

Darraasad Tayeed o ee Qoysaska leh Carruurta Qabta Autism ee Bulshada Soomaaliyeed
(A Qualitative Study of Families of Children with Autism in the Somali Community):
Isbar-bardhigga Waaya Aragnimada Kooxaha Muhaajiriinta (Comparing the Experiences
of Immigrant Groups)

Wasaaradda Caafimaadka ee Minnesota (Minnesota Department of Health)

Warbixin loo gudbinayo Xeer-dejiyeyaasha Minnesota 2014

(Report to the Minnesota Legislature 2014)

Febraayo 15, 2014

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Febraayo 15, 2014

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Darraasad Tayeed o ee Qoysaska leh Carruurta Qabta Autism ee Bulshada Soomaaliyeed (A Qualitative Study of Families of Children with Autism in the Somali Community): Isbar-bardhigga Waaya Aragnimada Kooxaha Muhaajiriinta (Comparing the Experiences of Immigrant Groups)

Warbixinta loo gudbinayo Wasaaradda Caafimaadka ee Minnesota

Febraayo 1, 2014

Waxaa soo gudbiyey Kooxda Cilmi-baarista Autism-ka (Submitted by the Autism Research Team):

- University of Minnesota, School of Public Health
- The Confederation of Somali Community in Minnesota
- West Side Community Health Services -- Somali, Latino and Hmong Partnership for Health and Wellness (SoLaHmo)



Kooxda Cilmi-baarista Autism-ka (siday xarfuhu u kala horreeyaan)

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Waxaan si kal iyo laab ah ugu mahad celinaynaa qofkasta oo kaalmo ka geystay darraasaddan.

Waxaan u mahad-celinaynaa u doodeyaashii bulshada Soomaaliyed ee u duubtay qoysaska ee suuragaliyey darraasaddan.

Waxaan u mahad-naqaynaa Xeer-dejiyeasha Minnesota iyo Wasaaradda Caafimaadka Minnesota ee maal-galiyey darraasaddan, isla markaasna nagu dhiirrigaliyey adeegsiga Darraasad Ku-salaysan Ka qayb-qaadashada Bulshada (Community-Based Participatory Research) (CBPR).

Xog-ogaalladii muhiimka ahaa ee bulshada ee la shaqeeyey qoysaska leh cunug autism qaba ayaa lagama maarmaan ahayd inay naga caawiyaan inaan fahamno hab-dhiska (system) isla markaasna fahamno caqabadaha ugu muhiimsan ee qoysaska hor taagan marka ay isku dayayaan inay adeegyo u helaan carruurtooda.

Waxaan kale oo u mahad celinaynaa Glendale & Brian Coyle Community Centers oo noo oggolaaday inaan xaruumahooda ku qabsanno kulammadii darraasadda. Goobahaasi ayaa ahaa meelo soo dhaweyn leh laguna shaqayn karo isla markaasna ay kooxaheennu u riyaaqayeen isla markaasna waxtar lahaa.

Ta ugu muhiimsani waa inaan u mahad-celinno waalidkii bulshooyinka Soomaalida, Latina iyo Hmong kuwaasoo waqtigooda iyo dadaalkoodaba u huray si ay noola wadaagaan khibradohoodi waxna noo baraan. Waxaa jiray waalidyo kale oo doonayey inay ka qayb qaataan darraasadda balse suuragali ay suura gali weyday sababtoo ah waqtigii oon noo saamixi waayey. Waxaan barannay in ka badan waxyaabaha lagu xusay warbixintan, waxaanan ka dhaxalnay faham dheeraad ah raad-reebka dhibta badan ee uu autism-ku ku hayo qoysaska. Waxaa si qoto dheer noo saameeyey kal gacalka, nafti-hurennimada iyo u firfircooniimada waalidku u hayaan inay carruurtooda u helaan nolosha ugu tayo wanaagsan ee la heli karo, waxaanan rajeynaynaa in warbixintani si ku habboon u iftiiminayso caqabadaha soo wajahay qoysaska, iyo adkaysiga iyo dulqaadkooda yaabka leh.

