Standardized In-Home Respite Tool

August 26, 2026

DDS Department of Developmental Services

Photo by Chona Kasinger, from Disabled and Here

HOUSEKEEPING (Webinar)

Interpretación en español: haga clic en el globo blanco en la parte inferior de la pantalla con la etiqueta "Interpretation." Luego haga clic en “Spanish” y seleccione "Mute original audio.”
이 회의를 한국어로 듣기 위해서는 화면 하단에 있는
'해석'이라는 라벨이 붙은 흰색 구슬을 클릭하세요. 그런 다음 '한국어'를 클릭하고
'원음 음소거'를 선택하세요.

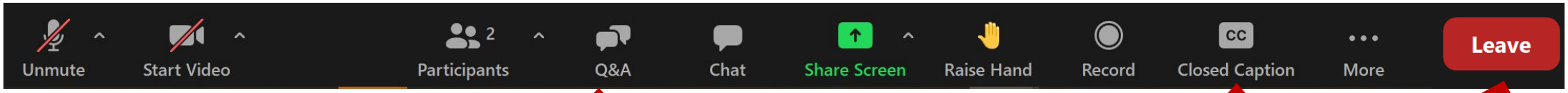
ASL interpreters have been “Spotlighted”, and Zoom's live closed captioning is active

This meeting is being recorded

Materials will be available online after the webinar.

Submit written suggestions and comments by completing the Microsoft Forms and/or emailing respite@dds.ca.gov

ZOOM TIPS



Attendees can type questions/ comments in the Q&A for everyone to see and/or upvote

Closed Caption feature is available.

Leave the webinar at the end of the meeting.

- For attendees, your video and microphone will not be available.
- You will only see and hear presenters on screen.
- Closed Caption feature is available.
- Features will vary based on the version of Zoom and device you are using.
- Some Zoom features are not available for telephone-only participants.

Welcome & Introductions

AGENDA

- Background
- In-Home Respite Tool
- Using the Tool
- Next Steps

Background

WHAT IS RESPITE?

Intermittent or scheduled non-medical care

Provided in the individual's home

Designed to

- Give caregivers a break
- Promote safety
- Maintain routines
- Support self-help and socialization

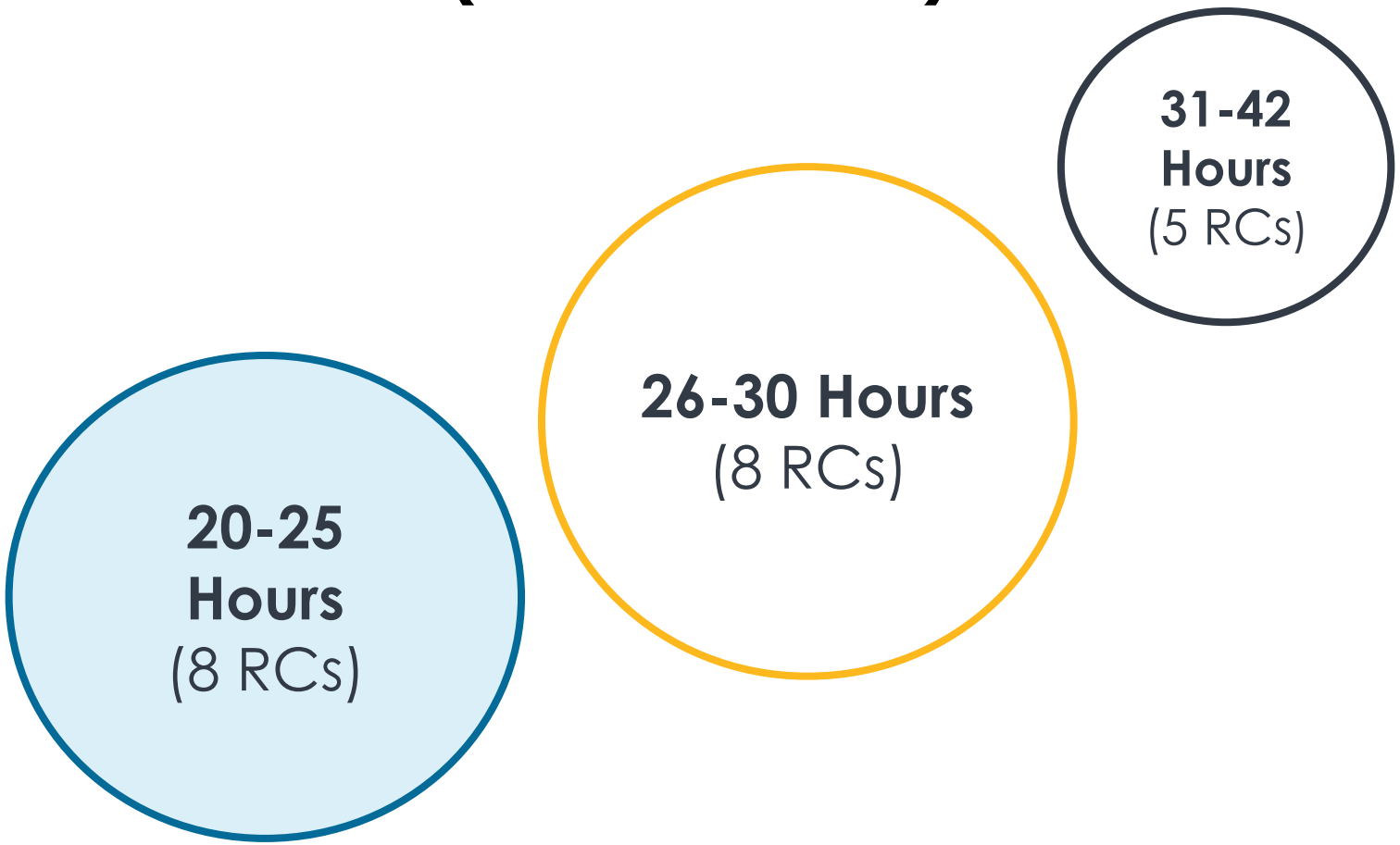
WHY CREATE AN IN-HOME RESPITE TOOL?

