general education curriculum** and academic goal attainment (e.g., Matzen, Ryndak, & Nakao, 2010; Roach & Elliott, 2006; Wehmeyer, Lattin, Lapp-Rincker, & Agran, 2003).

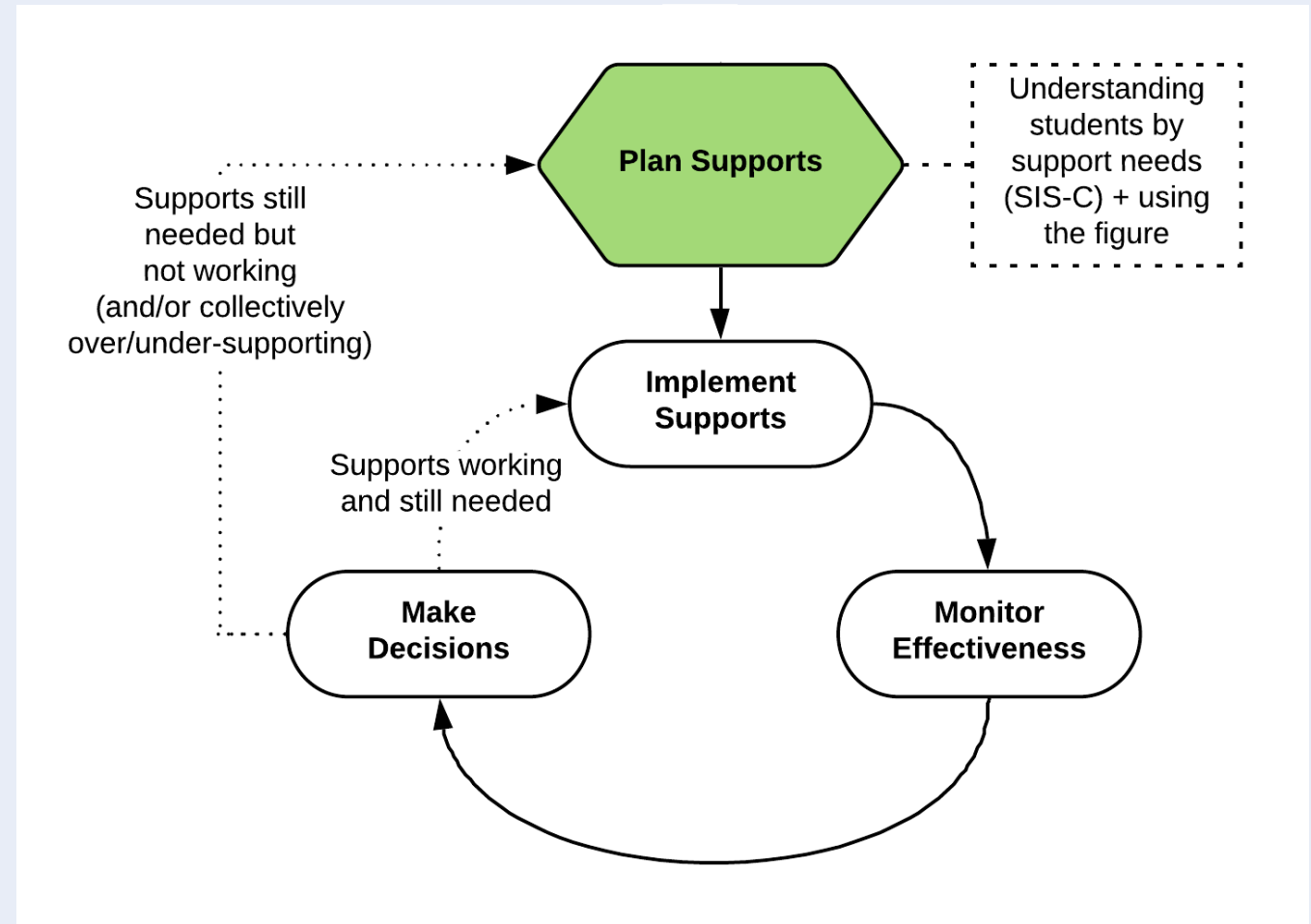
Background

Students with ID primarily receive special education services in **self-contained classrooms** (Klienert et al., 2015; Kurth, Morningstar, & Kozleski, 2014)

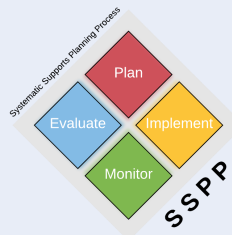
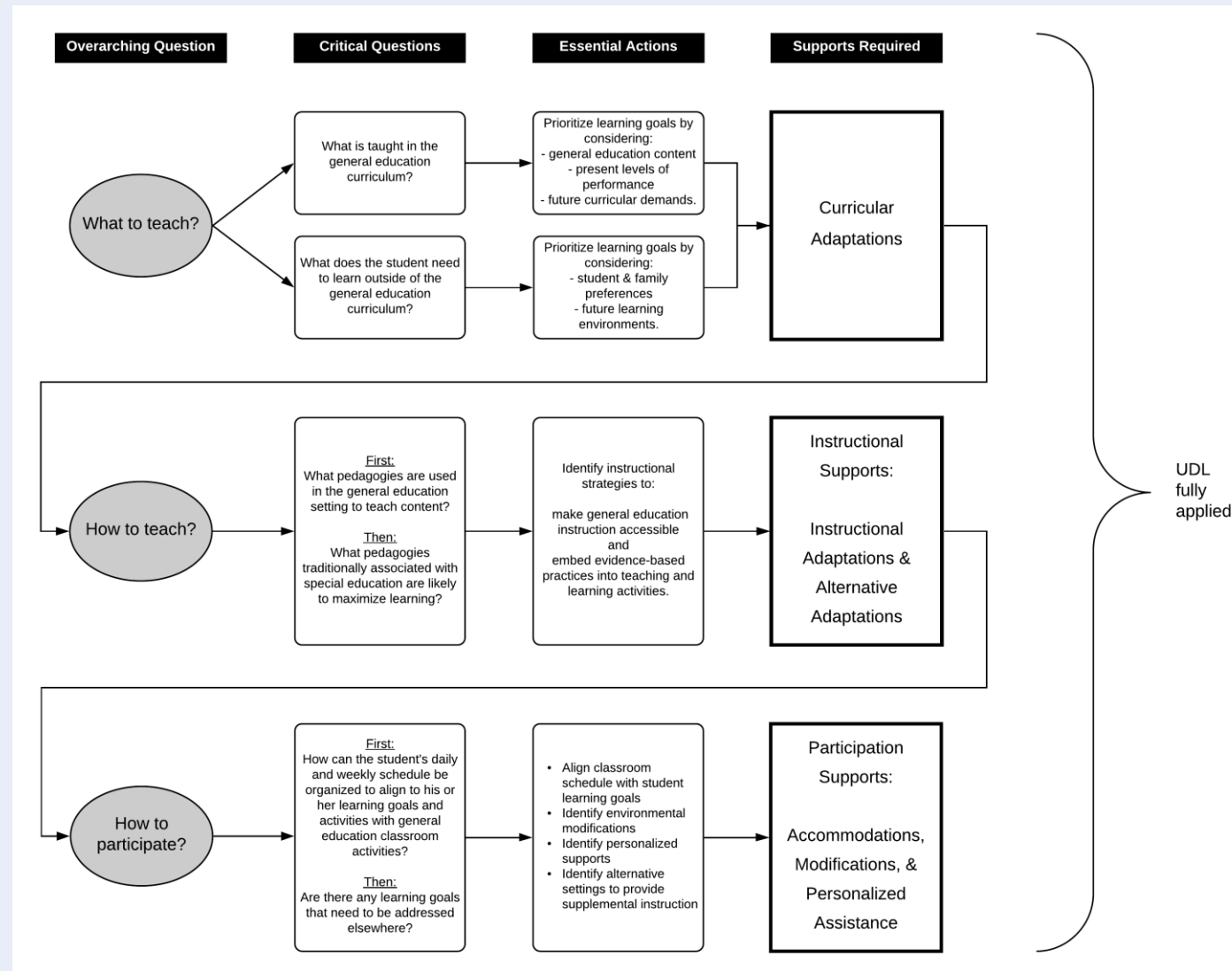
Consideration of student **support needs** can provide new ways to identify, arrange, and implement supports to promote access and meaningful participation in general education settings for students with ID.



Current Project



The Systematic Supports Planning Process (SSPP)



Educator Input: Findings from Six Focus Groups

Current Process

Informal and context- and educator dependent

Desire comprehensive information on the student *and* the general education context

Perceived SIS-C information as an important component of desired information

Current Challenges

Time

For planning | Competing responsibilities | To identify supports

Resources

Environmental | Instructional | Training

Personnel

Dispositions | Roles/expectations

Educator Input: Findings from Six Focus Groups

Attitudes Toward Using the Proposed Process



SSPP

Educators were supportive of using a systematic process as the basis for planning, arranging, and implementing supports, but had differing opinions about the ways it could be implemented effectively.

To implement effectively, they expressed the need for tangible resources and technical assistance.

