

HUMAN RIGHTS COMMITTEE 2015 ANNUAL REPORT



DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona

Division of Developmental Disabilities

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Geographical Composition by County and Chairperson

District Central:	Maricopa County (Central Area) Chairperson (Phoenix): Karen Van Epps
District East:	Maricopa (East Area), Gila, and Pinal Counties Chairperson (Mesa): Suzanne Kensington
District West:	Maricopa County (West Area) Chairperson: Mona Zucker
District South:	Pima and Yuma Counties Chairperson (Tucson): Lynda Stites Cochise, Graham, Greenlee, and Santa Cruz Counties Chairperson (Sierra Vista): Joseph Hunter
District North:	Coconino, Apache, and Navajo Counties Chairperson (Flagstaff): Cynthia McKinnon Yavapai, Gila (Northern Area), Mohave, and La Paz Counties Chairperson (Prescott): Valerie Meads

Human Rights Committees

Administrative Guidance

Human Rights Committees (HRCs) are required by ARS 41-3801 and 41-3804 and function as independent advisory and oversight bodies throughout Arizona. Currently, seven (7) HRCs serve five (5) Districts across Arizona. These Districts serve members in urban and rural areas, and HRC members generally serve on the HRC within the District in which they reside. Each HRC shall consist of at least seven and not more than fifteen members appointed by the director of the Department of Economic Security with expertise in at least one of the following areas:

1. Psychology
2. Law
3. Medicine
4. Education
5. Special education
6. Social work

Each human rights committee shall include at least two parents of children who receive services from the division of developmental disabilities.

Each year, the Division's HRC Statewide Coordinator compiles an Annual Report; the 2015 Annual Report presents the following:

- A summary of the purpose and operations of the HRCs in each of the Division's five (5) Districts from January 2015 through December 2015.
- The respective HRC Chairpersons' recommendations to the Division, which are annually presented to the Statewide Quality Management Committee (SQMC).

Committee Responsibilities

Per A.R.S. §41-3804, each HRC shall provide independent oversight to:

- Ensure the rights of clients are protected.
- Review incidents of possible abuse, neglect or denial of a client's rights.
- Make recommendations to the appropriate department director and the legislature regarding laws, rules, policies, procedures and practices to ensure the protection of the rights of clients receiving behavioral health and developmental disability services

In addition to independently overseeing responsibilities listed in law and rule, HRCs review compliance with the requirements specified in the Division's Policy Manual, Chapter 1000 Member Rights, Revision Date: January 29, 2016. Examples of information types and performance indicators submitted by the Division to HRCs for review include:

- Administration of medication which changes the individual's behavior either directly or as a side effect
- Medication errors
- Theft of, or missing medications
- Aversive or intrusive programs
- Client intervention techniques for medical treatment, e.g. a medical or dental appointments
- Copies of residential monitoring compliance reports and summaries homes monitored in the area along with corrective action plans
- Research proposals in the field of developmental disabilities which directly involve individuals receiving supports and services
- Copies of all Individual Support Plans (ISPs)
- Copies of Serious Incident Reports and resulting investigations involving the Division
- Division Clarification: HRCs are now given copies of all Incident Reports and any Fact Finder notes that are obtained and entered into the incident management system are included
- Copies of "substantiated/unsubstantiated" reports from Adult Protective Services (APS) and Department of Child Safety (DCS), when provided by the investigating agency
- Theft of client property and money; property damage/destruction
- Incidents and circumstances that pose a threat to the physical or emotional well-being of an individual or staff member
- Copies of provider investigations, subsequent analysis of report findings, and corrective action plans
- Data and trend analysis compiled by the Division's Quality Assurance Program

Who are the Human Rights Committee Members?

HRCs are comprised of volunteers who donate time to the Division and each of the districts. Each district HRC has a chairperson, vice-chairperson, by-laws, and functions under the Open Meeting Law. Although many professionals and paraprofessionals serve on the HRCs, frequently HRCs include parents and family members of individuals that are currently receiving services. Many HRC members have served for several years and in some instances decades. This longevity provides the committees with continuity, stability, and expertise. The HRCs are supported by the Division's HRC Statewide Coordinator and District-specific administrative staff, who provide professional and clerical support for their operations.

Activities Performed by the Human Rights Committees

HRCs perform activities on both District and statewide levels; these activities include:

- Recruitment of new HRC members
- Monitoring for human rights violations
- Providing technical help to the Division, families, and the providers
- Providing reports/recommendations, from a District perspective and a statewide perspective, in the form of an annual report to the Division

Recruitment and Training

The year 2015 was not as active as in previous years for recruitment of HRC committee members. The interested candidates have expressed their interest in-part to reading about the HRCs from the Human Rights Committees brochure.

The search for qualified individuals who are willing to serve as HRC members has historically been a challenge.

HRC Chairpersons and Division staffs agree that recruitment efforts should extend to the entire community served by the Districts, in order to ensure a broader representation. Realizing the cultural and ethnic diversity of Arizona, Chairpersons continue to focus on recruiting HRC volunteers who represent a diverse base from every county they represent. The inclusion of new volunteers, some with no history of involvement with people with developmental disabilities, has brought diversity and a flow of new ideas to the HRCs.

Technical Assistance to Families, Staff and Providers

HRCs provide technical help, as needed, to families, providers, and Division staff. In most cases, HRCs help to address areas of conflict within the ISP Team or Behavior Plans that may interfere with the individual rights of Division members. The situation may not infringe upon members' rights, but it may conflict with the principle of self-determination, independence, or least restrictive environment. Subsequent discussions and the free flow of ideas allow for a better understanding of the complex interactions between behavior plans and individual rights.

District HRCs have discussed monitoring group home settings to assess the quality of life of the residents. Currently, as a result of a settlement decree (Griswold vs Riley 1972), The ARC of Arizona is contracted by the Division to monitor quality of life indicators. The ARC of Arizona uses a Quality of Life (QL) assessment tool to assess quality of life outcomes. If there are immediate concerns, DDD Monitoring works with DDD Quality Assurance to address those concerns quickly.

Contact information for The ARC of Arizona was provided to all HRCs, so that the HRCs may request The ARC reports, which include The ARCs 2015 findings.

It should be noted that general consensus among the HRCs' is that because the Division pays for The ARC to assess quality of life , HRCs have expressed concerns regarding the quality of the ARCs oversight.

The Division is currently reviewing and updating the ARC's contract so that a more useful and qualitative report for group home monitoring is developed.

Research in the Field of Developmental Disabilities

HRCs are required by law to review and preapprove (or reject) any plan for developmental disabilities field research concerning Division members. The Division reports any research findings to the HRCs, prior to making them available to the public. During 2015, no research proposals were presented.

The Role of the Human Rights Committees in the Divisions Quality Assurance Program

Data analysis is critical to a Quality Assurance Program, the primary goal of which is the improvement of conditions and outcomes for Division members and their families. In all Districts, HRCs and the Division's Quality Assurance Program work together on issues (e.g. abuse, neglect, and exploitation) concerning member rights.

Annually, District HRC Chairpersons and HRC Liaisons attend a meeting of the Statewide Quality Management Committee (SQMC) to present their annual report. The report includes an update on the District HRCs' activities and emerging issues/trends affecting their communities. The SQMC develops its annual goals, in part, to address the recommendations identified by the Statewide HRC Chairpersons' Annual Report, which is compiled from the individual annual reports of District HRCs. The 2015 Annual Report was presented to SQMC, as well as to the Division's Assistant Director Dr. Laura Love.

