

2023 Survey on the Human Rights Process at DBHDS Licensed and Operated Providers

Prepared by

The disAbility Law Center of Virginia

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INTRODUCTION

In 2023, the disAbility Law Center of Virginia (dLCV) worked together with the Department of Behavioral Health and Developmental Services' (DBHDS) Office of Human Rights (OHR) to survey service recipients and their families about their experiences with the available complaint processes.

The Human Rights Regulations, enshrined in Virginia Administrative Code 12VAC35, assures that each individual has comprehensive guaranteed rights¹, including the right to:

- Retain their legal rights as provided by state and federal law;
- Receive prompt evaluation and treatment;
- Be treated with dignity as a human being;
- Be free from abuse and neglect;
- Not be the subject of experimental or investigational research without prior informed consent;
- Be treated under the least restrictive conditions practicable;
- Not be subjected to unnecessary physical restraint or seclusion;
- Have visitors, send and receive mail, and make and receive phone calls;
- Have access to their medical records and be assured of their confidentiality;
- Have a say about their own treatment and participate in treatment planning;
- Participate in the Human Rights Complaint Process, including the right to have representation in this Process.

In order to ensure the above rights to individuals, DBHDS has regulations called the Human Rights Regulations to specify how these rights are to be guaranteed. The Human Rights Regulations afford individuals receiving services due process where their Complaints can be investigated. Additionally, individuals have the right to appeal any decision related to a Complaint or action plan by a provider through a Local Human Rights Committee (LHRC). The State Human Rights Committee (SHRC) is also available to hear Appeals from either the individual or provider after going through the LHRC fact-finding hearing.

Human Rights Advocates are employed by DBHDS to carry out the mission of OHR: to ensure compliance with the Human Rights Regulations by promoting the guarantee of human dignity, managing the DBHDS Human Rights Complaint resolution program, and advocating for the rights of persons with disabilities in our service delivery systems. While individual facilities may employ their own advocates, it is important for individuals to understand the difference between these facility-employed advocates and the actual Human Rights Advocates. Facility-employed advocates act as an arm of the facility-director and generally exist to resolve complaints. Human

¹ These rights are also largely restated in § 37.2-400 of the Code of Virginia

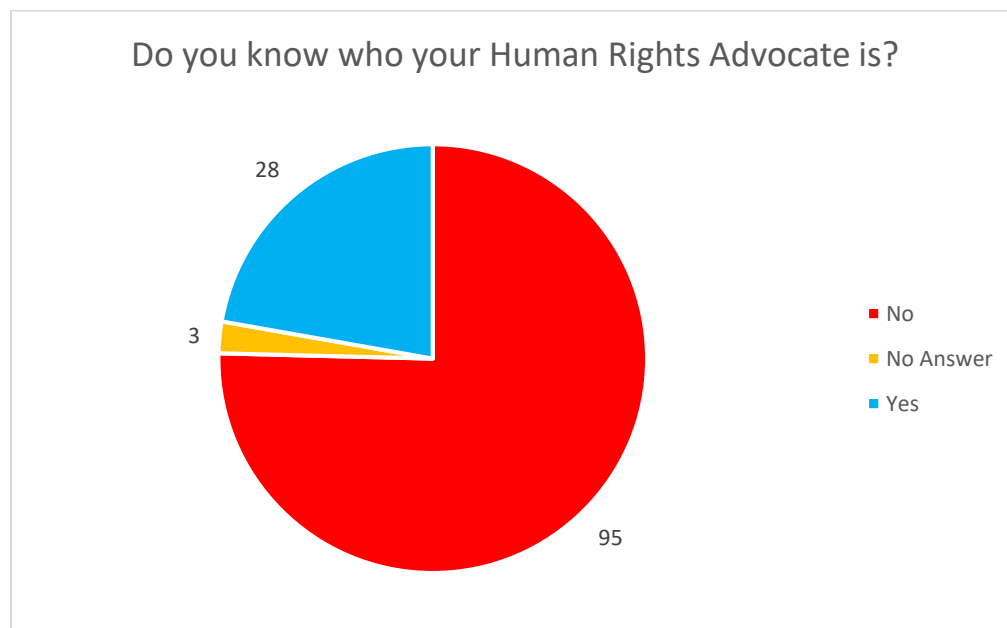
Rights Advocates assist individuals with the Human Rights Complaint Process, advise providers of their obligations, review incident reports concerning rights violations, and conduct Human Rights trainings for individuals and providers. Because Human Rights Advocates are employed by DBHDS and not individual providers, OHR Advocates are a somewhat more impartial party than a facility's internal advocate. This possible impartiality is critical to ensuring fairness and a sense of trust throughout the Human Rights Complaint Process