The SSPP Phase 1: Plan

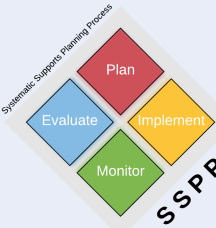
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Part 2: Results from the SIS-C Assessment

Section A: Home Life Activities	Type of Support	Frequency	Daily Support Time
1. Completing household chores	2 = verbal/gestural prompt		
2. Eating			
3. Washing and keeping self clean			
4. Dressing			
5. Using the toilet			
6. Sleeping and/or napping			
7. Keeping track of personal belongings at home			
8. Keeping self occupied during unstructured time (free time) at home			
9. Operating electronic devices			

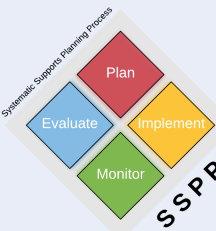
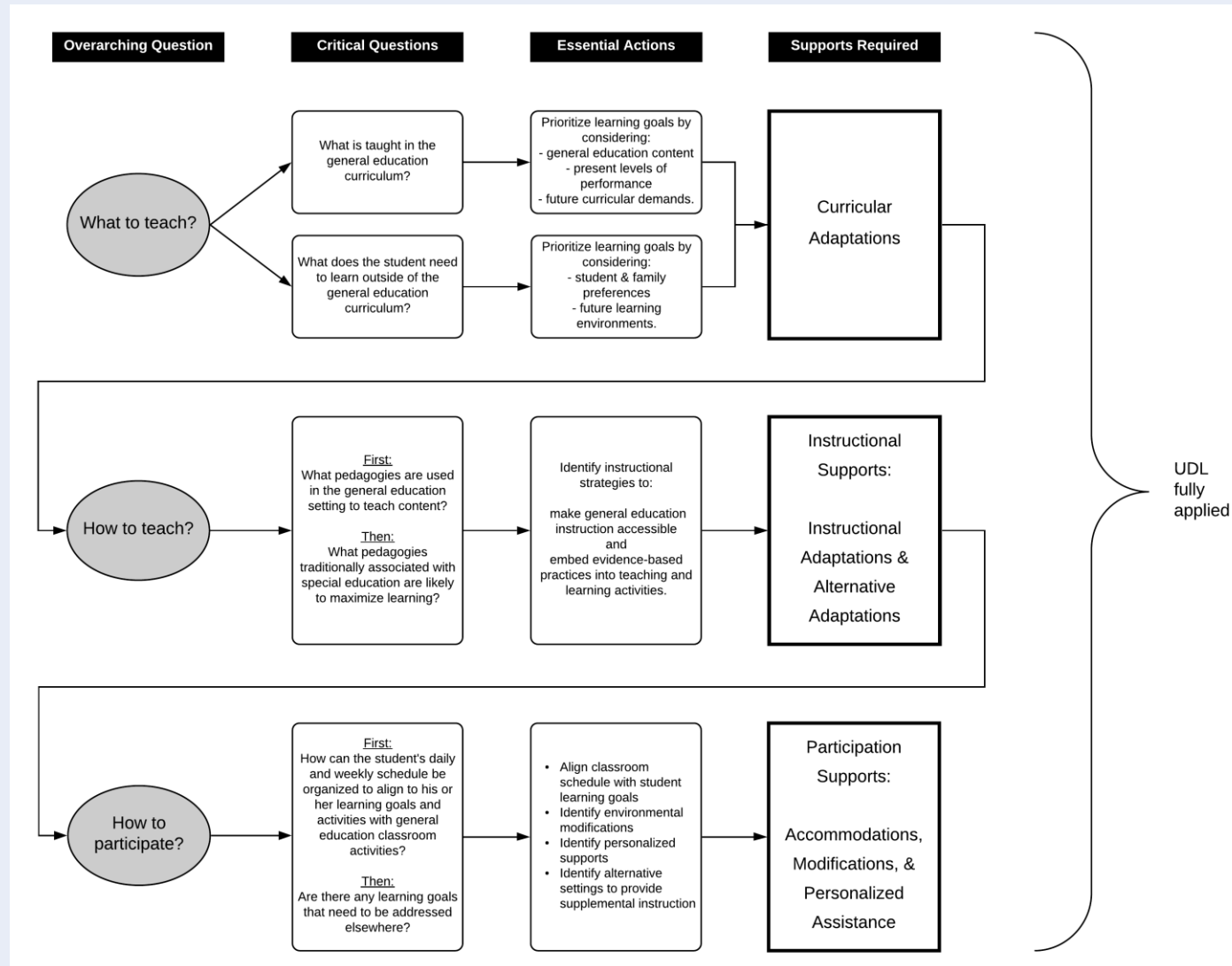
Total Score, Mean Rating, and Standard Score: Total Score is , Mean Rating is , Standard Score is

Briefly summarize/highlight the critical information educators should take away from these scores in regard to student strengths, needs for support at school, and any specific examples of supports that are in place or have been tried.



The SSPP Phase 1: Plan

2



The SSPP Phase 1: Plan

②.①

“What to Teach” - Quarterly Curricular Adaptations Plan (CAP)

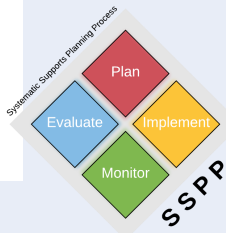
1. Review the learning standards and curriculum content that is going to be addressed in the general education class instruction during the upcoming quarter. Will the focus student work toward mastery of all of those standards/curricular measures in the same way as their peers?

☐ YES

☐ NO

- a. If NO, what expectations for this quarter need to be modified and what will the modified expectations be?

Table 1. Modified and Supplementary Expectations		
Expectations from General Education	<u>Supplementary or Modified Adaptations for Focus Student</u>	Modifications Action Plan (Who needs to do what to make these modifications?)
EXAMPLE: Write essay on Abe Lincoln	EXAMPLE: Answer true/false questions about Abe Lincoln (Modified)	EXAMPLE: SpEd teacher creates list of true/false questions. Para supervises peer delivering questions and recording focus student's answers



The SSPP Phase 1: Plan

②. ②

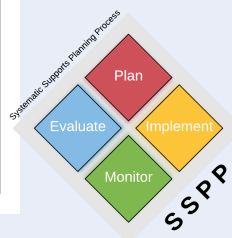
“How to Teach” - Quarterly Instructional Supports Plan (ISP)

3. [Click here to review the learning activity types](#) and identify those that are going to be used to teach this quarter’s content. Will the focus student require different and/or additional instruction and/or accommodations to master all of the learning outcomes identified in the CAP?

☐ YES ☐ NO

a. If YES, what learning activities for this quarter need to be adjusted and/or accommodated and how?

Table 3. Adjusting & Accommodating Learning Activities		
<u>Learning Activity Types</u> (list all that need to be adjusted and/or accommodated)	Adjusted/Accommodated Activity [select one for each activity] <ul style="list-style-type: none">• Same activity with accommodations• Different activity	Instructional Adjustment Action Plan (Who needs to do what to make these instructional adjustments?)
<i>EXAMPLE: Writing: Organizing and outlining (for Abe Lincoln essay)</i>	<i>Different activity</i>	<i>Para practices answering true/false questions with the student in preparation for the CAP Action Plan.</i>



The SSPP Phase 1: Plan

②. ③

“How to Participate” - Quarterly Participation Supports Plan (PSP)

4. Are there any additional participation supports that the student will need to successfully participate in the general education classroom and content this quarter? This could include **accommodations** that provide alternative ways to access general education instruction but do not change the difficulty level, **modifications** that change the difficulty level, or **personalized supports** that enable the student to more fully participate in learning activities by providing support from another person or through using technologies.

☐ YES

☐ NO

a. If YES, complete this table:

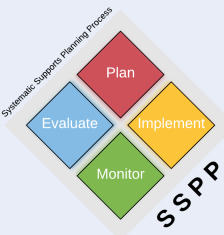
Table 5. Participation Supports	
Contexts for Support	Participation Supports (Who needs to do what to ensure the student’s successful participation and learning?)
{Copy and paste from Column 3 of Table 3 }	
{Copy and paste from Column 2 of Table 4 }	
Learning Activity Types that will be used this quarter but were not adjusted above. (type one per row)	
Any other considerations (e.g., transitions, gathering materials, behavior intervention plans) (type one per row)	