HRC Statewide Coordinator

The HRC Statewide Coordinator and District staff will work with each of the HRC in their appropriate Districts, and will continue to provide clerical support to each of the seven (7) HRCs across the state. It is the Division's intent to hire 3 employees for the purpose of providing clerical support to the HRCs statewide under the guidance and supervision of the Human Rights Statewide Coordinator.

Human Rights Committee Chairperson Approval

Consistent with Arizona Revised Statute 41-3804 G. "Each committee shall issue an annual report of its activities and recommendations for changes to the Director of the appropriate department, the President of the Senate, the Speaker of the House of Representatives and the Chairpersons of the Senate Health and Human Services Committee and the House of Representatives Health Committee, or their successor committees." A copy of this annual report will be provided to the appropriate Director as well as elected officials.

DISTRICT REPORTS

DISTRICT CENTRAL: Central Maricopa County

HRC Committee Membership

Karen Van Epps, HRC Chairperson; Family Member/Advocate – Phoenix

Carol McNulty, Vice-Chairperson; Parent – Scottsdale

Eduarda Yates, Parent – Tempe

Andrea Potosky, Parent – Scottsdale

Eva Hamant, Parent /Advocate – Tempe

Linda Mecham, Parent/Advocate – Mesa

Lisa Witt, School Psychologist/Family Member – Chandler

Debbie Stapley, Parent – Mesa

Mary Ann Germain – Member

Mandy Harman – Receives DDD Supports– Member – Phoenix

DISTRICT CENTRAL HUMAN RIGHTS COMMITTEE 2015 CONCERNS

January: Members whom have monies in excess of \$2,000.00 may and are losing eligibly because of the excess beyond this threshold. Spend down restrictions seem to be a barrier. This District's committee feels that a person with behavioral health experience should be a panel member on Program Review Committee (PRC). The Chairperson of PRC in the District, has a Master's Degree in Applied Behavioral Analysis. A reoccurring concern is that the HRC members need to receive all categories of Incident Reports. ARC monitoring was last done in 2013, this is a concern. HRC members assisted PRC review mechanical restraints.

February: Concerned with DDD Client Funds requesting that members find alternative representative payees. House Bill 1400 was introduced by Senators Barto and Ward, which amends sections 41-3803 and 41-3894 to allow committees to exchange information. The Department of Behavioral Health moved to AHCCCS.

March: HRC continues to requests an independent investigator due to lack and/or delay of not getting reports from Adult Protective Services and Department of Child Services. Room and Board billings are not consistently accurate. Concern about the increase of group home staff calling the police, when members are in crisis. Request to meet with SMQC.

April: Committee has concerns that the Employment Initiative is not suitable for all members.

May: Senate Bill 1400 passed. Concerned that the incidents with "approved techniques without injury" techniques are not reported.

June: Assessment for Services-gives from at 90-Day review prior to Annual ISP, so that families can prepare. Support Coordinators should be handing out HRC brochures at each ISP meeting. Michael Churchill stated at the Statewide HRC meeting that HRCs would be getting all Incident Reports. Bed bug issues. PRC needs a Behaviorist.

July: The number of missing members who are able to flee even with a 1:1 staff. Michael Churchill stated that revisions to the incident reporting system will include antecedents and precursors. Concerned about the lack of monitoring of Adult Developmental Homes. Contracts is supposedly looking into this.

August: District Central HRC does not accept the Statewide HRC Report, specifically as presented by District East. The individual concerns submitted, should be given to the Consumer Resolution Unit. Mandy Harman submitted her resume' to become an HRC member.

September: HRC will submit their own reports for the 2015 report instead of having a consolidated report with the other Districts.

October: Mandy Harmon approved as an HRC member. Concern that a Behavior Treatment Plan denied in District Central was resubmitted in District West. It was eventually denied. Transitions of members from hospitals to Skilled Nursing Facilities for 100 days. Following this, our members should be transferred to a DDD facility. HRC does not feel that Skilled Nursing Facilities are appropriate for our members.

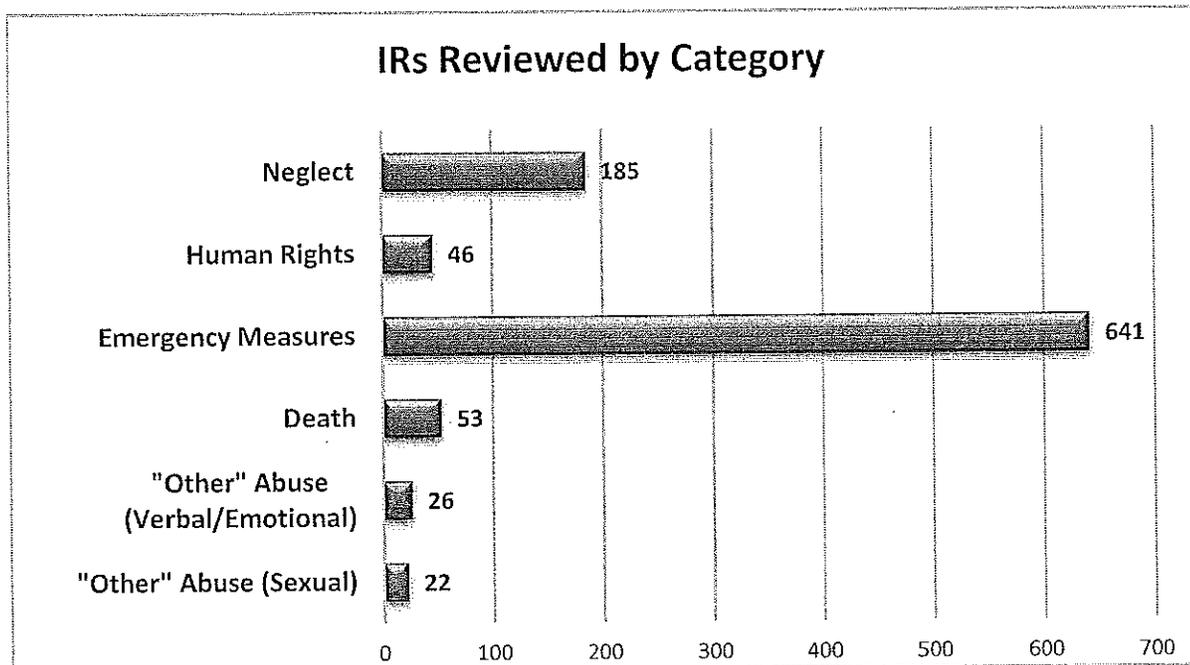
November: the Division's Five year Strategic Planning Forums have been held, members heard from other families that there is a preference for a congregate housing option for our members

One of our reoccurring concerns continues to be that Adult Developmental Homes (ADH) and Children's Developmental Homes are not being monitored by the Division of Developmental Disabilities, rather they are self-monitoring.

Another reoccurring concern continues to be that there is a lack of guardianship for many members that are receiving services from the Division of Developmental Disabilities. Members whom have monies in excess of \$2,000.00 may and are losing eligibly because of the excess beyond this threshold. Another concern that has been identified in past reports has been, Day Treatment Adult (DTA) Programs that are not running Behavior Plan Objectives that have been identified and agreed to by the individual teams.

Chronically ill and disabled children are being removed by Department of Children's Safety from Phoenix Children's Hospital. Residential billing services provided by the Division of Developmental Disabilities as well as revenue desk issues continue to be of concern. These systems have been flawed since the new system was installed.

The Human Rights Committee needs to be notified of all incarcerations of all members and deaths of members.