In total, 126 respondents completed dLCV's Human Rights Survey between January and May of 2023. Fifty-three of these surveys were completed with the assistance of dLCV staff during institutional and group home monitoring visits. Other surveys were completed with the assistance of Human Rights Advocates and by self-reporters who found the survey on the dLCV website or in the dLCV newsletter. The majority of respondents (99) were individuals receiving services, with only 27 surveys being completed by family members, guardians, or authorized representatives.

Respondents reported receiving a variety of DBHDS licensed and operated services, including:

- Day support programs (14 surveys)
- Adult group homes (13 surveys)
- Inpatient psychiatric hospitals (53 surveys)
- Children's psychiatric residential treatment facilities (PRTFs) (8 surveys)

“DO YOU KNOW WHO YOUR HUMAN RIGHTS ADVOCATE IS?”



One of the most shocking findings of this survey was that 95 out of the 126 surveyed (75%) did **not** know who their Human Rights Advocate was, despite the Human Rights Regulations explicitly stating:

12VAC35-115-40. Assurance of rights.

B. Individuals are entitled to know what their rights are under these regulations; therefore, providers shall take the following actions:

1. Display, in areas most likely to be noticed by the individual, a document listing the rights of individuals under these regulations and how individuals can contact a human rights advocate. The document shall be presented in the manner, format, and languages most frequently understood by the individual receiving services.

It is important that individuals know their Human Rights Advocate by name so they are able to contact them if an issue arises. Of the 28 respondents who said they knew who their Human Rights Advocate was, only 13 knew their Advocate by name. Notably, 5 individuals asserted that they did know their Advocate by name, but then proceeded to name either facility-employed patient advocates, former Advocates, or other individuals. Respondents receiving services in residential settings (like hospitals and group homes) were more likely to know who their Human Rights Advocate was and to be able to name them, compared to individuals receiving outpatient or in-home services. This makes sense, as residential settings are required to display posters with this information that residents see every day. Per the Human Rights Regulations, clients are all to be notified of their Advocate, their rights, and how to file a Complaint upon start of services.

If an individual experiences abuse, neglect, or another rights violation, it is critical that they be able to get in contact with the Advocate in a timely manner. Abuse, neglect, and rights violations should not be allowed to persist because of confusion as to who to go to. If individuals don't know who their Advocate is, abuse and neglect may be under reported or not reported at all. Furthermore, OHR's oversight and review processes are only as good as the data they are receiving. If incidents go unreported, oversight agencies cannot be as effective in drawing conclusions about the service system.

“HOW DO YOU GET IN TOUCH WITH THE ADVOCATE?”

When asked how to get in touch with their Advocate, only 38 respondents (30%) stated they knew how to get in touch with their Advocate by phone, email, mail, or in person. Respondents were asked to share barriers they faced when contacting their Advocate. Some cited barriers included:

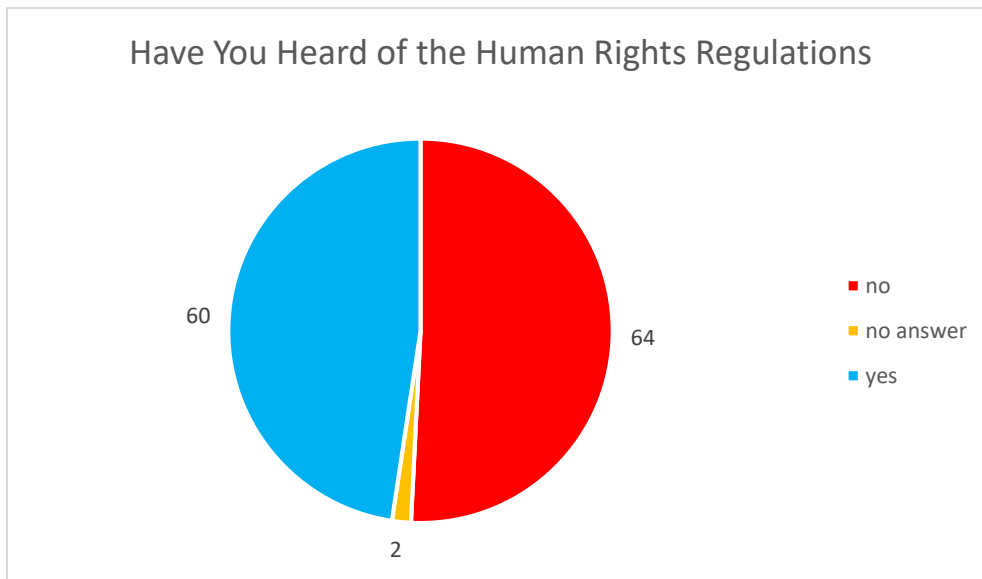
- Individual needed an ASL interpreter (1 respondent)
- Worried about retaliation (7 respondents)

- Reached out to the Advocate but received no response (9 respondents)
- Reached out to the Advocate and denied assistance (1 respondent)
- Program staff refused to connect individuals to their Advocate (1 respondent)
- Incorrect contact information for the Advocate (4 respondents)

The number of respondents who reported that they had attempted to contact an advocate is too narrow to draw definitive conclusions about their responses, but dLCV is concerned with the responses we received. We believe that the relatively high number of individuals who reported that they reached out to an Advocate and received no response may be reflective of both out-of-date signage and an Advocate staff that is extremely over-tasked (as we will discuss on page 10).

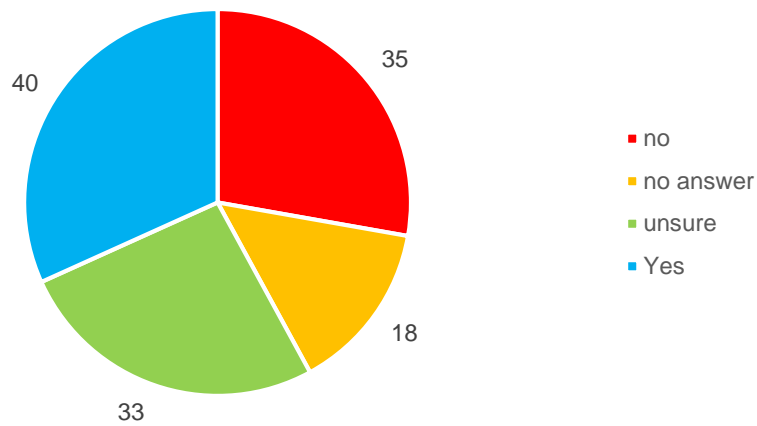
“HAVE YOU HEARD OF THE HUMAN RIGHTS REGULATIONS?”

The survey asked if respondents had ever heard of the Human Rights Regulations. Sixty respondents (47%) said they had, while 64 (50%) said they had not. Of the respondents who had heard of the Regulations, only 21 of them (46%) asked for a copy of the Regulations and, of those who asked, 67% received a copy.



We asked respondents if they knew what their rights were, and only 40 of the 126 respondents said yes—a mere 31%. It is a tremendous concern that most individuals state that they do not know what their rights are, considering that the Regulations require providers to educate individuals on this, specifically. Individuals cannot enforce their rights or report a provider if they do not know what their rights are. This lack of knowledge can lead to under-reporting, and offers undue protection to abusive or neglectful providers.