The SSPP Phase 1: Plan

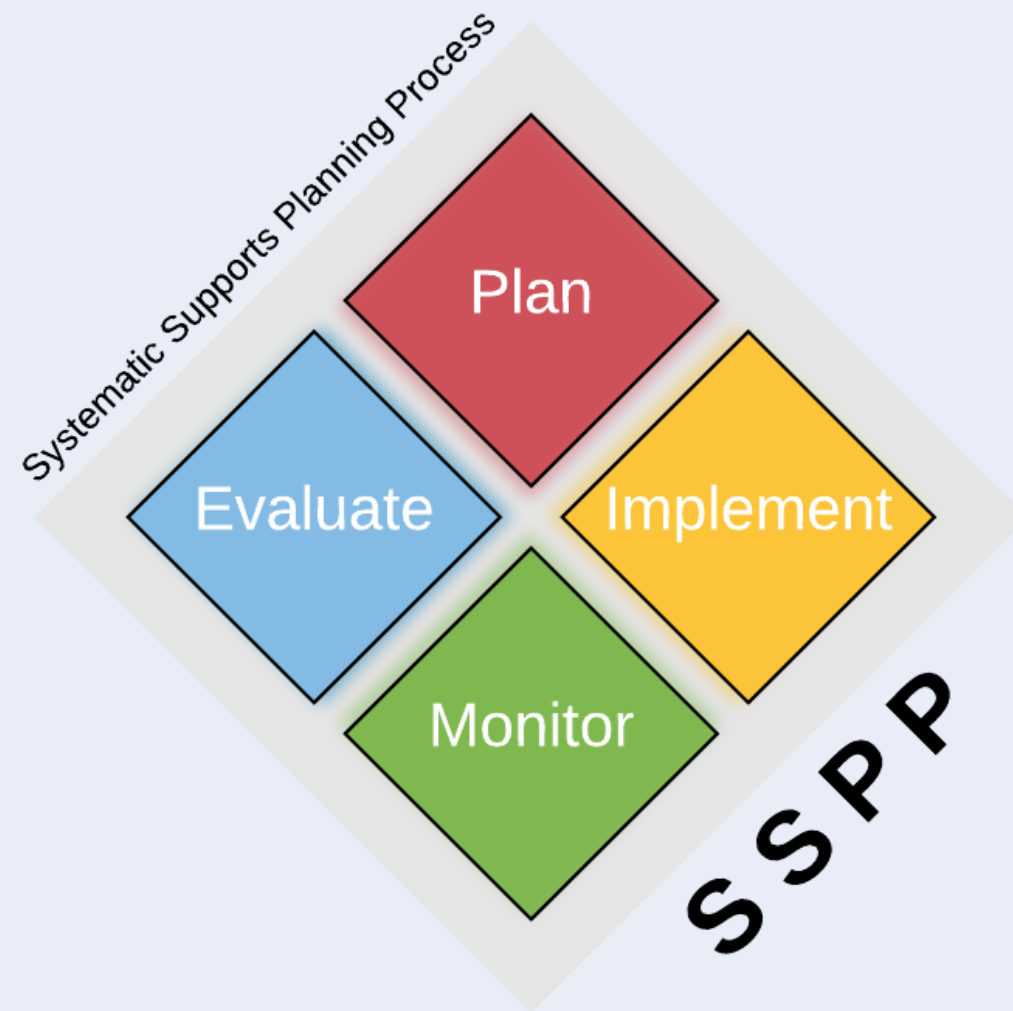
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SSPP for R. - Language Arts, Q3, 2020

Action Steps	Person(s) Responsible	Due Date	Date Completed
<i>What to Teach Action Plan</i>			
Sp.ed. Teacher will create Questions Prompts with visual supports and teach student how to use visual support before class	Sped Teacher	2/18/20	
Sp.ed teacher will prepare with similar lesson before lesson in general education. This will also help the assistant give similar prompts in gen ed as needed.	Sped Teacher	2/18/20	
Gen. Ed teacher will provide lessons/ assignments ahead of time. Sp.ed. Teacher will create visuals to go with lesson.	Gen Ed Teacher Sped Teacher	2/18/20	Gen Ed Teacher shared 2/10/20
Gen. Ed. teacher- classroom expectations Sped Teacher will create routine visual TA will support use of visual (different TA everytime)	Gen Ed Teacher Sped Teacher TA	2/18/20	Gen Ed- Shared in meeting
<i>How to Teach Action Plan</i>			
Gen Ed teacher will highlight words as reading, pre-highlight words he would be expected to read aloud	Ged. Ed Teacher	2/18/20	



The SSPP



Our Team

- Student
 - 7-year-old male with ASD and ID
 - Never included in general education
- Special Education Teacher
 - 6 years of experience teaching students with disability labels in a self-contained classroom
- General Education Teacher
 - 2nd year teaching
 - Minimal experience with inclusive education
- Parent

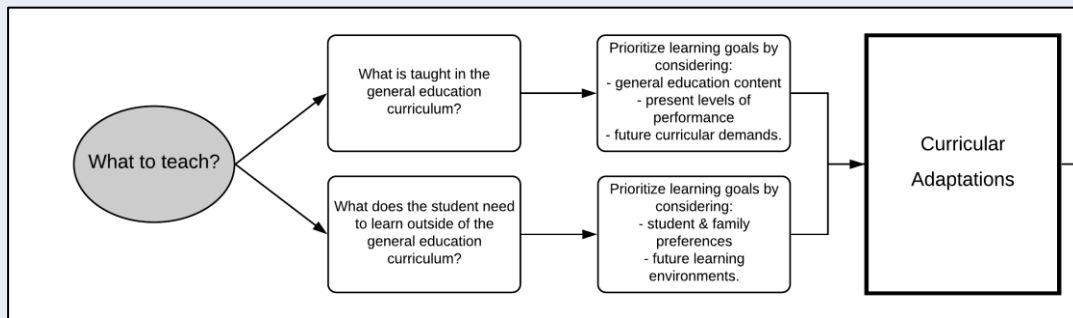
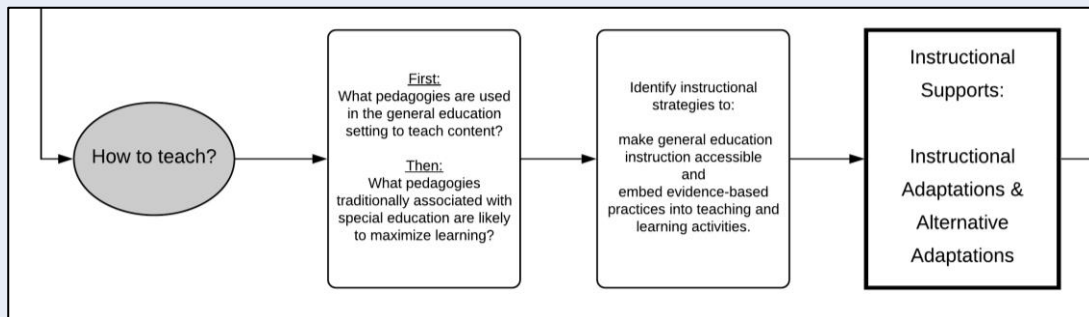


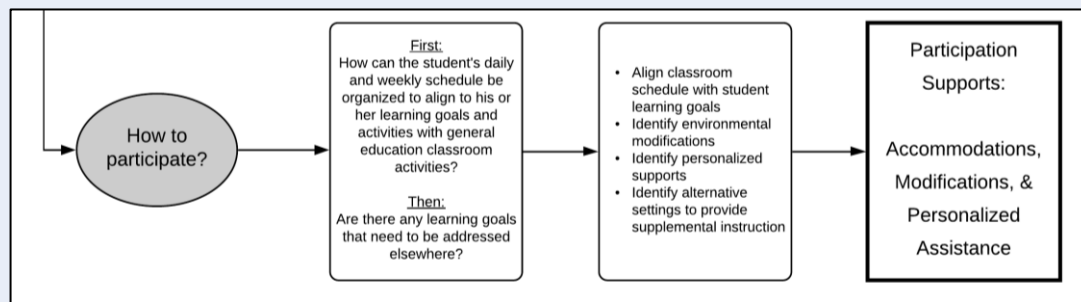
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<i>EXAMPLE: Write essay on Abe Lincoln</i>	<i>EXAMPLE: Answer true/false questions about Abe Lincoln (Modified)</i>	<i>EXAMPLE: SpEd teacher creates list of true/false questions. Para supervises peer delivering questions and recording focus student's answers</i>
Ask specific wh questions after reading	Ask general questions before, during, or after a text is read aloud to him	Sp.ed. Teacher will create Questions Prompts with visual supports and teach student how to use visual support before class
Find text to support answer to a question	Answer questions supported by the text	Sp.ed teacher will prepare a similar lesson before the lesson in general education. This will also help the assistant give similar prompts in gen ed as needed.
Make connections (e.g., between historical events and timeline, between scientific concepts, between text and diagrams, text features, between steps in a process)	Follow routine/ steps independently	Gen. Ed teacher will provide lessons/ assignments ahead of time. Sp.ed. Teacher will create visuals to go with the lesson.



a. If YES, what learning activities for this quarter need to be adjusted and/or accommodated and how?