Total number of IR's reviewed: 973

Number of BTPs reviewed by HRC = 393 BTP in 2015

Number of hours volunteered by HRC = 357 hours

DISTRICT EAST: Prepared by Suzanne Kensington Chairperson

Human Rights Committee Function

Human Rights Committees (HRCs) are required by ARS 41-3801 and 41-3804 and function as an independent advisory and oversight committee for members being served by the Arizona Division of Developmental Disabilities. District East serves the southeastern portion of Maricopa County, southern portion of Gila County and all of Pinal County, including the Arizona Training Program at Coolidge.

Each committee shall provide independent oversight to:

- Ensure that the rights of clients are protected.
- Review incidents of possible abuse, neglect or denial of a client's rights.
- Make recommendations to the appropriate department director and the legislature regarding laws, rules, policies, procedures and practices to ensure the protection of the rights of clients receiving behavioral health and developmental disability services.
- Each committee shall issue an annual report of its activities and recommendations for changes to the director of the appropriate department, the president of the senate, the speaker of the house of representatives, the chairpersons of the senate health and human services committee and the house of representatives' health committee, or their successor committees.

Our primary efforts have been focused on reviewing Incident Reports given to us by DDD Quality Assurance and Behavior Treatment Plans submitted to DDD, that have been approved by Program Review Committee for DDD, for individuals who live in a DDD residential setting and are taking any medication(s) that assist in behavior modification. In addition, we have advocated and counseled with individuals and their families.

Reports Requested to Review

We have requested to review the following reports which have not been delivered to our committee:

- Residential monitoring compliance reports and summaries of homes monitored in the area along with corrective action plans
- Reports of special investigations received by the Division
- Provider investigations, subsequent analysis of report findings, and corrective action plans
- Data and trend analysis compiled by the Division's Quality Assurance Program
- The ARC of Arizona Quality of Life reports for 2015
- Incident Reports for every category

There is no consistency in the committees across the state. Each committee operates autonomously and is provided information in a format as decided by their corresponding District. This has led to some committees not being provided with reports requested, over redaction to the point a report isn't readable and not receiving answers to questions.

Membership

Suzanne Kensington – Chairperson – Parent/Advocate, Realtor
Jennifer Huot – Vice Chairperson – Special Education Teacher
Gina Johnson – Parent/Advocate, Founder of Sharing Down Syndrome
Mary Lou Rangel – Parent/Nurse and Adjunct Faculty
Leon Igras – Parent/ASU Safety Director (Joined in February)
Sheri Reed – Parent/Special Education Teacher (Joined in November)
Lisa Roberts – Parent/Nurse and Adjunct Faculty (Joined in December)
Nancy Buyn – Nurse (Resigned in February)
Michael Miller – Family Law Attorney (Resigned in February)
Linda Jones – Parent/Special Education Teacher (Resigned in March)
Joe Priniski – Former PRC Chair and former DDD Employee (Resigned in September)

Per ARS 41-3801 our committee is to be comprised of at least seven and no more than fifteen members with members having expertise in the following areas: psychology, law, medicine, education, special education, social work and at least two parents of children who receive services from DDD.

Recruitment and retention is an ongoing issue. We had four members resign and three join in 2015. Each of our members share information about our committee, to help further the recruitment process. To improve retention, it is important for our members to feel that the time they are giving is making a difference in improving the lives of our members, as it is a large time commitment. This can be better accomplished through more transparent communications from the Division regarding outcomes. To improve retention as a committee, we have worked hard to create organization, efficiency, good communication, training, easy access to information and group harmony.

Our committee is made up of individuals who are employed full time, primarily parents who have children receiving a variety of services from DDD. As such, we all bring insight from our experiences with the Division and the agencies providing services. Our diverse insight allows our committee to openly discuss differing points of view to come to a collective decision on matters before us. Dedicating the time necessary to participate on the committee has been a strain at times on our members as they also have had to handle issues experienced by their children served by the Division; however, they chose to serve in order to make a difference.

DDD Staff

Administrative staff for our committee is a temporary position due to the hiring freeze, which lead to having no staff, utilizing DPMs administrative assistant and short term staff which led to administrative duties falling through the cracks or being taken on by the committee itself. In June we were provided with staff who stayed with us throughout the year which has been extremely helpful.

In order to streamline administrative staff duties, as well as help our committee operate in the most efficient way possible, we have repeatedly requested a solution of some web based distribution. There are many available at little or no cost. DDD intranet or web based software program like Google Drive, Dropbox, OneDrive or Evernote are available. We haven't received any approval or support from DDD in those efforts. We created our

own Dropbox where we have references, resources, training, agendas, past minutes and time sheets available for easy access. We are currently working on collaboration and communication regarding IRs and BTPs through Dropbox. What we are requesting is that BTPs and IRs to be distributed to us through this manner. This would give us the ability to refer back to previously reviewed BTPs to ensure requested changes were made and previously reviewed IRs to track ongoing issues with individuals or agencies. This would eliminate the need for administrative staff to redact and produce copies, reduce paper waste and eliminate the need to collect and shred documents.

Dedicated support coordinators who specialize in clients with high behavioral needs would allow them to have a more comprehensive knowledge of the resources and supports available to those clients and their families. Raising a child with special needs can be exhausting physically, mentally, emotionally and financially. Support Coordinators and families many times are not aware of what resources are available. Specialized SCs can help navigate the system to access those resources and bridge the gap between services offered by DDD and RBHA.

The committee received complaints regarding Support Coordinators and Supervisors that had little to no experience, were rude, not returning phone calls and emails and not advocating for members.

Our committee was pleased to notice that there was a change in leadership in the Division starting at the top and working its way down: Deputy Director left in June, DPM, Area Manager, and PRC Chair all left in October with no replacements until January. We were told that the new Director of DES has made positive wide sweeping changes to the culture of the Division. We realized that due to all of the changes and need of hiring that there would be some growing pains. We also had three different HRC liaisons throughout the year, which caused issues raised in statewide meetings to not be addressed in a timely manner.

Incident Reporting Format

Our committee is only being provided a small number of the incident reports input in the system for our members. We are provided other abuse, physical abuse, neglect, emergency measures, human rights violations and death. We have requested to receive all of the reports; however, have been told that there is not adequate staff to redact the reports. The issue of redacting reports hampers our ability to provide the oversight the law requires.

The committee found that the current IRs do not provide enough information to form an opinion on what occurred. We need to have statistical and expanded information about these agencies, staff and clients to get the bigger picture. What was the antecedent? What was the precursor? Is there a guardian? Where do they reside? Is there a BTP in place? Is it working? Number of incidents regarding this client in the last 90 days? This information would allow us to make more informed recommendations to improve the quality of life. We also would like more information on specific actions that were taken regarding the IRs to protect our members and prevent further problems. Currently our reports show substantiated or unsubstantiated by APS or DCS but no report from those

agencies. This leaves us wondering as to the depth of the investigation as in most cases the reports show unsubstantiated.

Direct Care Staff

Our committee found that the quality of life of our individuals is severely impacted by the lack of quality direct care staff, poor training of that staff and low wages. We read wonderfully written ISPs and BTPs only to find that they are not being read by agency providers and therefore not being followed. There is substantial failure on the part of many providers to properly train direct care staff. Providers complain that there is a shortage of quality workers.

Standardized mandatory behavioral training for direct care staff who care for clients with extensive behavioral needs require ongoing mandatory continuing education to be provided by Behavioral Health Specialists. This would help to minimize use of emergency measures, decrease escalation of behaviors resulting in verbal and physical aggression, property damage, self-abuse, crisis and police involvement. Workers having specialized training will be able to better implement behavioral treatment plans and therefore experience less behavioral issues from the members. This would create better employee retention and reduce training costs for agencies.