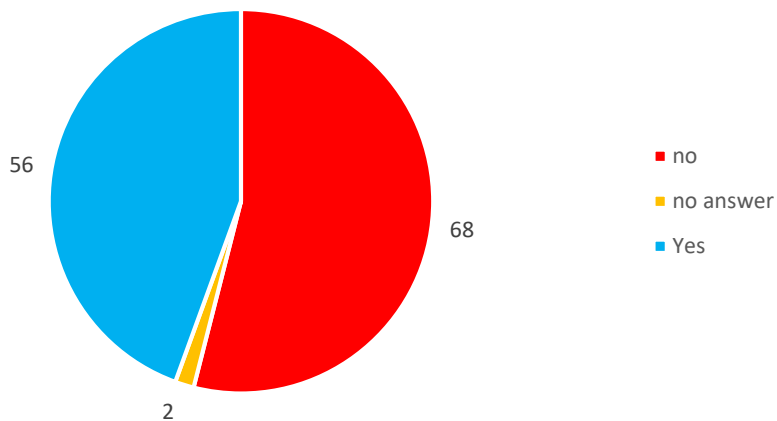
Do You Know What Your Rights Are?



ON FILING A COMPLAINT

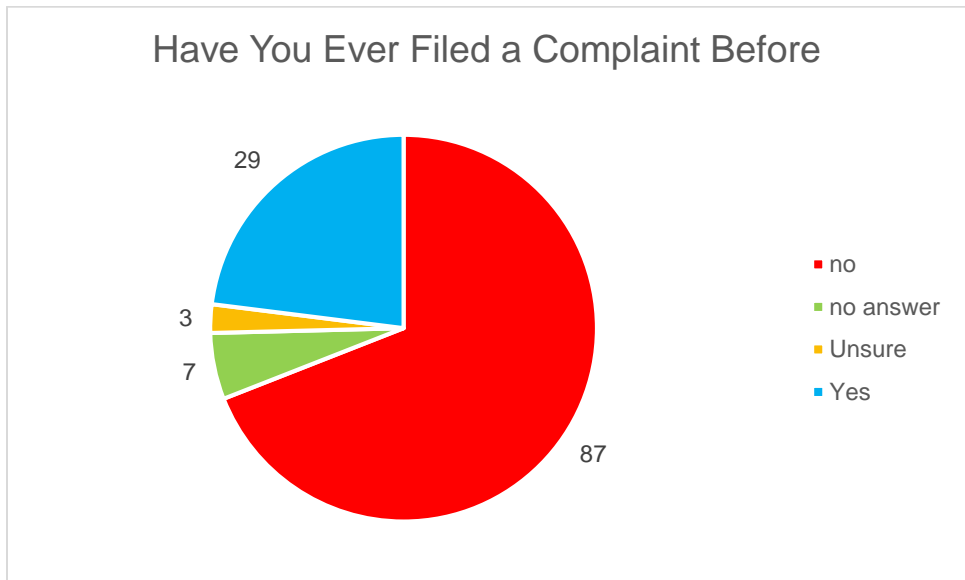
More respondents claimed that they knew how to file a Human Rights Complaint (56, 44%) than said they knew what their rights were (40, 32%) or who their Advocate was (28, 22%). While we are glad that relatively many respondents said they understood how to file a Complaint, our follow up questions reveal that individuals may not understand the Complaint Process as well as they think they do. For instance, only 38 respondents (30%) knew that they could enlist help and have someone file a Complaint on their behalf.

Do You Know How to File a Complaint?



Also, it is clear that most individuals have not used the Human Rights Complaint Process before. Sixty-nine percent of all those surveyed said they have not filed a Human Rights