Table 3. Adjusting & Accommodating Learning Activities		
<u>Learning Activity Types</u> (list all that need to be adjusted and/or accommodated)	Adjusted/Accommodated Activity [select one for each activity] <ul style="list-style-type: none"> • Same activity with accommodations • Different activity 	Instructional Adjustment Action Plan (Who needs to do what to make these instructional adjustments?)
<i>EXAMPLE: Writing: Organizing and outlining (for Abe Lincoln essay)</i>	<i>Different activity</i>	<i>Para practices answering true/false questions with the student in preparation for the CAP Action Plan.</i>
Read aloud	Same activity with accommodations	Gen Ed teacher will highlight words as reading, pre-highlight words he would be expected to read aloud
Ask Questions	Same activity with accommodations	Visual Chart created by Sp.Ed. Teacher



TA will provide additional prompts and General Education Teacher will ensure he has the opportunity to participate	
Learning Activity Types that will be used this quarter but were <u>not</u> adjusted above. (type one per row)	Making Predictions Think Aloud
Any other considerations (e.g., transitions, gathering materials, behavior intervention plans) (type one per row)	Learning new routines (e.g., hand signs, where to sit on carpet first time) --Gen. Ed. teacher will add a dot to the carpet for him

Action Steps	Person(s) Responsible	Due Date	Date Completed
<i>What to Teach Action Plan</i>			
Sp.ed. Teacher will create Questions Prompts with visual supports and teach student how to use visual support before class	Sped Teacher	2/18/20	
Sp.ed teacher will prepare with similar lesson before lesson in general education. This will also help the assistant give similar prompts in gen ed as needed.	Sped Teacher	2/18/20	
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Gen. Ed. teacher- classroom expectations Sped Teacher will create routine visual TA will support use of visual (different TA everytime)	Gen Ed Teacher Sped Teacher TA	2/18/20	Gen Ed- Shared in meeting
<i>How to Teach Action Plan</i>			
Gen Ed teacher will highlight words as reading, pre-highlight words he would be expected to read aloud	Ged. Ed Teacher	2/18/20	
Visual Chart created by Sp.Ed. Teacher	Sp.ed teacher	2/18/20	
Visual Checklist for participation	Sp.ed. Teacher	2/18/20	

Telling your state's story with the Supports Intensity Scale

Presenters: Colleen Kidney, PhD
Megan Villwock, MPH, MSW

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Integrated service delivery
and whole-systems views

Collaborative cross-program,
cross-agency efforts can
provide the right mix of
services to promote
community integration and
self-direction



Human Services
Research Institute



About Us

Improving the systems that improve lives

Are we allocating Medicaid LTSS funds appropriately?

What do we need to know to answer the question?

What are my policy intentions?

Who is being served?

What resources did they have access to?

How much money did each person **ultimately spend**?

What is their assessed **level of need**?

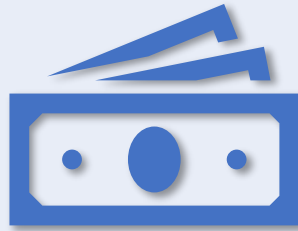
And, ideally...

Did this make a difference?

Are we allocating public funds appropriately?



Chapter 1:
People



Chapter 2:
Money



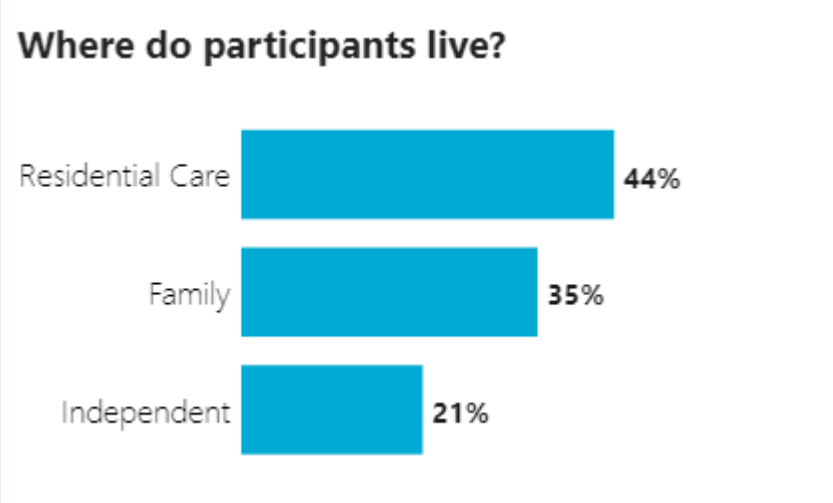
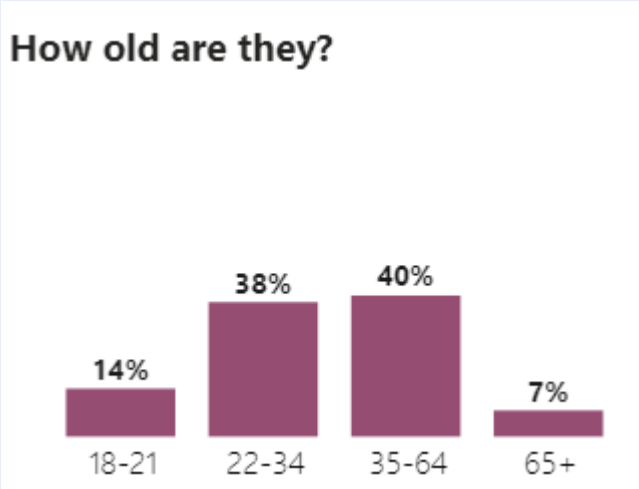
Chapter 3:
Support

Data Story Chapter 1

People

In Jurisdiction Anecdote, there are **5,934** individuals receiving Medicaid Waiver services. We know that in order to receive Medicaid Waiver services, an individual must have a developmental disability. What else do we know about this population?

Thanks to data collected from Anecdote’s case management system (more on that later), we know that **most people either live at home with their families or in a residential care facility**. However, significant numbers of individuals also live independently.

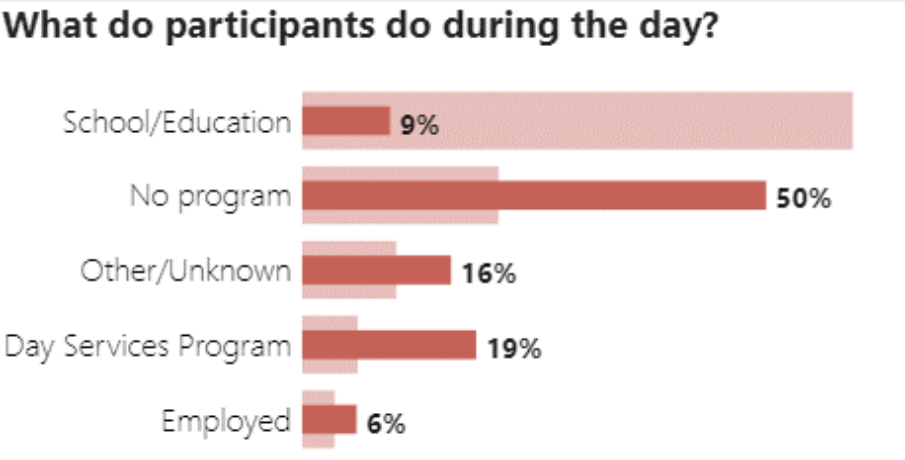
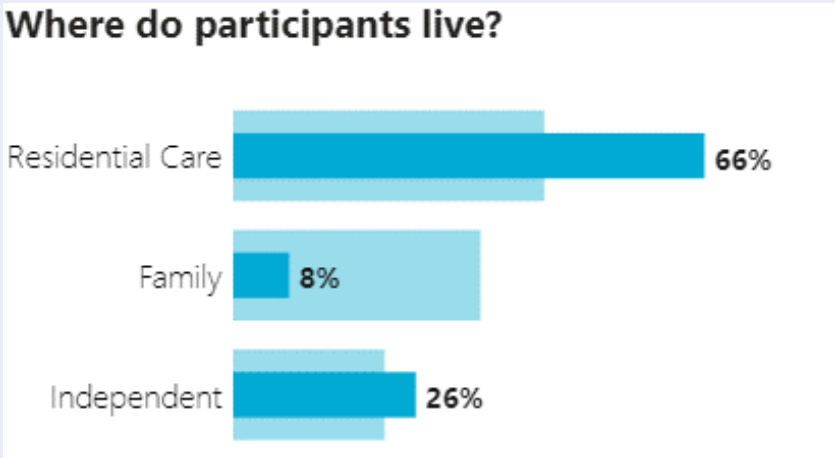


We also know their **age distribution**. It’s about what we’d expect. In this jurisdiction it tracks with the overall population age distribution.

(In some jurisdictions we notice differences here)

As a policymaker, I'm interested in knowing more about the **443** people over the age of 65 in my service system.

Compared to everyone else, a lot more people over the age of 65 live in a residential care facility. **Only 8% of people over the age of 65 live at home with family.**



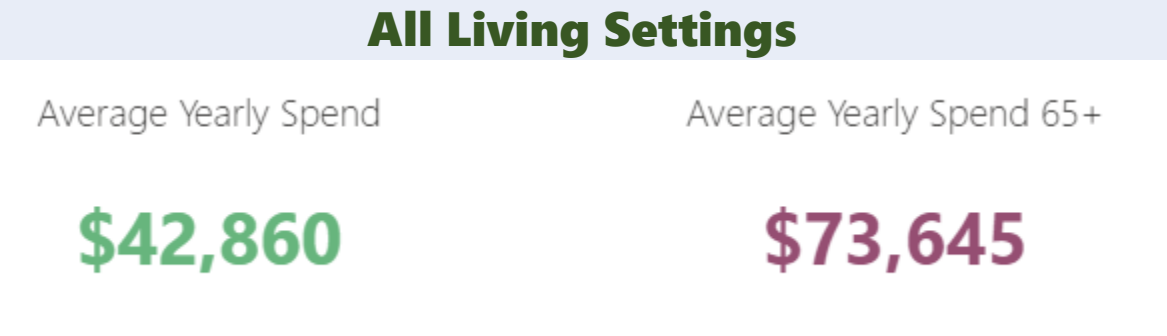
Half of all individuals over the age of 65 do not have a funded day program.