- Share with families the questions that will be used to identify the need for respite, creating a transparent process in all regional centers.
- Establish a consistent method to determine the number of respite hours recommended based on the needs of the individual under service codes 310, 420, 465, and 862.
- WIC 4435.1(c) requires the use of a standardized tool to assess the need for respite. This requirement is designed to promote statewide uniformity, consistency, and equity in regional center practices.

VARIATION IN AUTHORIZATIONS

Median Authorized Respite Hours FY 25-26 for

Children (17 and Under)

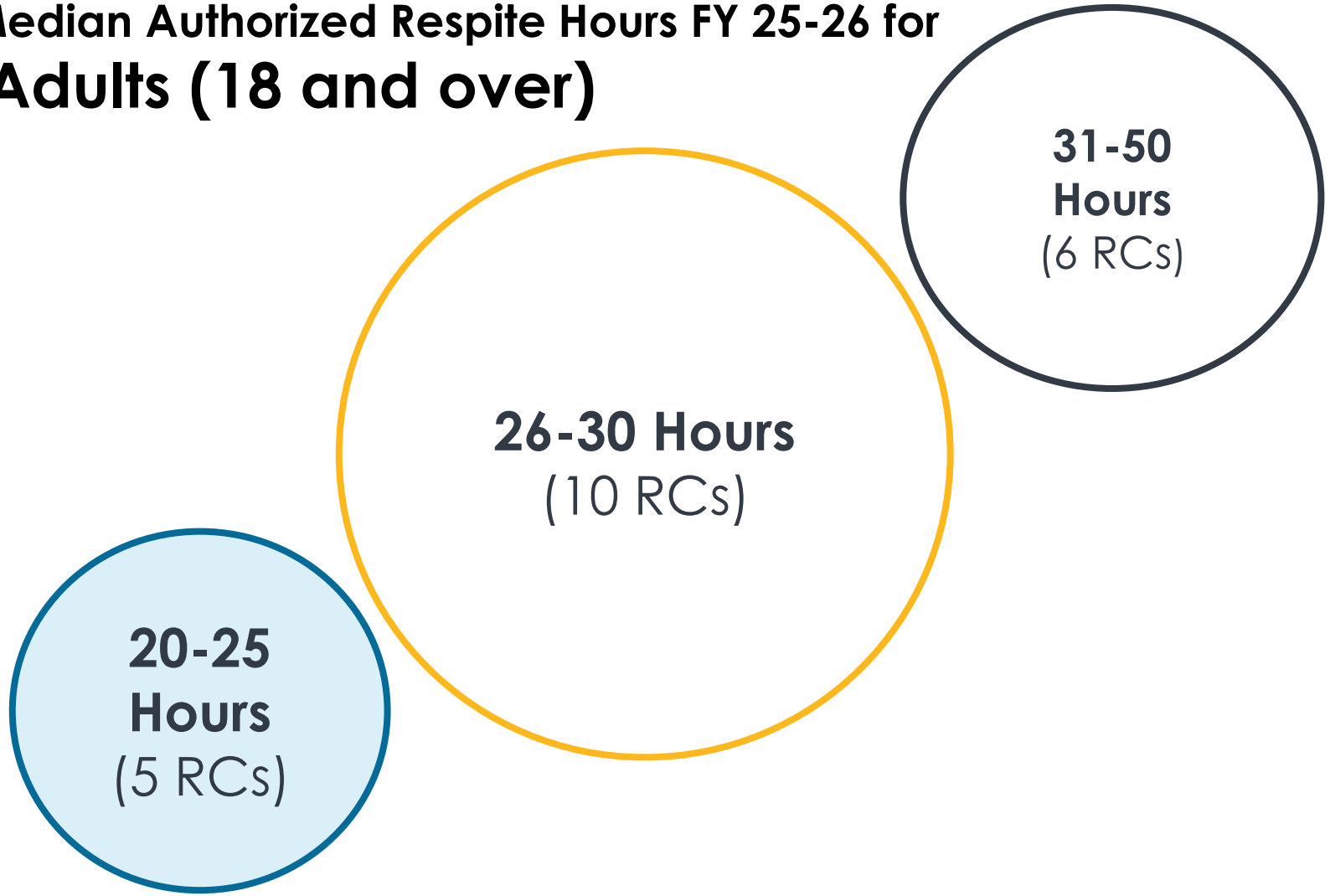


- This shows the range of hours authorized for CHILDREN in all the regional centers.
- Looking at the middle (median) of all respite hours, some regional centers were the same.
- The **median** means about half of all the authorizations are higher, and half are lower.