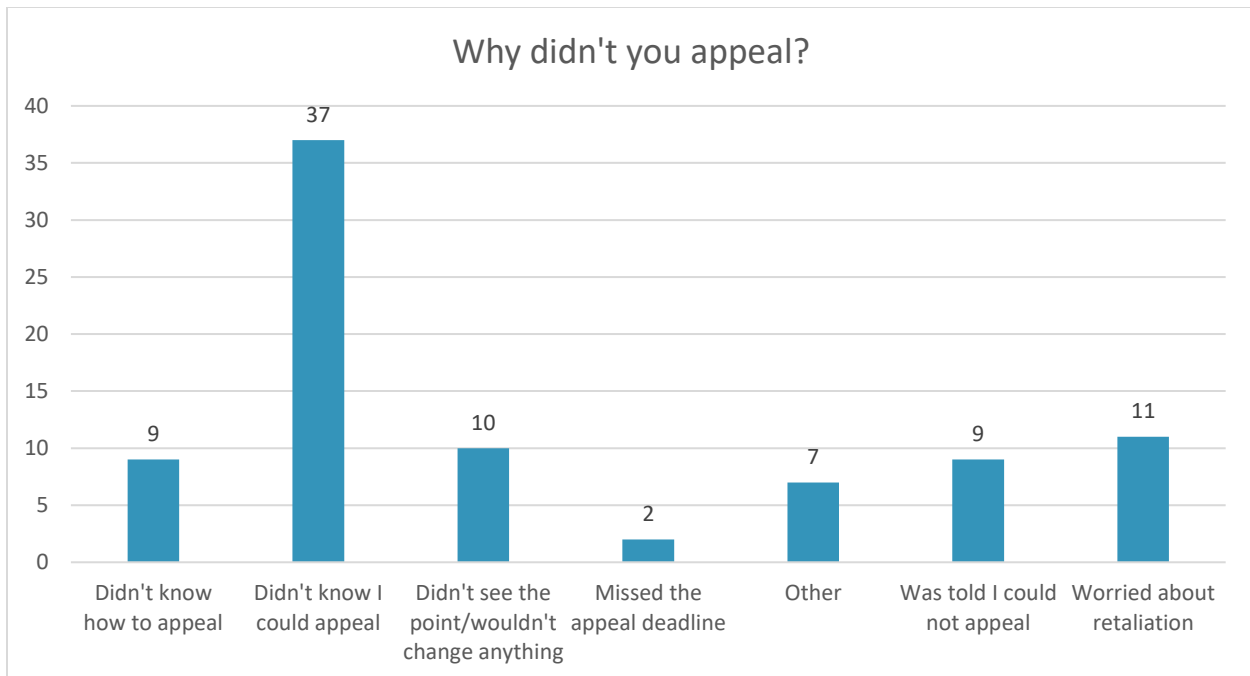
Complaint before. While we hope that they have not needed to use the Complaint Process because they have not experienced a Rights violation, the fact that so few respondents know and understand their rights casts doubt on this.



Furthermore, most of the respondents who did report filing Complaints appear to have experienced difficulties with the Process. Of the 29 respondents who said they have filed a Complaint before, only 4 people (14%) received a response within 24 hours, as is required by the Human Rights Regulations. The Appeals Process appears to also be inaccessible for many individuals. Eighty-eight out of 126 respondents (69%) said that they did not know how to file an Appeal; of the 13 respondents who *did* know how to file an Appeal, only 5 respondents stated that they had done so.

Respondents gave a variety of reasons as to why they did not appeal, with the most common² reason being that they did not know they could appeal (37 respondents). Eleven respondents said that did not appeal, in part because they were afraid of retaliation; we believe this underscores the need for an impartial Human Rights Advocate to guide individuals through the Complaint Process, rather than relying on facility-employed advocates for assistance. The responses to this question—including “I didn’t see the point” (10) and “I was told I couldn’t appeal” (9)—suggest a general attitude of resignation among our respondents. Most did not understand the Process and those that did often did not trust it.

² Respondents were allowed to give multiple reasons, so categories are not mutually exclusive.



We asked respondents if they participated in a hearing through the LHRC. Only three said yes and none of these individuals reported a result in their favor. None reported appealing these findings to the SHRC.

OTHER COMMENTARY

Respondents were asked to share any other thoughts about the Office of Human Rights and Complaint Process. Their responses largely spoke to the difficulties in making their complaints heard, especially at facilities without a strong, onsite Advocate presence. Many, especially those in inpatient hospital settings, were scared to speak up because they were afraid they would be punished, silenced, or chemically restrained. Other responses from inpatient settings included:

- “It feels like everything is punishment based.”
- “Every time that I had appealed something, I was told that my complaint was either not valid, they were not gonna [sic] do or say anything to the staff or they tell me that the [decision] stands.”
- “The HR [Human Rights] process doesn't work because the [facility] controls the process.”
- “New administration has caused problems and discrepancies with privileges.”
- “This facility does not have due process when a resident break[s] [a] facility rule. There is no pre-disciplinary hearing [...]”
- “[Staff] wants to put [me] in seclusion and restraint any time [I] argue [...] Doctor claims he is allowed to give medication against [my] will.”
- “DBHDS staff are not as accessible as they have been in the past.”