AHCCCS implemented Direct Care Working training and testing programs for workers providing in-home care services (attendant care, personal care and homemaker services). This program does not apply to licensed settings. This program would be a good start, however not comprehensive enough for working with members with extensive behavioral needs.

There is an overall theme seen both in BTPs and IRs regarding members wanting to be respected by not being rushed, not being spoken to like a child, not having power struggles with staff, not saying no and not giving reasons behind the no, not being sincere, staff not being aware of tone of voice and body language, not being aware of who is working with them in advance, and not being aware of their schedule.

Behavior Treatment Plans

Behavior Treatment Plans should be in a consistent format like Individual Service Plans created by Support Coordinators. This would allow ease of reading for Support Coordinators, Providers, Direct Care Staff, PRC and HRC. It would ensure that all necessary information be in the plan. It would provide consistency from member to member, agency to agency and district to district. This would prevent agencies from seeking out presenting their plan to the district they feel is easiest to get approval from, as well as help those agencies struggling with creating appropriate plans.

We were disappointed by providers' submission of BTPs with many misspelled words and grammatical errors. We reviewed plans that did not address the function of the behavior in the methodology. There were plans that behavioral data did not match the narrative causing us to wonder if the data was indeed valid.

It is hard for our committee to make a determination as to whether an individual is on an appropriate amount of medication or is over medicated. Our committee requests that an expert in this field be provided to review to ensure members are not over medicated.

Our committee requests that it be provided with a behavioral consultant to provide expertise into the effectiveness of the plans that are presented.

Currently DDD has no tracking system to ensure that provider agencies have current BTPs in place for members that are required to have them. There were many plans that were submitted that were way overdue or about to become due again. This is a huge human rights violation as agencies are not properly handling members' behaviors. They hire staff that babysit, rather than follow ISP outcomes and run BTP outcomes. Members' behaviors escalate out of control resulting in provider agencies calling crisis and/or the police and press charges against our members. There is a systemic problem of agencies having a policy of calling the police on our members for behaviors, rather than having appropriately trained staff in place to manage the behaviors. During training, all staff must follow Crisis Prevention Intervention strategies.

In reviewing BTPs we are provided a copy of the ISP. We found that the ISP needs to be one fluid document with spell check capabilities. Many ISP "Working with Me" sections were sparse and not conveying the necessary information regarding the member's abilities and needs. There were lots of misspelled words and grammatical errors. We found ISP outcomes not supportive of providing growth for the members.

There were Support Coordinators and providers who didn't respond to requests and recommendations made by the committee on the BTP. There were some that expressed to our administrative assistant that changes requested were beyond HRC scope. Our committee was very saddened that any DDD employee or agency provider would not want to make changes that would improve the lives of our members.

Police Involvement

Many times when agencies call "crisis" they are told to call the police. The police do not have the appropriate training to deal with our members. The police, as well as the jails and courts are not the appropriate place for our members. Involving the police can result in tragedy such as death, which was experienced in our district this year. Members have services to provide supports that are needed to function in our society.

The jails treat them as a typical criminal and don't understand their unique specialized needs. Members have been denied their medications while in jail resulting in further behavioral and medical issues. The experience with the police, jail and the judicial system causes an escalation of behaviors and/or PTSD. Policy changes need to be instituted to prevent these things from happening. These issues are directly in opposition to laws and policies in place to ensure our members human rights.

Provider Accountability and Provider Report Cards

DDD needs to provide more transparency with members, their families and guardians. When incident reports are made regarding their member, families deserve to know the outcome of the investigation and any course of action taken by DDD or the agency.

Families should be provided a copy of the contract that an agency has with DDD when caring for their member. This provides clarity of what is being expected for their compensation. There should also be transparency as to the amount of compensation received for services rendered.

Families have the right to know who is working with the member, what their background results are, agency policy for drug tests, and violation consequences/follow up when incidents occur.

Many members and their families are afraid to report agencies and direct care staff for the very real fear of retaliation against the member in their care.

Cameras should be allowed in day programs and residential settings if requested by guardian. We have seen all too often DCS and APS come back from their investigations with "unsubstantiated" because it is a he said, she said situation. Cameras would eliminate these ambiguities and provide protection against false allegations for providers. We find that more often than not our members are not believed and are blamed for circumstances that could very easily be abuse. In addition, many times direct care workers are removed from working with vulnerable members for long periods of time while awaiting the results of the investigation.

A report card system needs to be in place so that families can make educated and informed decisions as to the providers that they want to work with. The report card system should utilize feedback from QA, SC and families/guardians and be available on DDD's website for public access. This has become a common practice for professionals like attorneys, doctors, realtors, general contractors etc. and should be no different for providers. Questions such as: How long have they been in business? Number and category of incidents? Were they corrected? Systems in place? How many homes? Total number of clients? Staff ratio? Staff turnover? How often are clients leaving or provider is releasing them? Would be beneficial information.

Agencies experiencing issues should not be given more members to service when they are failing to provide quality of care to the members that they are servicing. There seems to be a lack of accountability of enforcing provider's contracts to the detriment of our members.

Health Issues

Dental care for our members is not covered after the age of 21. Many members are having teeth pulled resulting in additional health problems, such as digestive issues and gum cancer. Providers are not providing adequate daily dental hygiene to the members.

Diabetes, obesity, digestive and other health issues are often times a direct result of group homes not providing nutritional meals for our members. Direct care staff eats fast food and drink sodas in front of the members which not only provides a poor example but also results in behaviors due to members wanting the fast food and sodas as well.

We read a few incident reports regarding a group home or DTA van arriving at their destination, only to later discover a member was left in the van by themselves. Incidents such as this can lead to neglect, medical issues or death. It is extremely important that group homes and DTAs have systems in place to ensure that this never happens.

Human Rights

The issue of human sexuality was addressed by our committee where BTPs were restricting the right to consensual sexual activity of adult members. In an effort to control sexual activity, members were not being given the proper training regarding healthy sexual activity and relationships.

Providers are refusing to take and support members in their religious activities because it differs from their own religious beliefs. It is important that agencies train and enforce direct care workers to understand that their job is to support the member in the activities they wish to participate in.

Agencies are not respecting cultural sensitivity of our members. Members are forced to have direct care staff that are very different from the members causing the members to be uncomfortable and not get their needs met. These cultural differences were seen in having a skin color which causes distress, thick accents which caused problems in communication, religious preferences not being respected, meal preparation of an origin not comfortable to member, staff not knowing how to brush hair different from theirs and staff not comfortable with member's pets due to cultural differences. Our members have the right to have staff that they are most comfortable with.

Adequate Residential Settings

There is a lack of agencies able and willing to service members with high behavioral needs. This results in members living for long periods of time in unstable and/or potentially harmful situations where they are not happy. This results in decomposition of the member and a worsening of behaviors. Members have the right to be in a happy stable home.

Behavioral Health Hospitals

There are no behavioral health hospitals in Arizona prepared to appropriately meet the needs of our members when psychiatric hospitalization is required due to medication changes that need to take place in an inpatient setting. They are thrown in with mentally ill, criminals and drug addicts. This is true in outpatient facilities such as UPC and SMI clinics as well. There needs to be specialization for our members that are set apart as their needs are very different due to the developmental issues and would be more effectively managed with specialization. Furthermore, the division between DDD and Regional Behavioral Health causes the dually diagnosed members to navigate an extremely confusing system which has either side pointing fingers at who is supposed to be providing services. Behavioral health needs to be under one umbrella for our members. This collaboration of cooperative care should be a high priority.