VARIATION IN AUTHORIZATIONS

Median Authorized Respite Hours FY 25-26 for

Adults (18 and over)



- This shows the range of hours authorized for ADULTS in all the regional centers.
- Looking at the middle (median) of all respite hours, some regional centers were the same.
- The **median** means about half of all the authorizations are higher, and half are lower.

In-Home Respite Tool

FIRST DRAFT

- Review of existing Regional Center tools
- Modified an existing tool
- Families and service coordinators used the draft tool and gave feedback
- The Department shared the tool with community for public comment
- Received 852 comments

HOW DID FEEDBACK SHAPE THE TOOL?

Based on comments, changes were made to the tool

- Used more plain language
- Changed the example stories
- Shortened the tool
- Removed questions that the community did not favor (e.g., race, ethnicity, language, and natural supports)
- Simplified questions and response options

What resulted is a revised tool requiring new data collection

SHORTENED THE TOOL

Changes Made:

- Consolidated sections of the tool
- Consolidated similar questions
- Reduced headings
- Reduced the number of pages

Example:

Reduced and consolidated this section to only include:

- Caregiver Stress
- Caregiver Circumstances
- Family Circumstances
- Additional Dependents

5 - Special Circumstances

Please answer these questions about any special circumstances and/or changes in your family in the past year only. Choose all that apply. Special Circumstances cannot score higher than 15.

Caregiver Stress:

☐ I/we (parent/caregiver) am experiencing stress due to changes in my job schedule, my availability to provide care, or other caregiver duties (e.g., I am caring for an aging parent/family member or I have other children with disabilities in the home)

☐ I am the only caregiver available to provide most care (e.g., single parent)

☐ N/A

Family Changes:

☐ I/we have added new family members (we had a baby, are fostering, or have adopted).

☐ I/we have had significant life events (we recently moved, we recently lost our home).

☐ I am often acting as a single parent (my partner is deployed, my partner has a job with extended travel).

☐ The individual has recently lost a caregiver.

☐ N/A

Caregiver Needs:

☐ My/our health is getting worse.

☐ I/we recently had new medical/mental health needs.

☐ I/we have difficulty providing care because I and/or my partner have/has developmental disabilities.

☐ I/we have difficulty providing care due to my/our age (65 or older).

☐ N/A

Needs of the individual:

☐ The individual's health is getting worse.

☐ The individual recently has new medical/mental health needs or personal care requirements.

☐ The individual currently has increased support or personal care needs due to having experienced trauma.

☐ N/A

Additional dependents age 17 or younger that reside in the home (select one)

☐ 1 sibling

☐ 2 siblings

☐ 3 siblings

☐ 4 or more siblings

N/A

REMOVED NON-FAVORED QUESTIONS

Changes Made:

Removed questions that the community did not favor (e.g., race, ethnicity, language, and natural supports)

Example:

Removed this section from the first draft

2 - Resources & Supports
Individuals should have natural supports and use local and community resources *before* using regional center services (see Welfare and Institution Codes Sections 4512, 4648, 4659, and 4644).
Natural supports are unpaid relationships and connections with people in the community. These relationships improve people's lives and include, but are not limited to family, friends from diverse backgrounds, classmates, coworkers, neighbors, and people met through clubs, organizations, and community activities. Generic resources are services or supports offered by agencies that must serve everyone and are funded by public money. Please list all natural supports and generic resources used now by the individual/family (e.g., IHSS, personal assistance or respite through private insurance, generic day care [Regional Centers may list specific resources].

REMOVED

SIMPLIFIED QUESTIONS AND ANSWER OPTIONS

Changes made:

Reduced complexity in questions

Previous communication question focused on whether communication is understood.

Communication: The extent to which the individual can communicate, whether by talking, using sign language, or other methods as it impacts the level of supervision or care they need.	☐ Communication is understood by others, and the individual can effectively get their needs met across settings (e.g., at home and in the community/school). ☐ Communication is not always understood by other and it creates difficulty in getting needs met across some settings. (e.g., home versus community/school). ☐ Communication is not always understood by others, and it creates difficulty in getting needs met across most settings. ☐ Communication is rarely understood by others, and it creates significant difficulty in getting needs met across most settings. ☐ Individual does not have a reliable form of communication and needs full support to communicate across all settings.