Kooxda Cilmi-baarista Autism-ka (Autism Research Team)

Guud-mar Hawl-fulin (Executive Summary)

Asal-ahaanta (Background)

2012^{dii} Xeer Dejiyeyaasha Minnesota ayaa amray darraasad ee khibradaha lagala kulmo lahaashaha cunug qaba Autism ee bulshada Soomaaliyeed. Darraasadda ayaa loogu talagalay in la fahmo dhinacyada dhaqanka iyo dhigaallada/agabyada su salaleysan ee ASDga (“cultural- and resource-based aspects of autism spectrum disorders) (ASD) ee u gaarka ah bulshada Soomaaliyeed. Kaddib marka ay oggolaatay Wasaaradda Caafimaadka Minnesota, darraasadda ayaa lagu soo daray bulshooyinka Hmong & Latino.

Ujeedooyinka/Dulucda (Objectives)

- In la qayaxo caqabadaha goor hore u ogaashada autism-ka;
- In la aqoonsado caqabadda ay waaridiintu la kulmaan marka ay raadsanayaan adeegyada;
- In la sameeyo talo jeedin wax looga qabanayo caqabadaha hor taagan qoysaska.

Hannaanka (Methods)

Darraasadda ayaa lagu adeegsanayaan cilmi-baarista ku-salaysan Ka qayb-qaadashada Bulshada (Community-Based Participatory Research) (CBPR) taasoo dhincayadeeda kala duwan ay si buuxda uga qayb qaadanayaan xubnaha bulshadu, haddii ay noqon lahayd aaaulka su'aalaha cilmi-baarista, qaabaynta talo jedinnada , iyo baahinta ama faahinta.

Cilmi-baareyaasha University of Minnesota, School of Public Health, Iskaashiga Somali, Latino & Hmong Partnership for Health and Wellness (SoLaHmo) of West Side Community Health Services and the Confederation of Somali Community in Minnesota (CSCM) ayaa iska kaashaday hirgalinta cilmi-baarista.

Cilmi-baarista ayaa loo kala sameeyey labo heer. Markii hore, waxaan waraysannay 33 xog-ogaal muhiim ah ayna ka mid yihiin hoggaamiyeeyaasha caqidooyinka, dhakhaatiir ,adeeg-bixiyeyaa autism, u doodeyaal, cilmi-baareyaal, shaqaalah xaruunta autism & naafada, shaqaalah degmada iyo xirfadleyaal ku lug leh adeegyada autism-ka ee hannaanka waxbarashada. Ujeedada waraysigaasi waxay ahayd in la kordhiyo fahamka caqabadaha hortaagan waalidka leh carruurta autism-ka qabta, lana cadeeyo su'aalaha khaaska ah ee cilmi-baarista si aad loogu kuurgalo wajiga/heerka labaad ee darraasadda.

Wajiga/heerha labaad ee cilmi-baarista, waxaan waraysannay 70 waalid: 38 Soomali ah, 17 Hmong ah iyo 17 Latino ah. Waraysiyada waxaa ka mid ahaa Guddi Talo-wadaag & waraysi shakhsiyeed (Focus Groups & Individual interviews). Su'aaluhu waxay ku wajahnna garashada/fahamka laga qabo autism-ka, dib u dhaca in si habboon loo garto ama tilmaansado cunugga autism-ka qaba, caqabadaha hortaagan helidda adeegyada aadka loogu baahan yahay, iyo talo jeedin ku aaddan hagaajinta sidii adeegyada loo helo.

Natiijooyinka (Results)

Aqoonta Autism-ka (Knowledge of autism):

- Hal-ku-dhega guud ee xog-ogaallada iyo waalidka la waraystay ayaa ahayd garasho la'aanta guud ee autism-ka, iyo aaminsanaanta aqoonto koboca cunugga iyo astaamaha iyo calaamadaha autism-ka inay kordhiso hore u ogaanshaha iyo dawaynta. Dhabitii eray bixinta “autism” kuma jirto luqadaha Soomaaliga iyo Hmong.
- Inkastoo waalid badan u arkaan autism-ka hab koboc koriimooyo xaaland daawo, bulshada Soomaalida iyo Latino ayaa aaminsan inuu ku lug leeyahay tallaallada. Bulshada Soomaalida iyo Hmong ayaa sidoo kale aaminsan arwaaxda sababisa autism.