What else can I learn about the over 65 crowd?

Data Story Chapter 2

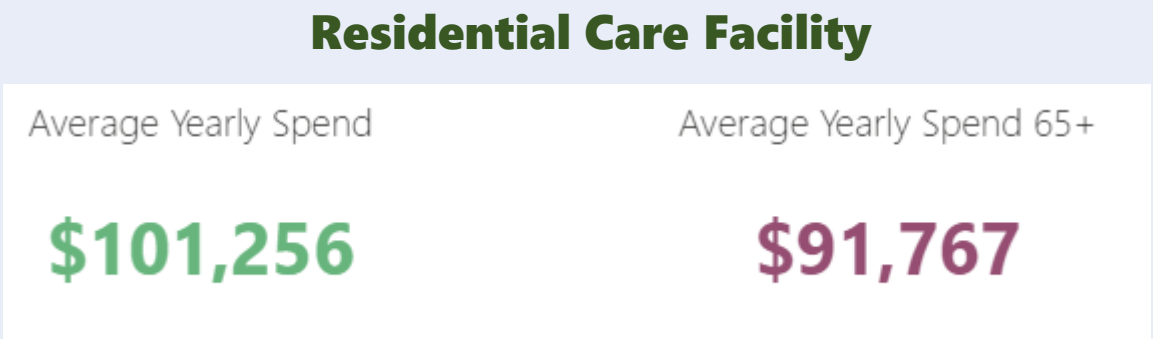
Money

If I merge in data from the Medicaid Management Information system, I can see how much money I spent per person last year.



It looks like I spent a lot more per person on average for older individuals than younger individuals.

However, we already learned that you are more likely to live in a more expensive living setting (residential care facility) if you are older than if you are younger. We also know that half of all individuals over the age of 65 do not have a day program, but that may also be a function of where they live. What happens when we control for living setting, and only look at people living in the same type of setting?



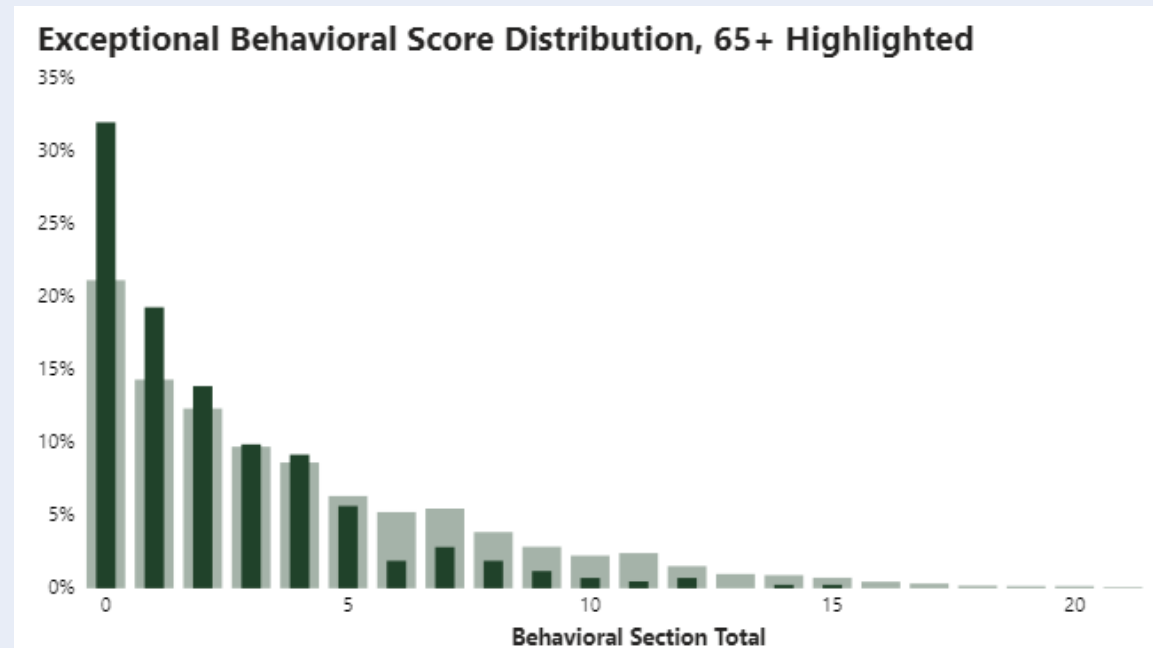
Data Story Chapter 3

Support

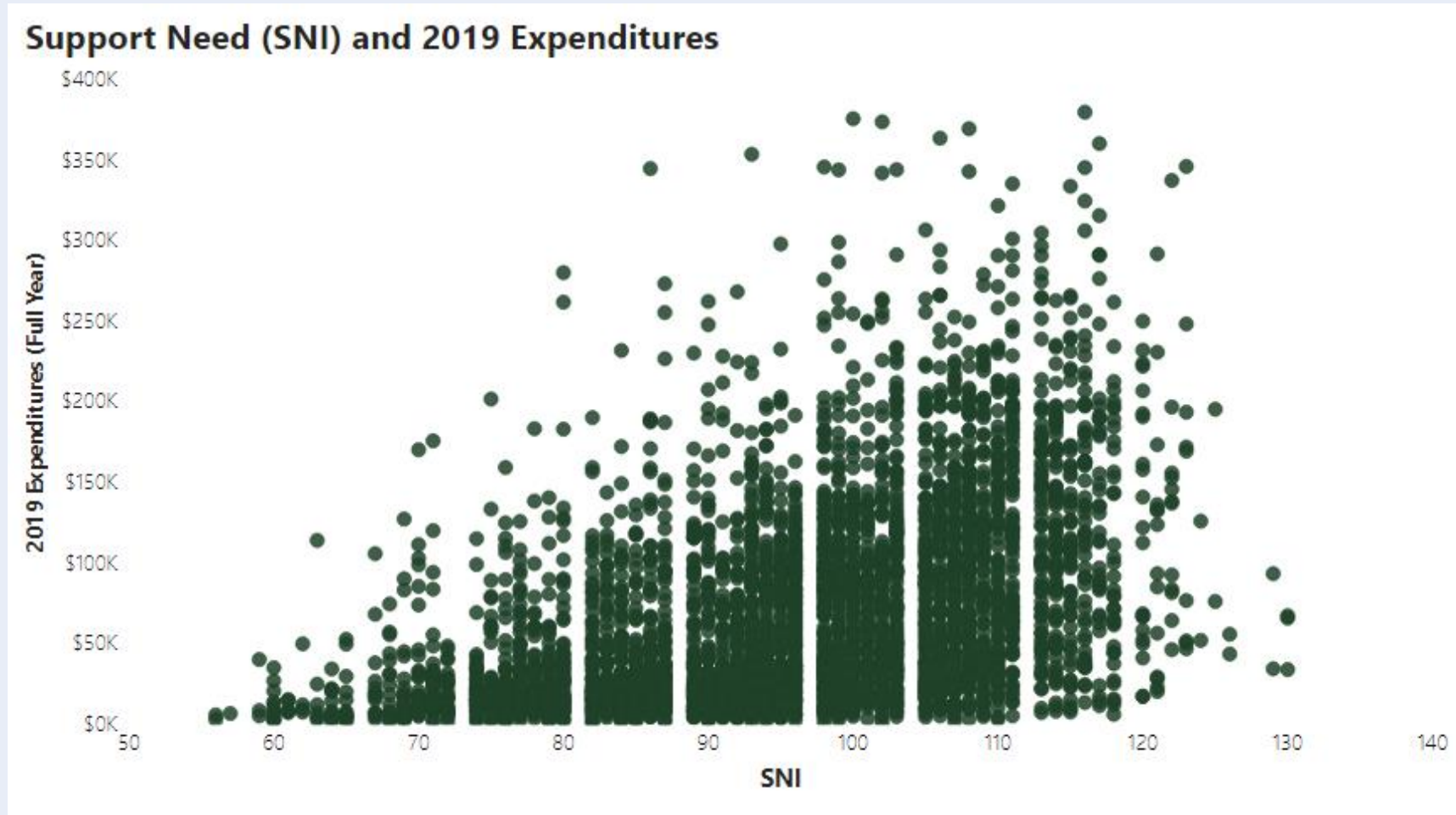
Adding it all together – All living settings

Participants with full year of expenditures and completed SIS assessment (n = 4,408)