The current question focuses on how much support is needed for communication.

Communication: The extent to which the individual requires support with expressive or receptive communication.	○ Does not require support or is independent with communication or rarely needs support. ○ Sometimes requires support with communication. ○ Frequently requires support with communication. ○ Does not have a reliable form of communication and always needs support with communication.

CONSISTENT ANSWER OPTIONS

The community suggested consistent answer options.

Example:

Inconsistent answer options between sections in the first draft

Mobility: Ability to walk or need for wheelchair(s), walker, assistance, or total care for transferring or positioning, as it impacts the level of supervision or care they need.	☐ Independent with **no** equipment at home or in the community with minimal care needs. ☐ Independent with equipment at home or in the community with minimal care needs. ☐ Independent with equipment or chair(s) at home or in the community with moderate care needs. ☐ Not independently mobile with equipment or chair(s) at home or in the community or requires constant support. ☐ Not mobile, requires total care and lifting/repositioning regularly.
Social Needs: The amount the individual socially interacts with others as it impacts the level of supervision or care they need.	☐ N/A Does not often interact with others due to being medically fragile. ☐ Interacts well with others. ☐ Parent(s)/caregiver(s)/supporters provide consistent support to help individual engage with others. ☐ Difficulty interacting with others even with support and needs close supervision. ☐ Requires constant supervision for health and safety of self and/or others due to aggression towards others and/or medical fragility.

CONSISTENT ANSWER OPTIONS

Changes made:
The second draft created consistent answer options

Mobility: The extent to which the individual requires mobility support or support to use mobility equipment (e.g., wheelchair, walker, cane).	○ Does not require support or is independent with mobility equipment or individual is under the age of 3. ○ Sometimes requires support with equipment or mobility. ○ Frequently requires support with equipment or mobility. ○ Always requires support with equipment or mobility. ○ Not mobile, requires full support with mobility and lifting/repositioning multiple times a day.
Social Needs: The extent to which the individual requires support with social interaction.	○ Is independent or does not need support to interact with others. ○ Sometimes requires support to interact with others. ○ Frequently requires support to interact with others and needs close supervision. ○ Always requires support and supervision to interact with others due to health needs or safety of self and/or others.

MORE PLAIN LANGUAGE

The community felt the first draft was too complicated

Respite

Respite is a family support service for an individual and their family/caregiver that helps the family live together in the community. Respite offers care and supervision regularly or only when needed. Respite does the following: "(1) Assist family members in maintaining the individual at home; (2) Provide appropriate care and supervision to ensure the individual's safety in the absence of family members; (3) Relieve the family members from the constantly demanding responsibility of caring for the individual, and (4) Attend to the individual's basic self-help needs and other activities of daily living including interaction, socialization, and continuation of usual daily routines which would ordinarily be performed by family members." Respite is not meant to cover all care needs.

Changes made:

The second draft includes a simplified, plain language definition

Respite is a family support service that helps individuals and their families or caregivers live together in the community. The purpose of respite is to:

1. Help families keep the individual at home.
2. Provide safe care and supervision when family members are away.
3. Give family members a break from the constant demands of caregiving.
4. Support the individual's daily needs, such as self-care, social activities, and routines usually handled by family members.

Respite staff provide care and supervision either on a regular schedule or as needed. Respite is not intended to meet all an individual's care needs.