ARC Reports

Our committee started making requests in August 2015 to the ARC to receive their reports for 2015. These requests were repeated every month. No reports were provided during

2015. Reports were received in February 2016; however, six of them were the same reports received in February 2015 and were for year 2014. There were a total of only 39 reports made for 4 agencies and all the reports were from 2014. At face value, the reports look to be comprehensive quality of life indicators, however upon further inspection they appear to be a check the box with each report almost identical. Our committee suspects these reports to be disingenuous. The reports mention supporting documentation such as the guardian questionnaires were not included. Numerous requests were made to the Division to provide answers as to how many inspections are expected to be made by the ARC during a year. During the statewide meeting in 2015, we were told by DDD that they paid the ARC \$50,000 a year to do these inspections. HRC respectfully requests that the \$50,000 be diverted to pay an investigator who reports directly to HRC. This would pay for a full time inspector who could visit 1 group home a day for approximately 250 inspections per year. This could greatly improve the quality of life for our members.

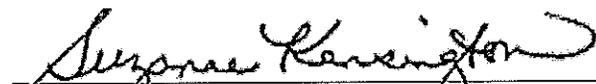
Placement	All Other	District East	Statewide
Total ADH	895	105	710
Group Home / Specialty GH	2486	356	2842
SOGH Are included in GH numbers	29	21 at ATPC	50
Home	23973	7654	31627
ICF Private	35	2	52
ICF/IID state operated	33	65	98
State Hospital	4	0	4
Desert Vista	1	0	1
Totals	27476	8280	35756

Incident Report Type	Number
Other Abuse	37
Death	54
Emergency Measures	155
Human Rights Violations	9
Neglect	166
Physical Abuse	57
Total	478

BTP Reviewed	IR Reviewed	Meetings Held	Volunteer Hours	Valuation of Donated Hours
358	478	11	810	\$18,119.70

These issues and recommendations have been previously discussed with DDD management via phone, email, District East meetings, statewide meetings, and individual meetings.

This report is a compilation of District East meetings, statewide meetings, review of Behavior Treatment Plans for DE, review of Incident Reports for DE, meetings with families, providers and DDD employees and personal experiences of our committee members during 2015.



Suzanne Kensington, Chairperson

DISTRICT WEST

HRC MEMBERSHIP:

The District West Committee is made up of dedicated community members including; parents, family members, professionals, and paraprofessionals who volunteer their time and knowledge to advocate for our members.

CHAIRMAN:

PAT THUNDERCLOUD - PARENT, PHYSICIAN ASSISTANT (JAN-AUGUST 2015)
MONA ZUCKER – PARENT, RESPIRATORY THERAPIST (AUGUST 2015- PRESENT)

VICE CHAIRMAN:

PAT THUNDERCLOUD – PARENT, PHYSICIAN ASSISTANT (AUGUST 2015-PRESENT)
MONA ZUCKER - PARENT, RESPIRATORY THERAPIST (JAN – AUG 2015)

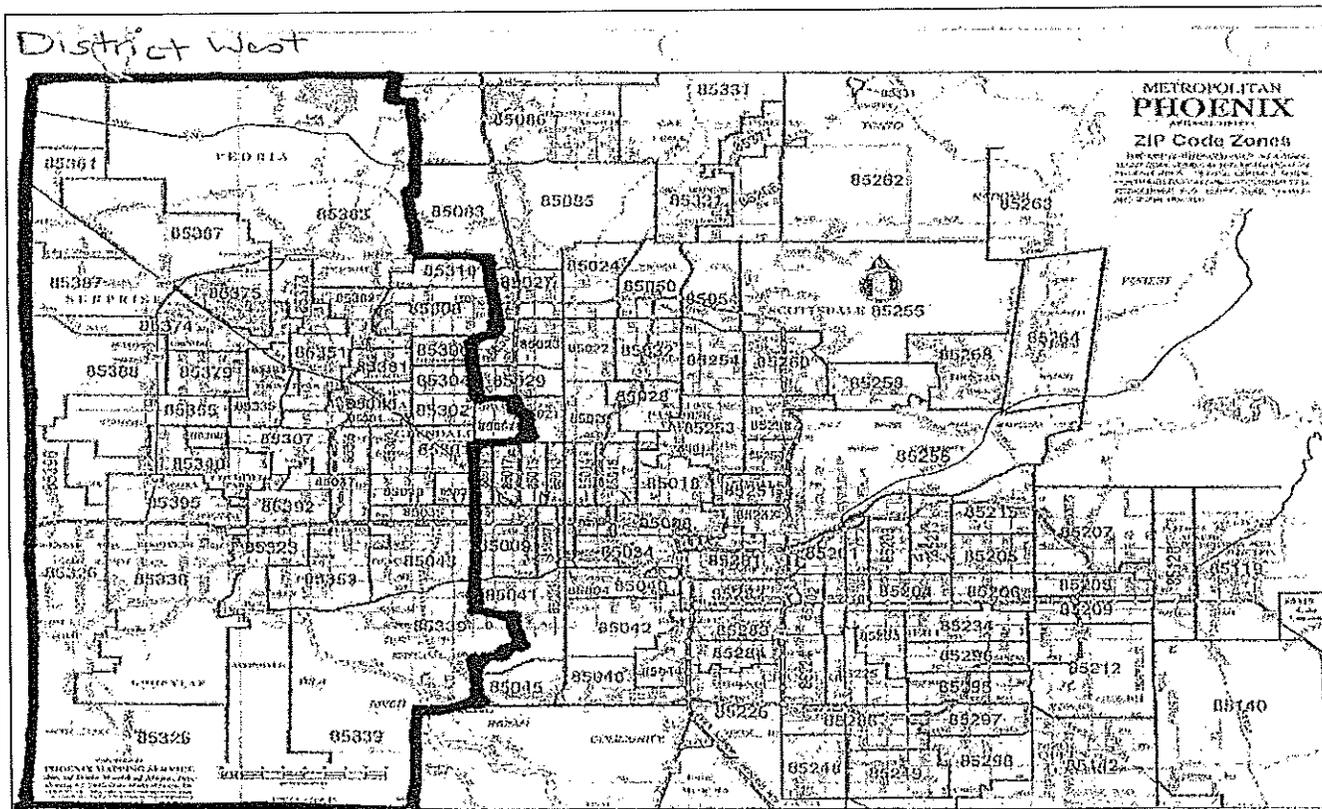
HRC MEMBERS:

EMILY TAYLOR – ATTORNEY AT LAW – SPECIAL NEEDS & ESTATE PLANNING
EILEEN ROSSBACK – PARALEGAL – ELDER LAW & ALTCS PLANNING
PHILIP DOVICO – BUSINESS OWNER, PRIVATE FIDUCIARY

INTRODUCTION AND BACKGROUND:

The Human Rights Committees were established to promote and protect the rights of members with developmental disabilities who are receiving services from the Department of Developmental Disabilities.

District West is located on the west side of Maricopa County and extends south to and including portions of the Gila River Indian Reservation, to North Phoenix, and West to the border of Arizona. In 2015 District West served approximately 8,000 members.



2015 ACTIVITIES

ADVOCACY:

The District West Chairman(s) advocated for the rights of its members, parents, and guardians, by attending ISP's, BTPs, IEPs and other meetings to support the members and families and advocate for the best interest of the member.

In addition, the District West HRC has taught many of its members and families how to advocate for themselves and their family members.

ISSUES:

District West found that many of its members BTPs were seriously delinquent and/or non-existent. This was brought to the attention of our Statewide HRC, DDAC, the Department of Disabilities including; District West DPM, QA, and Family & Community Resources. The DPM of District West sent out a letter to the Service Providers that the delinquency and not providing a current BTP would not be tolerated. As a result, District West has seen fewer delinquent BTPs.