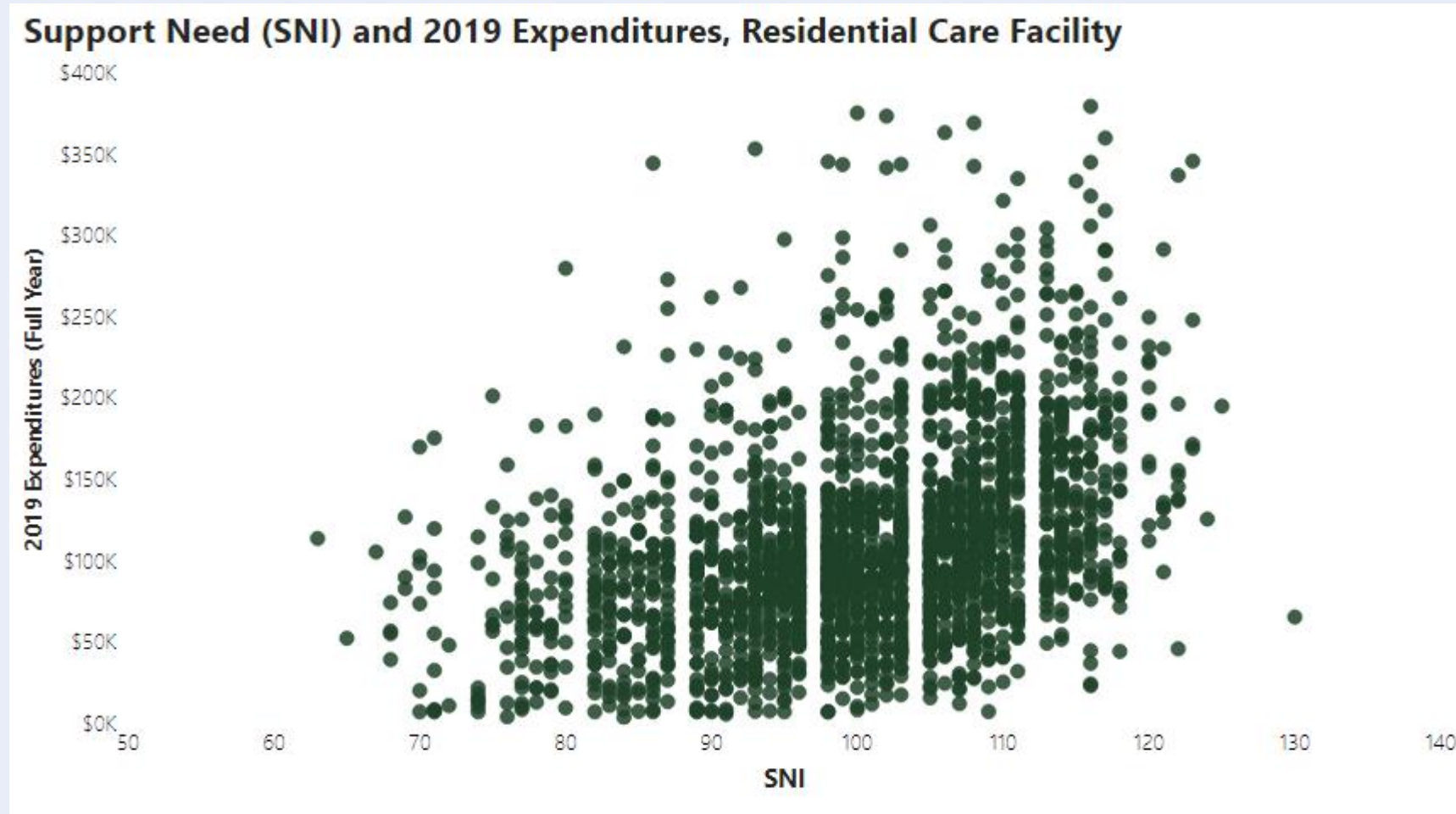
	n	Avg. SNI	Avg Medical Score	Avg. Behavioral Score	Median Spend
Under 65	4,035	95.05	1.72	4.01	\$42,680.25
65 +	373	97.35	1.74	2.30	\$73,644.84