The Revised Tool: Second Draft

SECOND DRAFT

21 regional centers used the second draft

3,380 families used the tool with their service coordinator

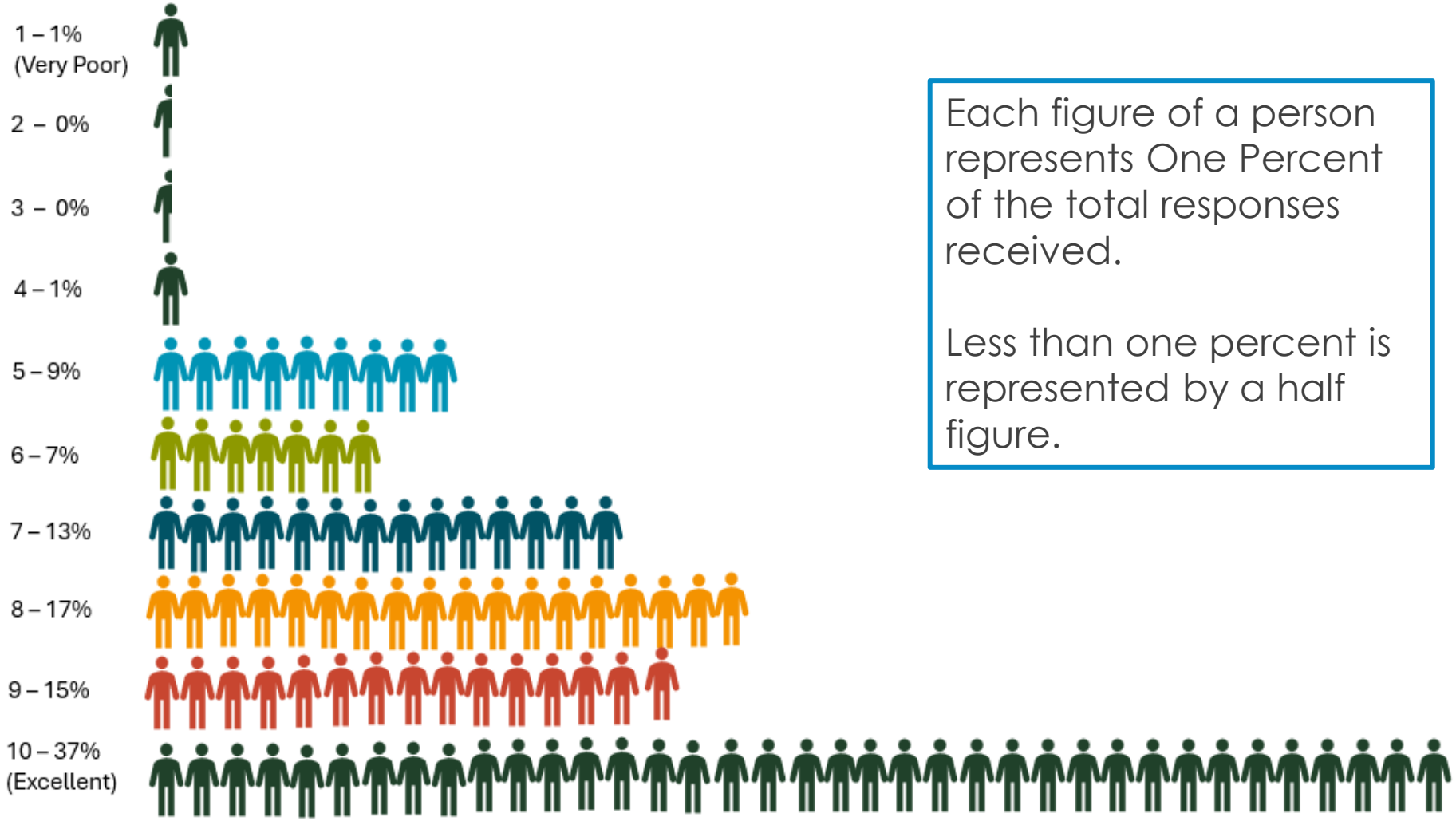
Families were asked to share their experience

Tool results were analyzed

WHAT DID FAMILIES THINK OF THE NEW TOOL?

On a scale of 1 (very poor) to 10 (excellent), how would you rate this process?

3,092 families rated their experience



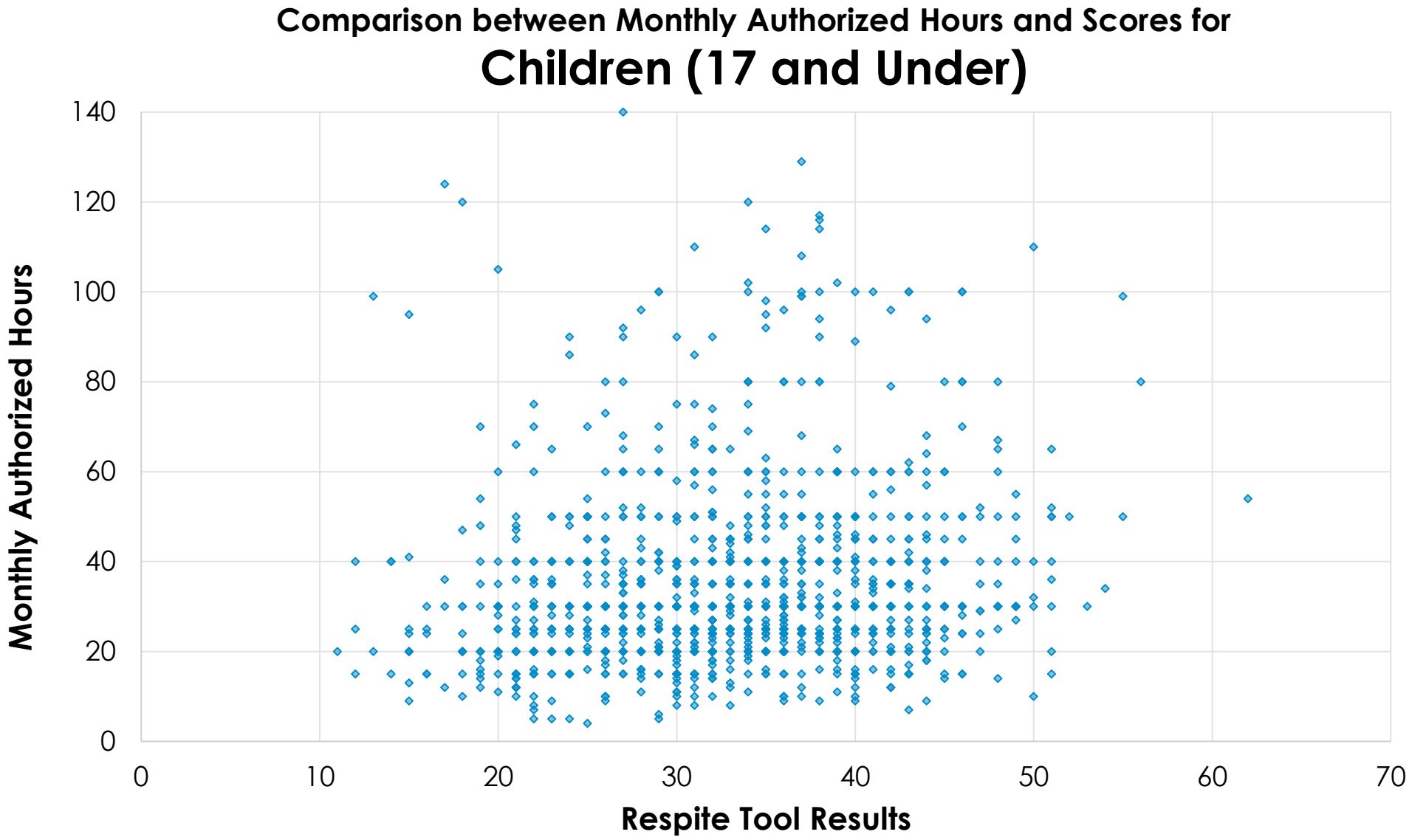
Each figure of a person represents One Percent of the total responses received.