While advocating for a member in District West who was in a Nursing Home, we found that member's needs were being neglected, the Nursing Assessments were incomplete and inaccurate, which was brought to the attention the Department of Developmental Disabilities including QA, Deputy Director, and Health Services. As a result, the member was moved to an ICF for evaluation and active treatment, and the Nursing Assessment Process is being reviewed by the Division.

In District West, there were several issues identified with specific DD – funded group homes, who were violating the rights of its members including programmatic abuse, human rights violations, abuse and neglect of its members. District West, East and Centrals Chairman’s and Vice Chairman’s attended many meetings to advocate for the member and families. These issues were brought to the attention of the Department of Disabilities, including; QA, District Wests DPM, Family & Community Resources, District Lieutenants, OCR Administrator, and the Contract Management Unit. As a result, further investigations and corrective action plans were put into place, some of its members were moved, and one Group Home agency was closed.

RECRUITMENT AND TRAINING:

District West recruited 2 new members in 2015. In both cases the recruitment and appointment process took many months to complete. This was very discouraging to both the new members and the chairs, as we felt the process was too long. Most of the recruitment has come by word of mouth from the committee members.

District West has requested training on IR’s BTPs and Article 9. In March, 2015, Sam Rogers, QA – Supervisor, trained our committee on the IR’s and its process. There has been no training on either BTPs or Article 9 in 2015.

RESPONSIBILITIES AND DUTIES OF THE HUMAN RIGHTS COMMITTEES:

The Human Rights Committees are made up of dedicated volunteers, who dedicate their time to serve the members within their districts. The HRC operates under the Open Meeting Laws of Arizona, and follows specific HRC By-Laws created by their district. District West Committee meets approximately 10 times per year. The Chairman’s and members also attend and participate in the Quarterly Statewide Meetings. The Chairman and other HRC members, also attend other various public, state, and community meetings.

Our committee provides independent oversight, review, research and also makes recommendations to the Department of Developmental Disabilities. The committee reviews incidents of Abuse and Neglect, Emergency Measures, Human Rights Violations and Death. The committee members review Behavior Building Plans. The Chairman of the HRC Committee, review, recommends, and approves the plans.

DISTRICT WEST VOLUNTEER HOURS:

**VOLUNTEER HOURS
DISTRICT WEST - HRC 2015**

DW HRC MEMBER	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	TOTAL
Pat Thundercloud	6	6	19	17	5	18	20	12	0	13	13.5	2	131.5
Mona Zucker	20	12	13	12	12	12	10	12	20	22	20	12	177
Emily Taylor	4	4	4	4	4	4	0	4	4	4	2	2	40

Eileen Rossback	4		4	5	4	8	0	5	6	8	4	4	52
Phillip DeVico								4	4	4	4	4	20
Total Hours	34	22	40	38	25	42	30	37	34	51	43.5	24	420.5

****APPROX. VOLUNTEER HOURS INCLUDE****
STATEWIDE AND OTHER MEETINGS, ADVOCACY, RESEARCH, PAPERWORK, E-MAILS, ETC.

PRC/BEHAVIOR BUILDING PLANS:

REVIEWED BY DISTRICT WEST - HRC 2015:

DW HRC MEMBER	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	TOTAL
Phillip DeVico											4	4	8
Pat Thundercloud	15	9	17	9	19	18	9	5	9	9	16	10	154
Mona Zucker	0	2	0	0	0	0	0	16	8	10	1	0	37
Total Hours	15	11	17	9	19	18	9	5	17	19	21	14	199

INCIDENT REPORTS:

In 2015, Incident Reports in District West have been an ongoing and frustrating issue for our HRC. In total for the year our HRC received only 426 Incident Reports for approx. 8,100 approx. members, in comparison to 2014 when we received 730 Incident Reports for 7,100 for approx. members. In November and December of 2015, District West HRC received ZERO Incident Reports for its members, due to a Division redaction issue.

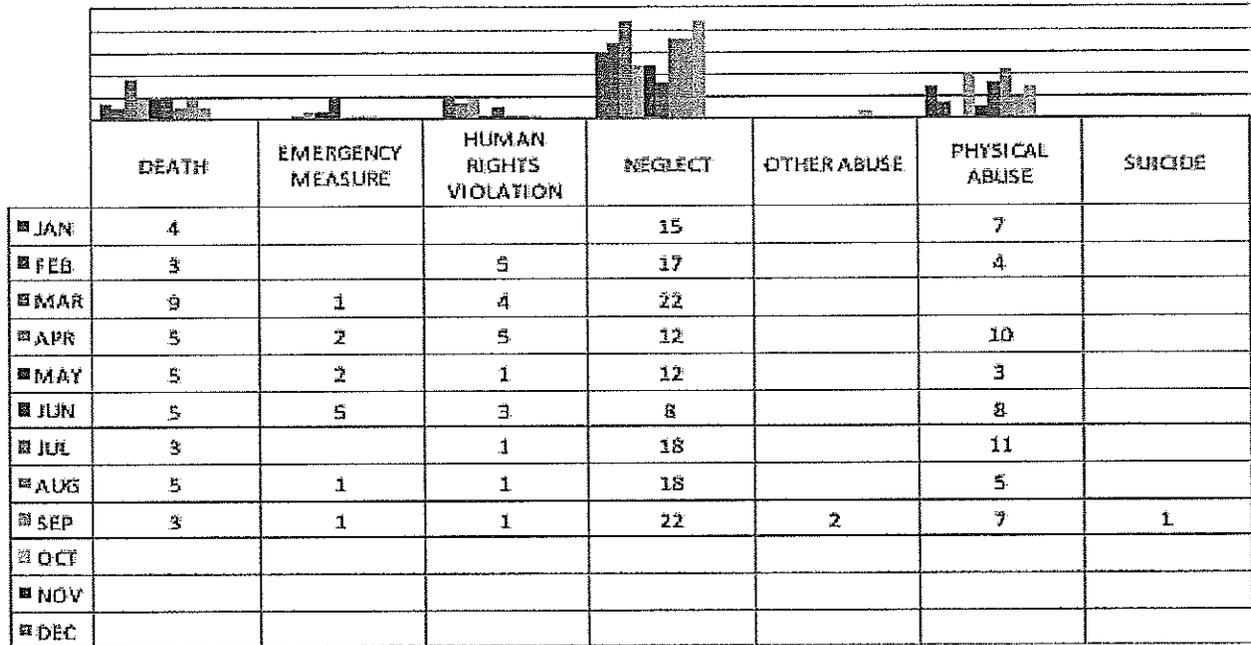
We feel that for the number of members in District West, that we are not receiving as many reports as we should be getting. In addition, we are not getting the types of Incident Reports that we have requested; this includes; Physical Abuse, Sexual Abuse and Other Abuse, Neglect, Accidental Injury, Client Missing, Emergency Measures, Human Rights Violations, Medication Errors, Death, Suicide, Hospitalization, and Legal.

We feel that not receiving or having access to the Incident Reports that are occurring with our members, is a violation of their Human Rights. Subject to federal law, committee members have access to client information and records, and review incidents of possible abuse, neglect or denial of a client's rights.