Ammin hore garashada autism-ka (Early identification of autism):

- Sida badan, waalidka ayey ahaayeen kuwa ugu horreeyey ee dareemay in cunuggoodu ka duwan yahay ilmaha kale, in bandanna isku dayeen inay kaalmo u raadsadaan ammin hore.
- Waqtiga ku dhumay inta lagu ogaanayo mushkilada iyo sidii lagu heli lahaa cillada iyo dawaynta ayay ahayd il ugu wacneyd niyad-jabka waalidka.
- Waalidka ayaa sheegay caqabaha ogaanshaha amminka hore in ay ku dhacaan heerka shaqsiga(sida, aqoon la'aanta autism-ka iyo ilaha agabyada la heli karo, diidmo/dafirid ama in caadi laga dhigo hab-dhaqanka cunugga, takoorida naafannimada), heerka adeeg bixiyaha-(sida, si khaldan cillad u sheegid, midab takoor,caqadaha isfaham la'aan luqadeed), iyo Heerka hab-dhiska ama nidaamka- (sida, liis ama saf muddo dheer la sugayo si loo helo khabiir ku takhasusay cillad bixinta iyo dawaynta, mashaakilaad sidii loo naaquudi laha hab-dhiska ama nidaamka iyo helidda dhigaallada/agabyada ee ay uka sii dartatey caqabada aqoon la'aanta luqadda, mashaakilaad ka jira dhinaca daryeelka caafimaadka (insurance coverage) iyo kharajka- gaar ahaan bulshada Latino).

Caqabadaha hortaagan adeegyada (Challenges accessing services):

- Waalidka ayaa sheegay mashaakilaadka la soo dersa marka ay raadsanayaan adeegyada iyo agabyada la xiriira autism-ka oo ku xirran heerka shaqsiga (sida, kadeedka/walaaca uu ku hayo cunugga autism-ka qaba iyo cabsida ay u qabaan ammaankooda, baratanka/loolanka shaqada iyo baahida qoyska, ciribka ay ku reebayso waalidka , caafimaadka iyo daqaalaha qoyska, aqoon la'aanta dhigaallada/agabyada la heli karo), Ku xirran heerka Adeeg-bixiyaha (sida, caqabada is-faham la'aanta luqadda, cabashada adeeg bixiyeyaashu ayaan u sheegayn macluumaadka la xiriira adeegyada, dabagal la'aan, midab-takoor) , iyo Heerka Hab-dhiska (sida, muddo dheer sugid adeegyada, dhib badnaanta ama qalafsanaanta hab-dhiska maamulka, iyadoo ayan jirin adeegyo caawiya waalidka iyo xubnaha kale ee qoyska, caqabadaha luqadeed iyo dhaqan, cabashada

gaadiidka). Waxaa iantaasi dheer, waalidka Soomaaliyeed ayaa sheegay caqabado culus ee ka haysta sidii ay ku heli lahaayeen guryo ilmahoodu ku badbado ama amaan qabaan.

- Caqabadaha tas-hiilaadka adeegyada waalidka Latino ah waxaa sii culayseeyey xaaladdooda muhaajirnimo/socdaal oo ayan sharci lahayn (kuwaasoo ay suuragali karto in carruurtoodu Maraykanka ku dhasheen).
- Waalidka ayaa qiimeeyay adeegyada isla markaasna ka arkay soo wanaagsanaan cunuggoodii autism-ka qabay. Arrintu si kastaba ha ahaatee, daryeelka caafimaadku ma bixiyo adeegyo ku filan autismka (sida, adeegyada oon caymisku bixinayn, cadadka adeegyada oo xadidan, adeeg bixiyeyaasha oon aqbalin bukaanka haysta Medicaid). Waalidka ayaa tilmaamay inay dhib ku qabaan sidii ay u heli laheyn Medicaid; qaar ayaa tilmaamay in labada waalid midkood shaqadiisa ka tago, si ayan u dhaafin mushaarka laga rabo si ay ku helan daryeelka caafimaadka (Medical Assistance) .