Less than one percent is represented by a half figure.

ANALYZING THE RESULTS

- The information from the tools completed in every Regional Center was analyzed
- The respite tool results were used to develop a range of scores
- The score is needed so that there is a consistent way to recommend the level of need for the IPP Team to consider
- Scores were organized from highest to lowest levels of need. Scores ranged from a high of 70 to a low of 10.
- Individual tool results were compared to the number of respite hours currently authorized by the person's regional center
- Statewide results show gaps between a person's level of need and their current authorized hours.

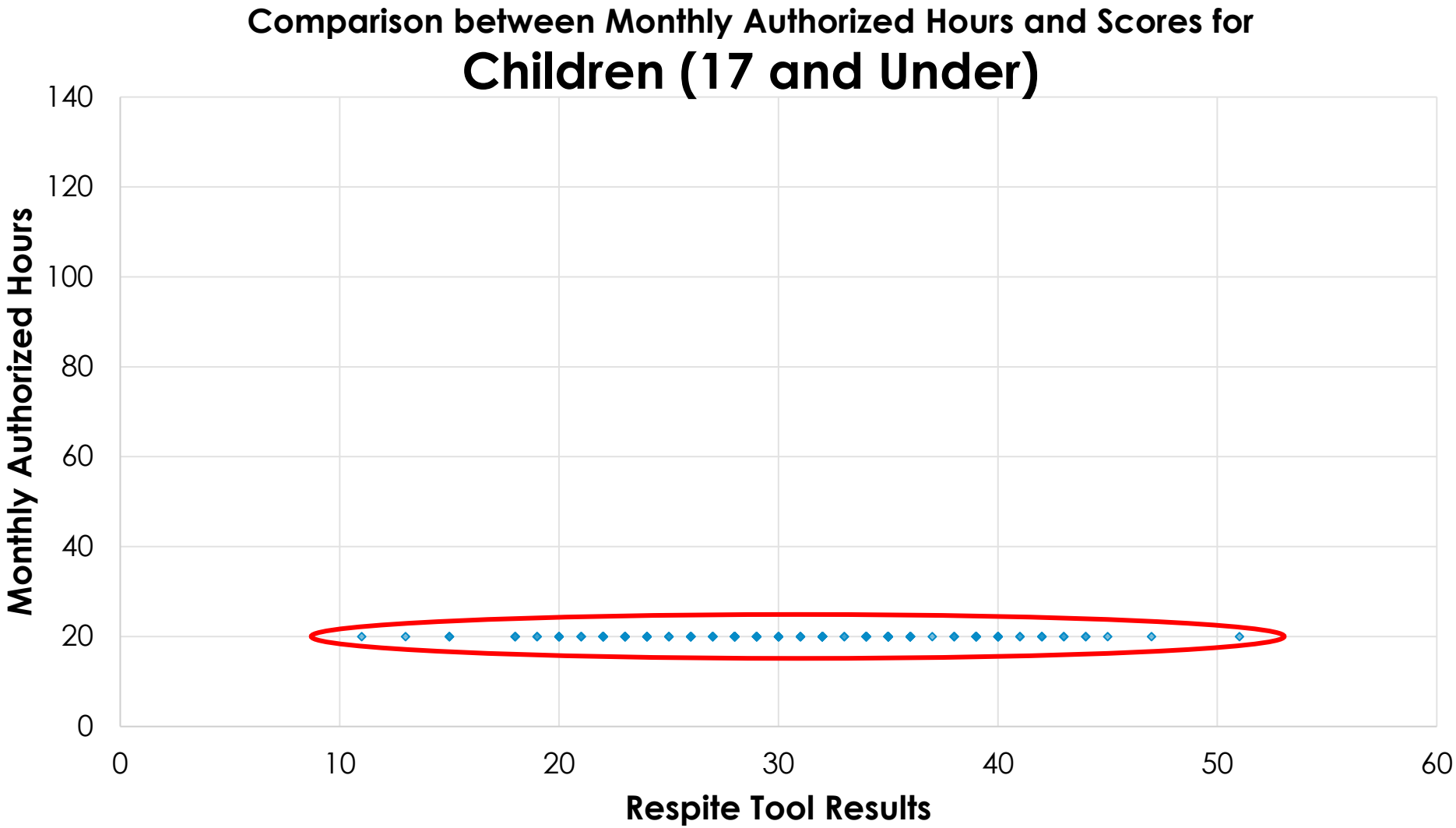
EXISTING AUTHORIZED HOURS AND RESPITE TOOL RESULTS



How the individual respite tool results compare to current authorized hours

Each dot represents one child whose family completed a tool with the Service Coordinator.

EXISTING AUTHORIZED HOURS AND RESPITE TOOL RESULTS

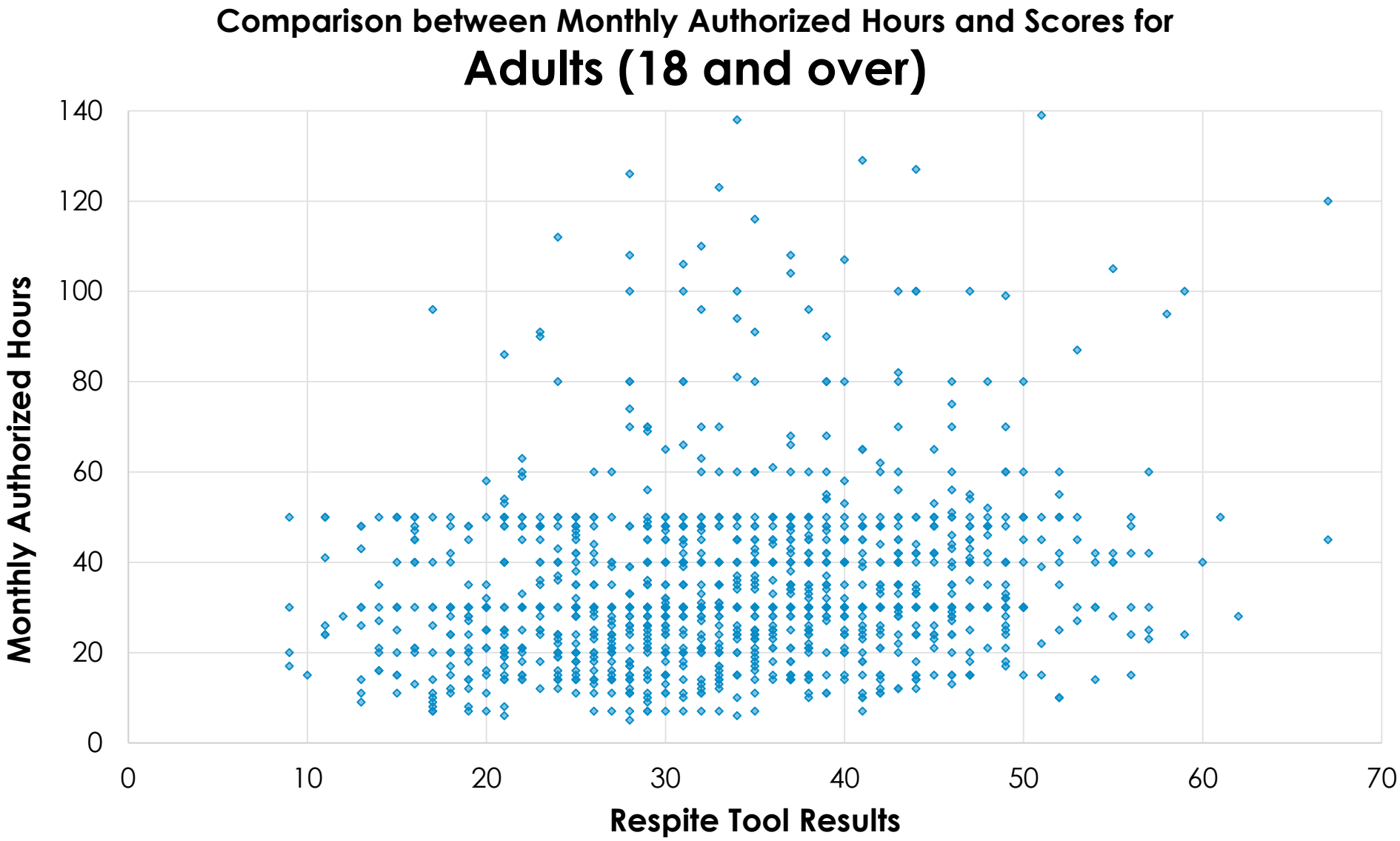


Each dot on this chart represents ONE child

This shows everyone who had 20 hours of respite authorized.