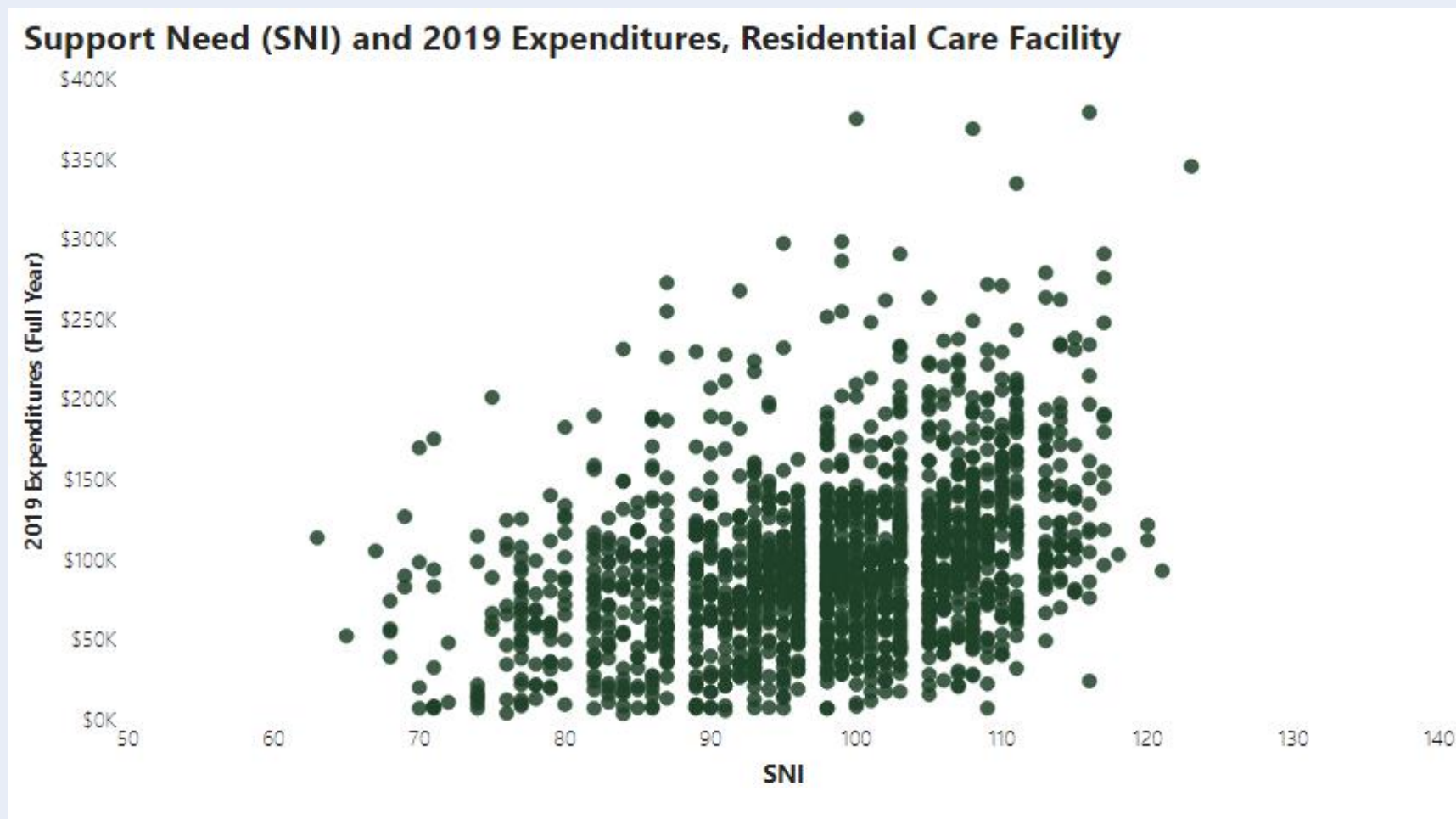
All Participants



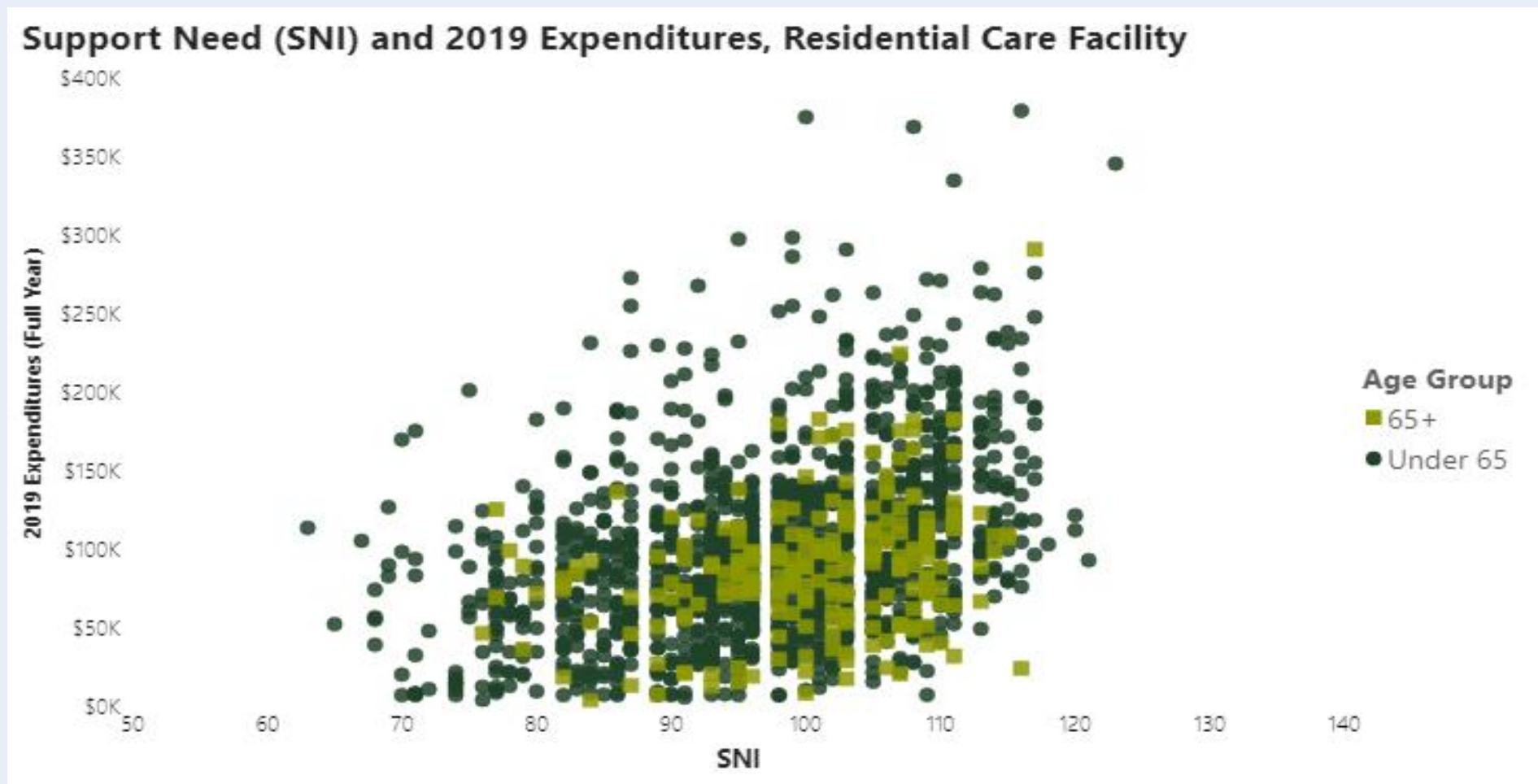
Participants in Residential Care Facilities



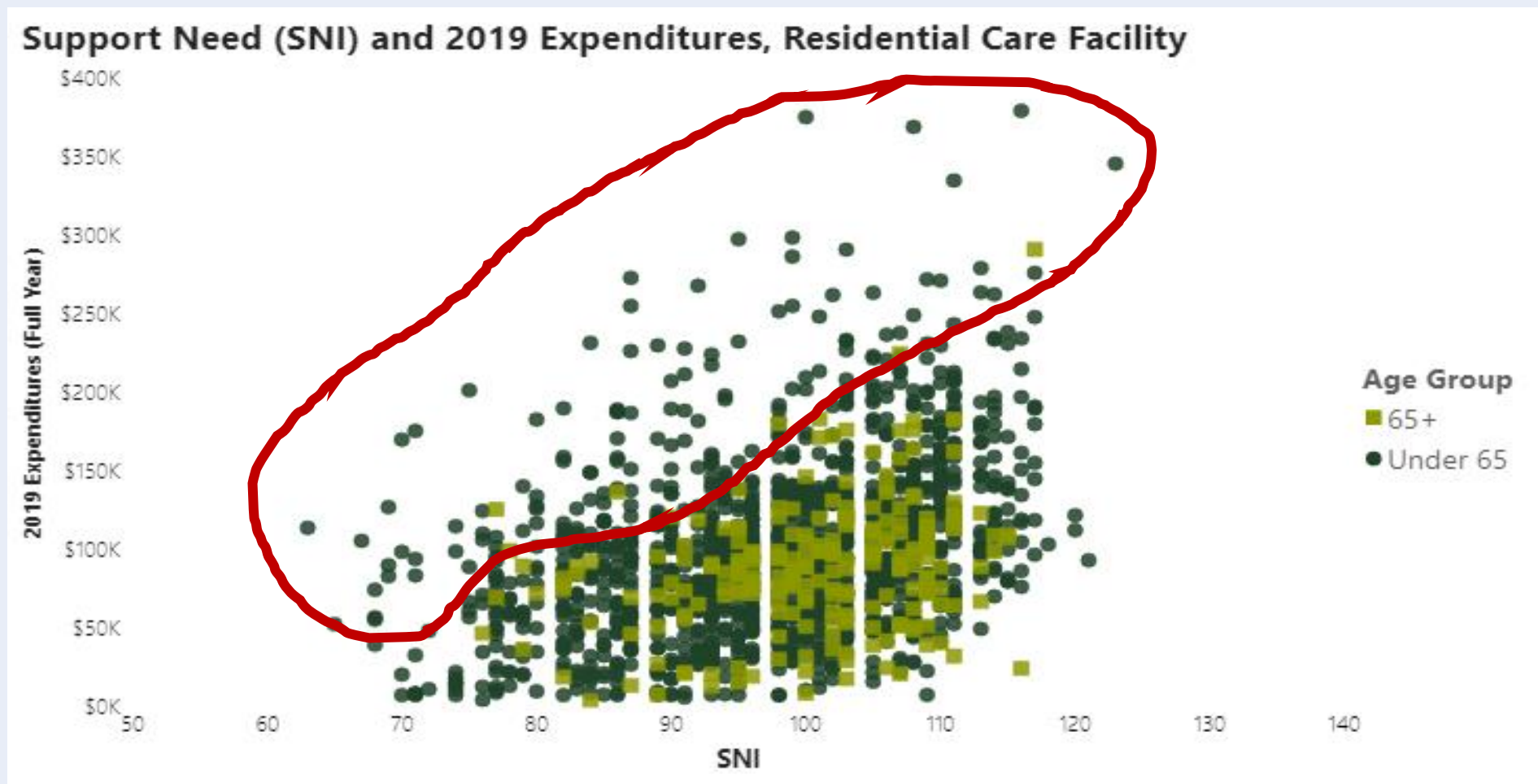
Participants without Extraordinary Medical and Behavioral Needs in Residential Care Facilities



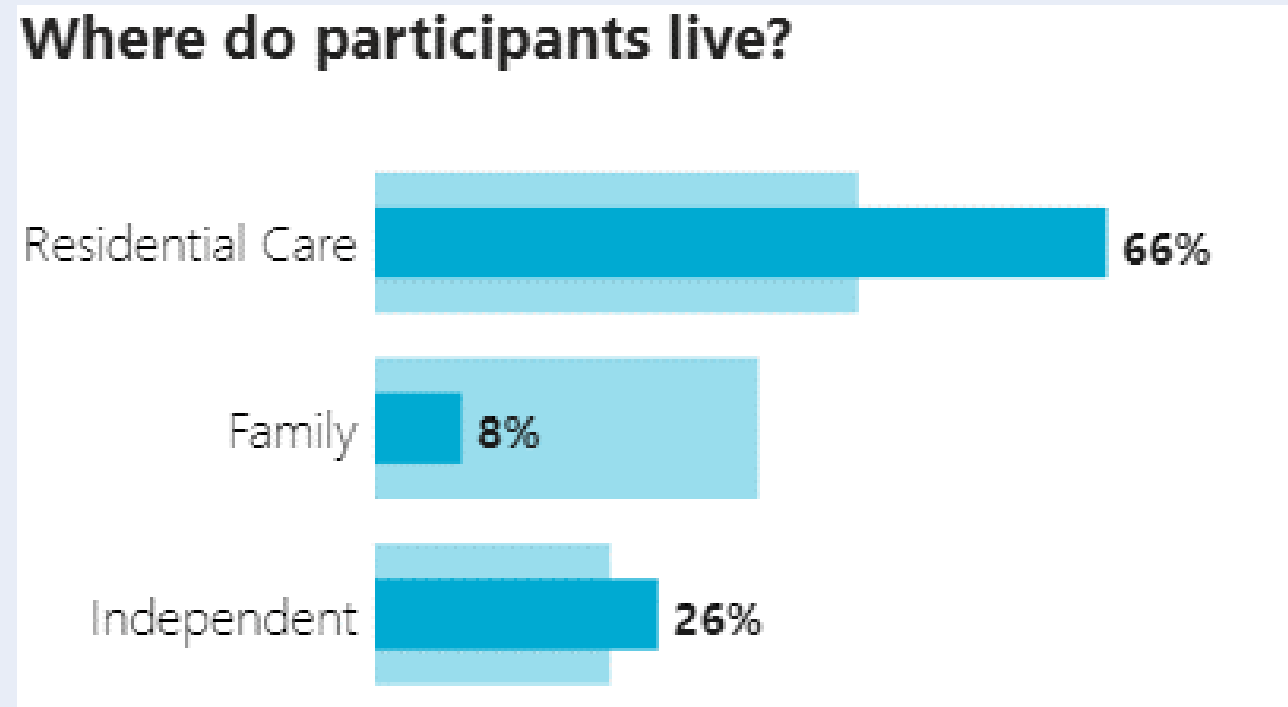
Age Breakdown of Participants without Extraordinary Medical and Behavioral Needs in Residential Care Facilities



Age Breakdown of Participants without Extraordinary Medical and Behavioral Needs in Residential Care Facilities