Bug-cadda ama duleelada u dhexaysa adeegyada (Gaps in services):

- Waalidka ayaa sheegay inay doonayaan adeegyo badan oo jira sida xirfadaha nolosha & maanka (occupational therapy), Cilmiga fallaqaynta ama dib-u-habaynta hab dhaqanka aadamaha (applied behavior analysis), iyo daryeel adeegeyaal (personal care attendants).
- Waxaa intaasi dheer oo waalidku xusay in loo baahan yahay noocyoo cusub oo adeegyo ah. Tusaale:
 - ✓ Adeegyada Kaalmada qoyska u baahan yahay ayaa dhaafsiisan la talin iyo adeegyo kooxo taageera una baahan in la ballaariyo dhabna loogu kuur galoo qoysaska leh caruurta autism-ka qabta. Kaalmadaasi ayaa noqon karta mid bulshada u gaar ah, waalidkuna horseed u yahay (community specific and parent-driven), waalidkana fursad u siinaya inay xubanaha bulshadooda la wadaagaan waxyaabaha ay barteen.
 - ✓ Waxyaabaha manhajka ka baxsan, bulshaynta iyo waxqabadyada isboortiga la xiriira ee caruurta autism-ka qabta.
 - ✓ Adeegyo la siyo carruurta qaan gaardhka ah ee autism-ka qabta; si loo buuxiyo kaalinta bannaan kaddib markii ay ka gudbaan da'da dugsiga/iskoolka (fill the current void after children leave the school system).
 - ✓ Daryeel nasin ay siiyaan xubnaha bulshada ay isku dhaqanka yihiin

Xooga iyo Ad Adeyga qoysaska (Strength and resiliency of families):

Inkastoon darraasaddu culays gaara saarin, dhawr waxyaabood ayaa is-daba jog u soo if-baxayey:

- kal gacalka lixaadka leh, nafti-hurennimada iyo bogsan ogida ama ad adeeyga waalidkaasi ka sokow walaaca iyo caqabadaha soo wajaha marka ay daryeelayaan cunug autism qaba.
- Rabitaanka waalidku ay ku doonayaan inay ku caawiyaan waalidka kale ayaa ah Agab aan la faa'ideysan ee bulshada dhexdeeda ah.

Talo jeedinta waalidka (Recommendations of parents):

Darraasadda ayaa waalidka lagu weydiiyey waxa ugu muhiimsan ee ay doonayaan inay u sheegaan xeer-dejiyeasha inay sameeyaan si loo wanaajiyo adeegyada isla markaasna loo yareeyo waxyaalaha xannibaya. Bulshooyinka oo idil ayaa ku taliyey:

- In loo kordhiyo wacyi-galinta iyo macluumaad dheeraada ee la xiriira autism-ka taasoo munaasib u ah dhaqan iyo luqada bulsho walba; iyo
- Adeegyada kaalmada oo la siyo qoysaska (Support services for families)

Waxaa intaasi dheer, bulshada Soomaaliyeed ayaa ku nuux nuuxsaday adeegyo la jaan qaadi kara dhaqanka xasaasiga ah iyo sida loogu baahan yahay xaruun bulsho/Xaruun autism ay ka heli karaan dhigaallo, iyo adeegyo iyo sida loogu baahan yahay, guryo ammaan ah oo la awoodo (safe and affordable housing). Bulshada Hmong ayaa sidoo kale ku taliyey kaalmo dhaqaale dheeraad ah iyo deeq daboosha adeegyada aanu bixin daryeelka caafimaadku iyo kordhintaa maal galinta hay'adaha u adeega autism.