The level of need identified by the respite tool ranges from 11 to 51.

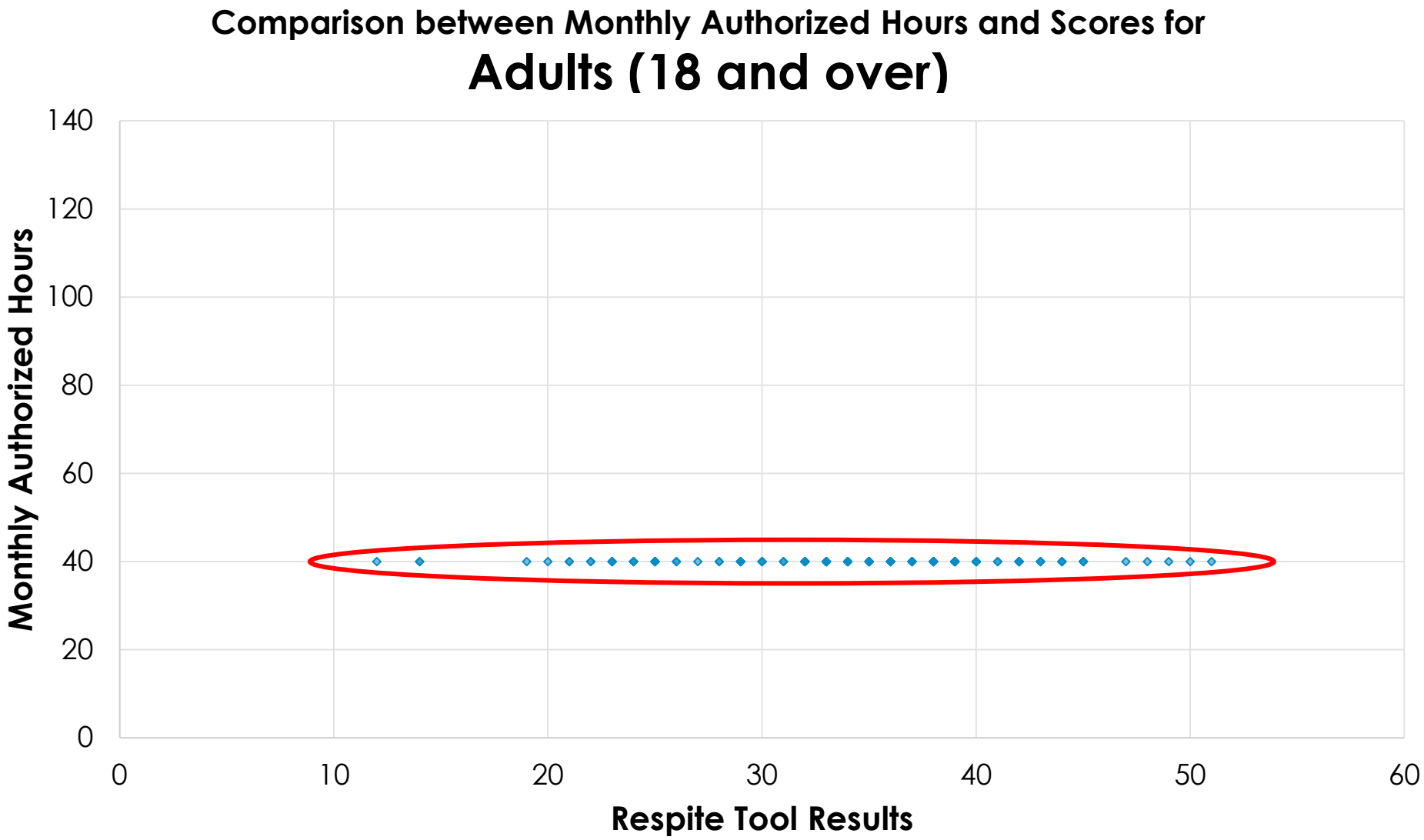
EXISTING AUTHORIZED HOURS AND RESPITE TOOL RESULTS



This shows everyone who completed a respite tool, for adults over age 18.

Each dot represents one adult whose family completed a tool with the Service Coordinator.

EXISTING AUTHORIZED HOURS AND RESPITE TOOL RESULTS



Each dot on this chart represents ONE adult

This shows everyone who had 40 hours of respite authorized.

The level of need identified by the respite tool ranges from 12 to 51.

What Does All of this Tell Us About Our Next Steps

NEXT STEPS

- Explore alternative services
- Develop a consistent respite definition and purpose
- Develop policy
- Develop training and materials for regional centers and families

Q&A

THANK YOU!

If you have any questions or suggestions regarding today's topic, please complete the Microsoft Form and/or email **respite@dds.ca.gov**.