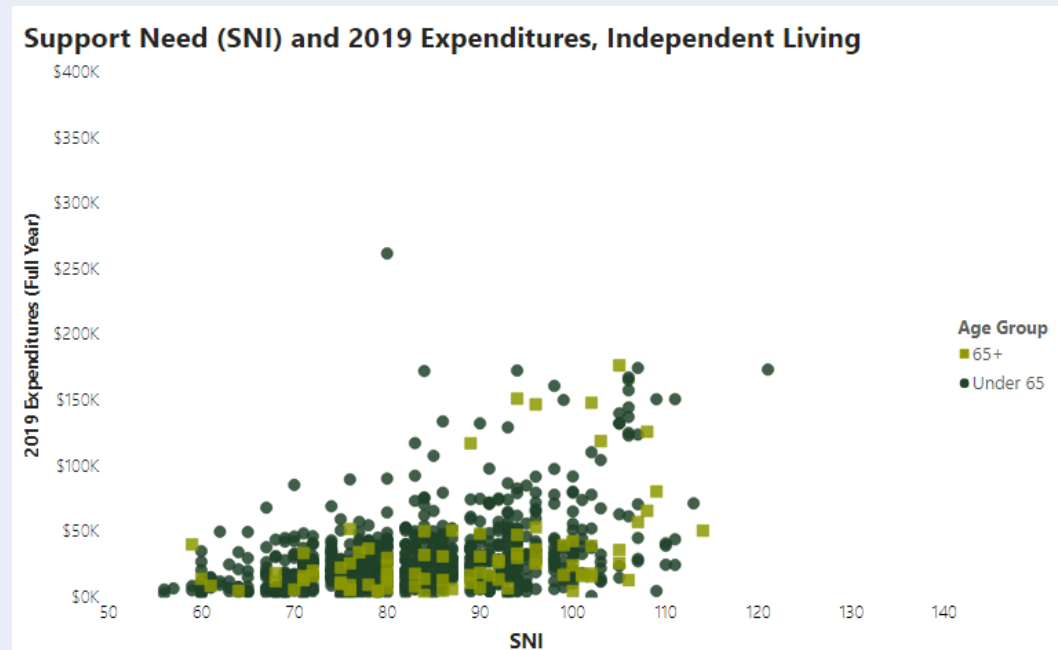
Sticking to the same story, we also noticed a potentially interesting fact: unlike the rest of the population, if a person over the age of 65 doesn't live in a residential care facility, they are likely to be living independently.



Adding it all together – Independent Living

Participants with full year of expenditures and completed SIS assessment in Independent Living (n = 914)

	n	Avg. SNI	Avg Medical Score	Avg. Behavioral Score	Median Spend
Under 65	827	83.43	0.84	3.00	\$22,370.85
65 +	87	87.33	1.57	1.42	\$16,748.77



What's the story?

SPOILER: We're not going to get to the bottom of it in 20 minutes.

TAKEAWAY: The Supports Intensity Scale provides policymakers with essential information that, when combined with other data sources, can help drive systems change.

When your full service population is assessed with the Supports Intensity Scale and these data are combined with other information, you can answer questions like:

- Am I allocating scarce resources fairly according to support need?
- Are the support needs of individuals living in residential settings in my jurisdiction similar, regardless of age or other demographic factors?
- Is my service system set up to meet the needs of the diversity represented in these data?

The problem isn't a lack of data

(Well, sometimes it is)

What do we need to do to answer the question?

The question was: **Are we allocating Medicaid LTSS funds appropriately?**

Context

- What background information is relevant or essential?
- What data are available?
- Who is the decision maker?
- What would a successful outcome look like?

Standards

- Data sourcing
- Rigorous filtering and transformation process
- Properly formatted physical structure
- Metadata
- Security and Privacy
- Usability

Technology

- Real-time visibility
- Always on
- Delivered *as a service*
- Business intelligence tools

Common Challenges



Multiple Sectors

Public health and social services issues span multiple sectors, and no single entity can claim the necessary expertise, authority, or resources to bring change



Governance

Functional and regulatory requirements of multiple programs are challenging for a single system to support



Siloed Data

Application portfolios reflect the evolution and development of programs and systems



Scarce Information

Though they may support operational, fiscal, and regulatory requirements, data systems can fall short in supporting day-to-day informational needs



Scarce Analytics

Program-centric emphasis of data systems makes it difficult to gain insights for policy-level decision-making

What data are available?



Case Management System



Houses data for case managers to keep track of information about the people they work with.



Medicaid Management Information System



Claims processing and information retrieval system that controls Medicaid business functions, including management reporting.



Assessment Data System



Database application that supports administering, scoring, and retrieving assessment data.



Unorganized Data



Relevant data from other sources, kept either formally or informally. Typically not housed in any structured database or file system.

Different **operational uses**

Different **vendors**

Different **formats** and **layouts**

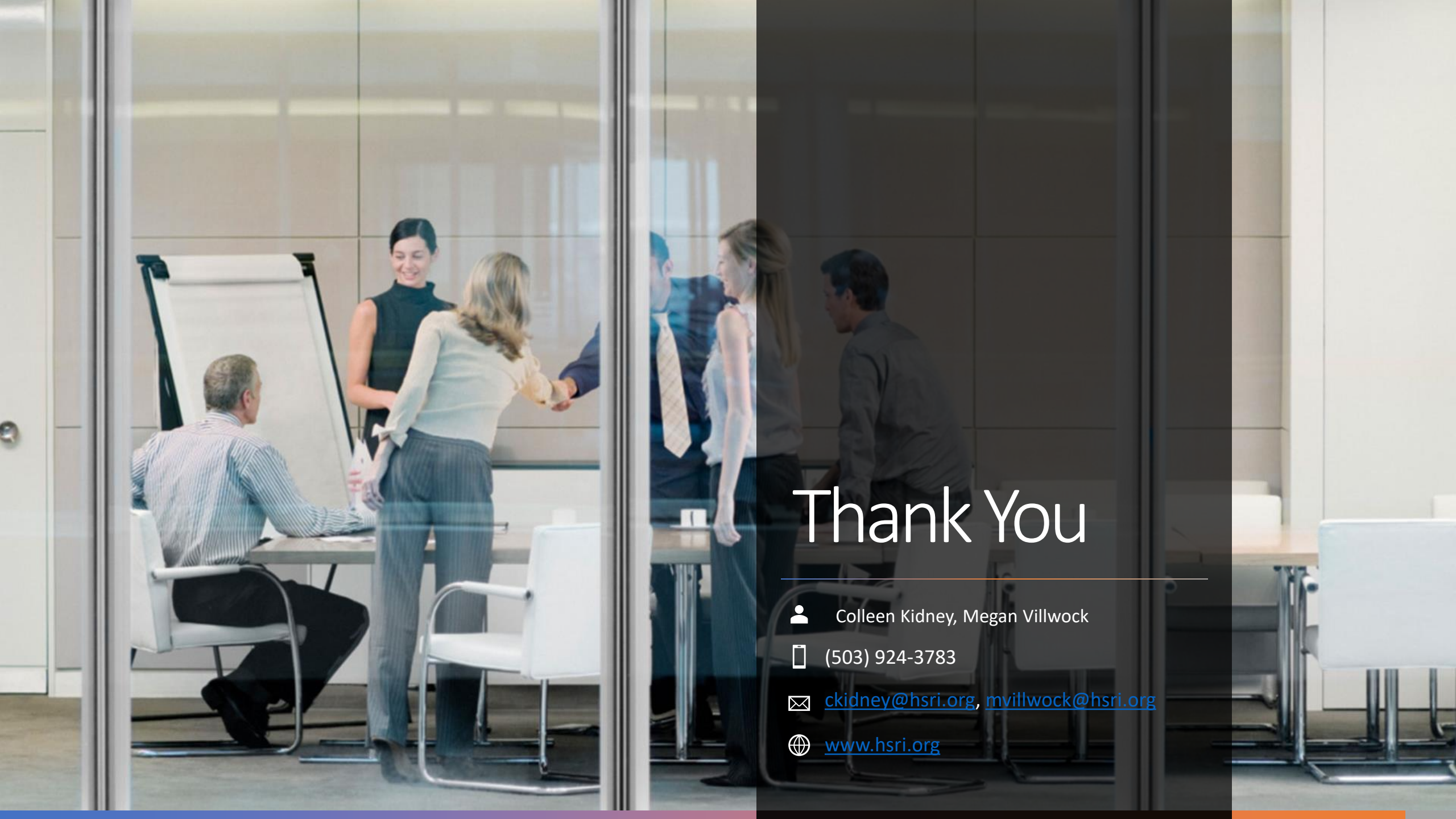
Different **definitions**

Different (or no) **standards**


Lessons Learned


How to not end up with a bunch of assessments you can't use


- Make sure everyone knows WHY you are doing assessment
- Make sure you take assessment seriously
- Make – and test! - your data integration plan BEFORE you start collecting assessments
- Technology is your friend





Thank You

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A photograph of two toucans perched on a dry, horizontal branch against a clear blue sky. The toucan on the left is facing right, and the one on the right is facing left. A speech bubble originates from the toucan on the right, containing the text 'Would you please explain your explanation?'.

Would you please
explain your
explanation?

Any Questions?