On a positive note, two respondents did report that they were usually or always able to get in touch with the patient advocate, though they did not clarify whether they mean the Human Rights Advocate or the facility-employed patient advocate.

DATA FROM DBHDS

DBHDS OHR has implemented processes in recent years to better evaluate the quality of their services, though some of these evaluations reached different conclusions than dLCV's survey. Most recently, in September 2023, DBHDS released their 2022 State Human Rights Committee Annual Report. This report detailed the activities and accomplishments of the SHRC and OHR. The report was intended to inform citizens about the protection of the Human Rights of individuals receiving services and the contribution of citizens who make up the SHRC to assure those rights. The report contained statistical information regarding alleged Human Rights violations reported through DBHDS' CHRIS (Computerized Human Rights Information System) incident and allegation reporting system³.

Though our survey demonstrated that most individuals do not fully understand their rights and may not know how to connect with an Advocate, OHR fielded a tremendous number of Complaints between July 1, 2022 and June 30, 2023 (DBHDS' Fiscal Year 2023). They reported a 27% increase in CHRIS Reports between FY22 and FY23, as well as a 19% increase in the number of abuse and neglect violations. Community providers reported 9,438 Complaints involving abuse, neglect, or exploitation in CHRIS in FY23, though only 1.26% of these were identified as "high priority"⁴. During this same period, DBHDS-Operated facilities (state hospitals, training centers, and the Virginia Center for Behavioral Rehabilitation) reported 585 Complaints involving abuse, neglect, or exploitation—5.8% of which were identified as high priority. In total, Human Rights Advocates completed 352 on-site visits in response to high priority Complaints (260 at community programs and 92 at DBHDS-operated facilities). OHR reported that 13% of reports entered into CHRIS were substantiated for abuse, neglect, and

³ It is of note that dLCV also receives CHRIS reports daily, which are reviewed by a dedicated Data and Incident Review Unit.

⁴ High Priority, in this instance, means resulting in an initial AIM24 response, in which a Human Rights Advocate would go out within one business day to the provider to assess and assure safety for the individual, initiate the DBHDS complaint resolution process, monitor provider follow up through verification that the provider investigation has been completed and appropriate corrective actions have been implemented, as well as assure appropriate notifications have been made and verify that the provider has explained the complaint resolution process to the individual /guardian if applicable and initiated an impartial investigation. There is also an AIM30 response where a human Rights Advocate verifies corrective actions for all substantiated complaints involving abuse, neglect, and or exploitation.

exploitation. In addition to Complaints involving abuse, neglect and exploitation, licensed providers entered 1,199 Human Rights Complaints about other rights violations, with 11% of those resulting in a violation. The majority of these related to the “Dignity” provision of the Regulations, which is a broad section, covering everything from privacy to pronoun use.

We mention these numbers to demonstrate the scale of the work OHR is doing with minimal staff. As of 12/11/23, OHR’s website showed 19 facility and community Advocates working in Virginia, with 13 additional management and administrative staff. In no world can a staff that small be expected to fully ensure that the rights of Virginians receiving services from DBHDS be enforced. DBHDS’ data seems to support our assertion that, under this tremendous burden, some rights—particularly related to Appeals—are not being fully supported. OHR’s data showed a high number of Complaints but a low rate of substantiation. Despite this, less than 1% of reports in FY23 were escalated to the Local and State Human Rights Committees. This tracks with our survey’s finding that only 2% of individuals are able to get their Complaint before the Local Human Rights Committee, with none of the respondents getting their Complaints to the State Human Rights Committee. While dLCV does not expect that all (or even most) Complaints would be appealed, we would expect that more than 31 out of 11,993 total Complaints would make it to a Local or State Human Rights Committee. The current appellate rate is a great concern, given the context detailed in this report.