IR STATISTICS:

2015													TOTAL
	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	
DEATH	4	3	9	5	5	5	3	5	3				42
EMERGENCY MEASURE			1	2	2	5		1	1				12
HUMAN RIGHTS VIOLATION		5	4	5	1	3	1	1	1				21
NEGLECT	15	17	22	12	12	8	18	18	22				144
OTHER ABUSE									2				2
PHYSICAL ABUSE	7	4		10	3	8	11	5	7				55
SUICIDE									1				1
TOTALS - ADMIN	26	29	36	34	23	29	33	30	37	0	0	0	277
TOTALS - QA	56	49	63	61	40	72	33	30	37	15	0	0	426

IR TYPE



DISTRICT SOUTH:

INTRODUCTION AND BACKGROUND

It is a pleasure to submit our 2015 Annual Report for the Human Rights Committees (HRC) in Tucson and Sierra Vista, with support to Yuma. Human Rights Committees were established under ARS 41-3801 and function as independent advisory and oversight bodies across the State.

RESPONSIBILITIES OF THE HUMAN RIGHTS COMMITTEE

The Human Rights Committee of dedicated volunteers, in addition to providing independent oversight and review and making recommendations, functions under the Open Meeting Law and follows District specific Bylaws. The Committee includes professionals and paraprofessionals.

SPECIFIC CHALLENGES

This calendar year brought several challenges to the basic functioning of the Human Rights Committees. Behavior Treatment Plans are inconsistent in structure and order and are difficult to read. The Tucson committee feels that the lack of consistent quality and general unreadability of the BTPs represent real violations of human rights for members due to the inability of care givers and service providers to understand the plans. We would like to see a more consistent format for BTPs and the use of wording that is easily understood by all service providers.

Additionally, despite numerous requests to fix the computer system in the new Office location, the Incident Reports prepared for committee review for several months consisted of e-mails sent to Barbara Carty because she was unable to view and print the Incident Reports in the formal format from her computer. The basic information was available in the e-mail, but the lack of consistent structure proved to be difficult for the committee to interpret and there was no information from fact finding in the initial e-mail. The computer problem seems to have been resolved now.

The committee was told that their questions regarding BTP's and Incident Reports would be answered by Statewide Management. Although meeting notes were sent to the proper authority, no response was received. The resolutions of incidents has still not been provided to the committee and the committee has been informed that results from cases investigated by APS and CPS are not routinely provided to Quality Assurance and are, therefore, not available to HRC for resolution of incidents. This is a direct violation of the purpose of HRC and the committee requests a routine monthly report from APS/CPS on all cases closed during the previous month.

The Tucson Committee continues to value Barbara Carty as liaison with DDD and requests that she remain in that position. Ms. Carty is very helpful to our committee and provides important information to help us to make our recommendations, and she helps to explain situations experienced by the members for whom we advocate. The HRC in both areas received clerical support through Ms. Lydia Martinez until she resigned to take another position. Clerical support is currently being provided by her replacement, Anzorena Fuentes, who is doing an excellent job. Pauline Selmer, Quality Assurance, did not

participate in the Tucson committee meetings throughout 2015, but the committee has requested that she be invited back to provide valuable information during the current year.

MEMBERSHIP

The Tucson Committee

The Tucson committee remained constant throughout the year.

The members include:

- Lynda Stites (Chair)
- Stacy Santos
- Genevieve Valenzuela
- Margarita Almeida

Despite recruiting two other members, Leslie Ledbetter and Hunter Howell, and their having submitted the required paperwork, which was approved, they are not considered to be participating members of the committee due to lack of attendance. Both have cited personal schedule limitations that have prevented them from attending our regular meetings and attempts to reach out via e-mail have largely gone unanswered.

DES Staff participating on the committee include:

Lydia Martinez, Liaison (Clerical Support) until her resignation, and Anzorena Fuentes, Liaison (Clerical Support), currently serving.

Barbara Carty, HRC Liaison.

Jack Villano (former), Roberto Ramos (former), Richard Kautz, Statewide HRC Liaisons

The Sierra Vista Committee

RECRUITMENT AND TRAINING

Nancy Johnson, Volunteer Coordinator for the District recruited and trained members of HRC. This was a difficult year to recruit and retain volunteers, but Nancy is to be commended for her efforts to do so.

ORGANIZATIONAL STRUCTURE

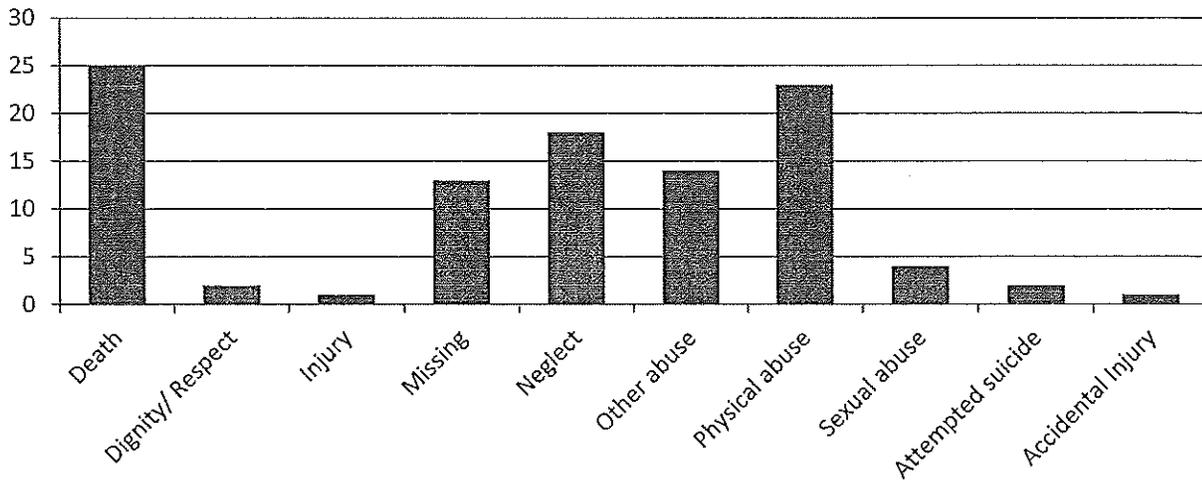
The HRC's are groups of volunteers with Lydia Martinez or Anzorena Fuentes present to take notes for the group to forward to the Human Rights Specialist in the Phoenix District. January 2015 until December 2015, Barbara Carty was the Liaison for the committee and provided valuable information regarding the committee's questions about specific members and incidents.

STATISTICS

	IR's Reviewed	BTPs Reviewed	Meetings Held	Volunteer Hours
Sierra Vista				
Pima County	103		10	**123

** In Pima County, the hours counted do not include the variables of time spent reading plans.

Types of Incidents reviewed



OTHER ACTIVITIES

The Tucson committee has drafted letters to potentially be sent to agencies or group homes that have an excess of Incident Reports that stem from the same type of mistreatment of the members. The committee has also maintained a tracking system of all Incident Reports reviewed in order to track trends and agencies over time. One parent of a member addressed the committee regarding the lack of nursing hours available from agencies in Tucson and the problem with low rates paid to nurses in DDD agencies which may account for shortfalls in staffing and available hours. This issue has been discussed at a state level with other HRCs and we are awaiting more information regarding nursing compensation rates.

This concludes the annual report of the Human Rights Committee, Southern Arizona.