CONCLUSIONS

The findings of dLCV’s survey highlight several key areas of concern. The first and foremost being individuals’ lack of knowledge about the Human Rights Complaint and Appeals Process. Providers are required by Virginia Code to relay these rights to individuals, but it is clear that the current system is not working. While OHR reports training thousands of providers and program staff in recent years, our survey demonstrates that this knowledge is not trickling down to most individuals receiving services. The only hope most individuals have of getting justice or their rights enforced is to know and engage with the Human Rights Process. DBHDS OHR must be fully accessible to the individuals it is charged to protect.

dLCV strongly believes that an expansion of the Office of Human Rights is critical for ensuring that individuals are receiving information and assistance consistent with their rights. An office of 19 Advocates to serve over 5,804 Virginians⁵ is simply not sufficient to ensure the rights of all individuals receiving Mental Health, Developmental Disability, and Substance Abuse Services in the whole of Virginia. Based on the data we received, we believe that Rights Violations are currently being underreported, as individuals overwhelmingly report that they do not understand

⁵ This number came from the FY2024 Annual Report from the Office of Human Rights, this number shows that 5,804 unduplicated people received services from DBHDS facilities. dLCV believes this number is an under-estimation, but demonstrates the need for more Advocates.

their rights or how to report violations. Even with this presumed underreporting, few reports are making it through the Complaint and Appeals Processes. By expanding OHR, DBHDS can ensure that Advocates are able to be proactive, and not simply react to an overwhelming stream of Complaints.

Further, we believe that better information at the provider level would help individuals with their understanding of the Rights, their Advocate and the Complaint Process. dLCV's ongoing monitoring at DBHDS licensed and operated providers has demonstrated that providers are not consistently informing individuals of the findings of their Complaints or the Appeals Process. This is supported by our survey's finding that 69% of respondents did not know how to file an Appeal. To make this information more available and more uniform in its quality, we recommend that DBHDS develop a template for this information, require all providers to use it, and initiate a review of this process to make sure this information is being provided. We recommend that such a template include (at minimum):

- The name and contact information for the current, local Human Rights Advocate
- A plain language description of the Regulations, detailing appellate rights (12VAC35-115-175 through 12VAC35-115-210)
- Information on how to submit Appeals to their local LHRC if they decide not to seek help from their Human Rights Advocate

Additionally, updated signs at all DBHDS operated and licensed providers could benefit individuals with identifying the Human Rights Advocate and understanding their rights. Signs should clearly identify the Advocate's name, contact information, as well as a picture of the Advocate for individuals with lower literacy, limited English proficiency, or cognitive impairments. We also believe that enhanced signage at DBHDS-Operated and Licensed providers would substantially help individuals understand their rights and who to go to when seeking support. This signage would likely also help individuals to direct complaints that fall outside the scope of OHR to the appropriate facility advocates, thus ensuring that they are not spending time on issues that they cannot assist with. Our survey shows (and our experiences working with this population corroborate) that many individuals do not know the difference between their Human Rights Advocate and a provider-employed advocate. While many provider advocates do a good job, individuals must have a right to an impartial Complaint mechanism, as laid out by the Regulations. We maintain that detailed, pictorial posters are the best way to help the greatest number of clients identify and contact the proper Advocate when they need help.

We hope the information gleaned from dLCV's survey will spur more client contact, more interactions in the community, and a deep look into how to improve the system in which these vulnerable people exist.

APPENDIX A: COPY OF HUMAN RIGHTS COMPLAINT PROCESS SURVEY

Human Rights Complaint Process Survey	Facility/Provider:
Surveyor:	Date:

Who is taking the survey? Individual Guardian/AR

What is the age of the individual? 1-17 18-21 22+

Section 1: Human Rights Advocate & Regulations	
1	What services are you currently receiving?
2	Do you know who your Human Rights Advocate is? <input type="checkbox"/> yes (go to question 3) <input type="checkbox"/> no (go to question 7)
3	If yes, do you know their name? (For surveyor: We ask this because sometimes people think the incorrect person is the advocate).
4	How do you get in touch with the human rights advocate? Check all that apply. <input type="checkbox"/> Phone <input type="checkbox"/> Mail <input type="checkbox"/> In-person <input type="checkbox"/> Email <input type="checkbox"/> Friend or family member <input type="checkbox"/> Through staff <input type="checkbox"/> Other: <input type="checkbox"/> Don't know how (go to question 7)
5	Do you have any problems getting in contact with them? <input type="checkbox"/> yes (go to question 6) <input type="checkbox"/> no (go to question 7)
6	If yes, please check all that apply: <input type="checkbox"/> Don't know their contact information <input type="checkbox"/> Worried about retaliation

	<input type="checkbox"/> Can't use phones/email/mail <input type="checkbox"/> Phone number doesn't work <input type="checkbox"/> Staff wouldn't let you <input type="checkbox"/> Phones don't work so can't make phone calls <input type="checkbox"/> Can't leave voicemail/mailbox full <input type="checkbox"/> Reached out to them, but didn't receive a response Other:	
7	Have you heard of the human rights regulations?	<input type="checkbox"/> yes <input type="checkbox"/> no
8	Have you ever asked for a copy of the human rights regulations?	<input type="checkbox"/> yes (go to question 9) <input type="checkbox"/> no (go to question 10)
9	If yes, did you receive a copy?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unsure
10	Do you know what your rights are?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unsure
Section 2: File a Complaint		
11	Do you know how to file a complaint if you think your rights were violated?	<input type="checkbox"/> yes <input type="checkbox"/> no
12	Did you know other people can file a complaint on your behalf if you want them to?	<input type="checkbox"/> yes <input type="checkbox"/> no
13	Have you ever filed a complaint before?	<input type="checkbox"/> yes (go to question 14) <input type="checkbox"/> no (go to question 15) <input type="checkbox"/> unsure (go to question 15)
14	If yes, did you receive a response within 24 hours?	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unsure
Section 3: Appeal Decision - LHRC		
15	If you make a complaint and get a decision that you don't agree with, do you know how to appeal, or get a second review?	<input type="checkbox"/> yes <input type="checkbox"/> no
16	Have you ever appealed, or asked for a review of, a decision that you disagreed with?	<input type="checkbox"/> yes (go to question 18) <input type="checkbox"/> no (go to question 17)

	If no, is there a reason why you did not appeal? Check all that apply. Then go to Section 5.	
	<input type="checkbox"/> Worried about retaliation <input type="checkbox"/> Didn't know I could appeal <input type="checkbox"/> Missed the deadline	
17	<input type="checkbox"/> Was told I couldn't appeal <input type="checkbox"/> Didn't know how to appeal	
	<input type="checkbox"/> Staff wouldn't let me send the appeal <input type="checkbox"/> Didn't see the point/wouldn't change anything	
	Other:	

18	If yes, did you participate in a hearing through the Local Human Rights Committee (LHRC)?	<input type="checkbox"/> yes (go to question 19) <input type="checkbox"/> no (go to Section 5)
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	If yes, what was the result?	
	<input type="checkbox"/> LHRC found in my favor <input type="checkbox"/> LHRC found in provider's favor	
19	<input type="checkbox"/> LHRC found some in my favor, some in provider's favor	
	<input type="checkbox"/> Never received the results <input type="checkbox"/> Didn't understand the results	
	Other:	

20	Did you have someone (representative) help you at the LHRC hearing?	<input type="checkbox"/> yes <input type="checkbox"/> no
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Section 4: Appeal Decision - SHRC

21	If you didn't agree with the LHRC results, did you appeal to the State Human Rights Committee (SRHC)?	<input type="checkbox"/> yes (go to question 22) <input type="checkbox"/> no (go to Section 5)
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	If yes, what was the result?	
	<input type="checkbox"/> SHRC found in my favor <input type="checkbox"/> SHRC found in provider's favor	
22	<input type="checkbox"/> SHRC found some in my favor, some in provider's favor	
	<input type="checkbox"/> Never received the results <input type="checkbox"/> Didn't understand the results	
	Other:	

Section 5: Anything else you'd like us to know that we haven't covered?