Respectfully submitted,

Lynda Stites
Pima County Human Rights Committee Chairperson

Joe Hunter
Sierra Vista Human Rights Committee Chairperson

Gregory Stewart
Division of Developmental Disabilities District South Program Manager

DISTRICT NORTH:

Yavapai, Mohave, LaPaz Counties, and Northern Gila (Payson)

Incident Reports reviewed during 2015: 313

INCIDENT TYPE	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Consumer Missing	2		1	4	3	4	8	11	1	4	5	
Death	4	1	1	3		4	1	1		4	3	2
Emergency Measures	8	4	6	9	6	11	8	13	11	5	4	7
Human Rights Violation	3	6	3	3	2	6	2		3	3	5	2
Legal	2	2	3	2	1	3	2	2	1		1	1
Neglect	7	2	11	7	1	7	6	7	2	2	2	5
Other Abuse		1		3		5	1	2	1	2	1	
Physical Abuse	3	4	4	2		5		2			1	
TOTAL	29	20	29	33	13	45	28	38	19	20	22	17

Table 1: Incident Reports reviewed by Prescott HRC during 2015 – (by category and per month)

Total Incidents Reports reviewed in 2015 by category:

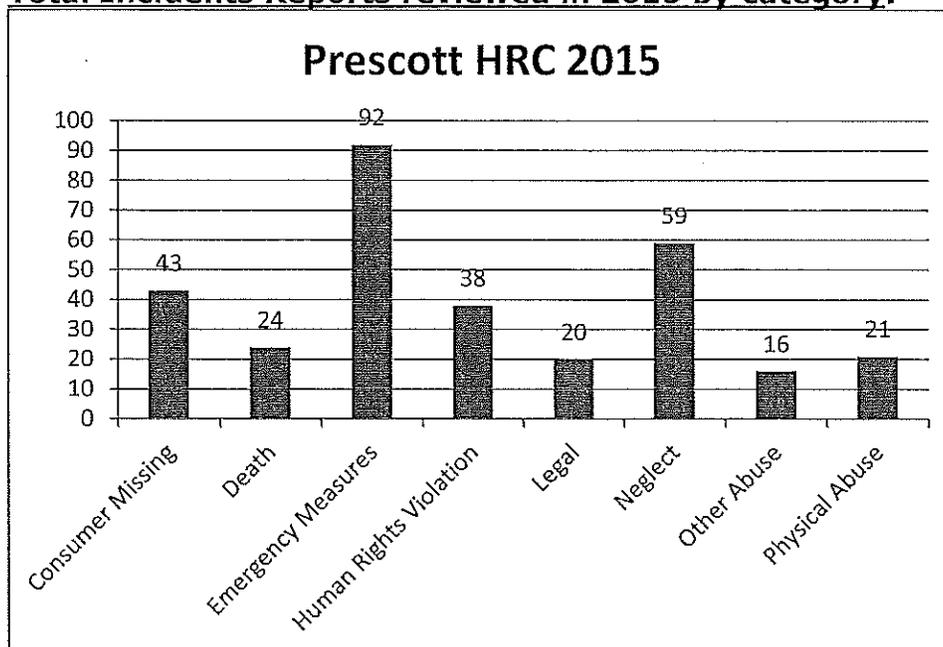


Figure 1: Incident Reports reviewed by Prescott HRC during 2015 – (by category)

Total Incident Reports reviewed in 2015 by month:

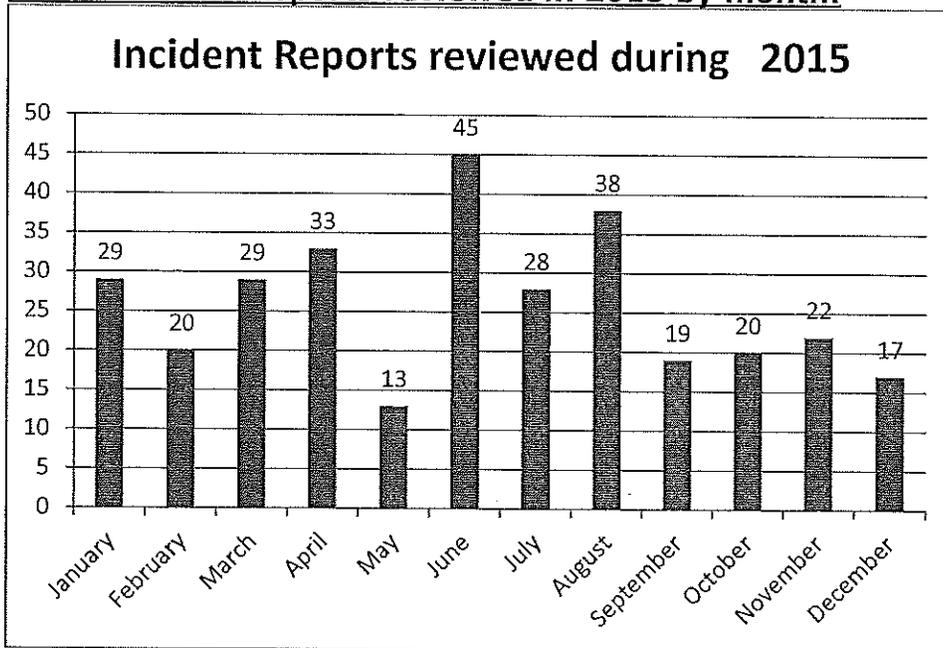


Figure 2: Incident Reports reviewed by Prescott HRC during 2015 – (by month)
Total Behavior Plans reviewed for Rights Issues by Prescott HRC – 2015

January	10
February	8
March	16
April	10
May	9
June	12
July	10
August	15
September	11
October	10
November	14
December	4
TOTAL	129

ACTIVITIES AND RECOMMENDATIONS:

DISTRICT NORTH HUMAN RIGHTS COMMITTEE – PRESCOTT AREA

Activities

During 2015, the Prescott Area HRC met at least monthly and requested the District North DES PRC Chair and QA Manager, also attend those meetings. In November 2015, a third HRC volunteer member joined the committee. Pursuant to the provisions of ARS 41-3804, written HRC *GUIDELINES* were drafted, subsequently adopted and submitted for approval as required by ARS 41-3804A.

Recommendations

That the DES Central Office ensure all DES HRC volunteers have executed and maintain a current *Volunteer Agreement* form (VOS-1009A FORFF) with a period of service (duration) identified therein, as a requirement for continued participation.

HUMAN RIGHT'S COMMITTEE REPORT 2015

DISTRICT NORTH - FLAGSTAFF

HRC MEMBERS

Cynthia McKinnon, Chairperson, Registered Nurse
Norm Wallen PhD, Psychologist
Ted Garland, Institute of Human Development, NAU, Consumer
Dora Harrison, Public Administration / County Management

District North Flagstaff Concerns:

We remain concerned about the lack of guardianship for individuals with severe cognitive abilities.

We are concerned that changes to Policies and Procedures are not being forwarded to the HRC for comments and review.

We recommend that ALL medications which may cause TD, not only certain psychotropics, be included in the TD screening.

We continue to be concerned about the quality and variety of food provided for consumers. Type 2 diabetes is a frequent diagnosis and is diet related. Clients desiring healthy foods have been unable to purchase these foods with personal monies. The Navajo Nation has instituted a program which includes education, healthy foods and organized physical activity which has resulted in consumers realizing weight loss and no longer having Type 2 Diabetes. An organized program of this type would certainly reduce morbidity; decrease both medical costs and deaths from complications as well as improving the quality of life for consumers.

The HRC is concerned that consumers are incarcerated for the very behaviors described in BTPs. Incarceration of an individual with cognitive issues and/or mental illness is NOT therapeutic but punitive and places vulnerable individuals in a perilous situation which ought to be used in extraordinary situation, not as a programmatic solution. If indeed there is a population for whom repeated incarceration is unavoidable, the HRC suggests that there is a need to develop, staff and fund an appropriate setting which can accommodate such individuals. Incarceration of DDD consumers is unacceptable. The HRC requests to see statistics on incarceration rates by consumer as well as by provider. The HRC requests to be informed of each incarceration.