Bulshooyinka Latino & Hmong ayaa labaduba ku taliyey in la wanaajiyo daryeelka caymiska caafimaadka, iyadoo bulshada Latino sidoo kale ay ku talinayaan caymis daryeel caafimaad ee qoysaska autism-ka een sharciga lahayn.

Gebo gebada & tala-jeedinno (Conclusions and recommendations)

Ka sokow jaah-wareerka waalidku tilmaameen markii ay noo sheegayeen caqabadaha soo wajahay si ay ugu helaan carruurtooda adeegyada ay u baahan yihiin, ma ahayn kuwo caajisan-oo iska fadhiya oo sugaya qof ku xira carrrrooda adeegyada ay u baahan yihiin. Lidkeeda, waalid badan ayaa sheegay sheekoojin ay si fir-fircoo adeegyo ugu raadiyeen carruurtooda, iskuna dayayay inay naftooda iyo qoyskoodaba wax uga bartaan isku dhex yaaca (disorder), isla markaasna waqtii xad dhaafa ku qaadatay sidii ay carruurtooda ugu heli lahaayeen adeegyo, iyagoo la daalaa dhacaya hawlahaa kale ee qoyska iyo shaqadooda looga baahan yahay. Midna toddobaatanka waalid een waraysannay ma diidsana qiimaha adeegyadu u leeyihin carruurtooda; kuwa si jookta u helay adeegyo waxay sheegeen waxtar qimo leh oo si fican u

saameeyay noloshooda iyo tan cunugooda. Waalidka ayaa xiiseeyay, muujiyeyna rabitaan ay doonayaan inay waxbartaan, isla markaasna na baraan waaya aragnimadooda iyo caqabada.

Isla markaasna, iyagoo waalidku ilaalinaya ayna shuqlan yihiin, hab-dhiska ayaa gabay (system has failed them). Caqabada hortaagan helidda adeegyo tayo leh ayaa fara badan, ahna kuwo aan loo baahnayn. Runtii inkastoo bulshada Soomaliyeed ay ku fir fircoonaayeen u doodidda iyo taageeradooda adeegyada la xiriira autism-ka muddo hadda ka badan toban sano, welina wajahaan caqabado aan loo dulqaadan karin si ay kaalmo ugu helaan carruurtooda mana aha wax la yeeli karo. Mashaakilaadka soo wajaha qoysaska & bulshada Latino iyo Hmong ayaan la tixgelin, sidoo kale loo baahan yahay in loo arko kuwo aan loo dulqaadan Karin. Waxaan bartamaha uga jirnaa xilli aan oran karno waxaan ku jirnaa khal khal caafimaadka guud (public health crisis) marka la eego raad reebka autism-ka ee bulshada Minnesota. Waxaa jira shacab qoysaska Soomaaliyeed, oo in kastoo ay halgameen ayna qaybna ka qaateen, weli ay hortaagan tahay xaalado add u culus oo liita oo carruurtoodii ay qaban autismka kan ugu darran kuna socda da' weyn ama qaan gaar. Qoysaska iyo bulshaduba waxay ku jiraan wal bahaar weyn oo ba'an. Madaxda sharci dejiyeyaasha ayuu xil ka saran yahay inay tallaabo cad ka qaadaan, dibna wax uga qabtaan fashilka/guul darrada hab-dhiska (redress the failures in the system).

Haddii kale, waxaan qarka u saran nahay in jiil carruur ah autism inaga qaado, markaasna khasaaro aan laga soo kaban Karin ku reebno bulshada dhaqammada laga tiro badan yahay ee Minnesota ka mida.

Waalidka ayaa noo sheegay waxyaabaha soo wajaha iyo waxay u baahan yihiin. Talo jeedintenna waxay ku salaysan tahay ra'yi bixintooda.

Talo jeedin 1 (Recommendation 1)

In la ballaariyo mugga hadda jira ee waalidka si ay u kaabaan waalidka kale ee bulshooyinkan.

- In la abuuro barnaamij shaqaale bulshada (Shaqaale Bulsho ee autism-ka ka shaqeeya) (Community Autism Workers), loogana dayana barnaamijka Shaqaalaha Caafimaadka Bulshada (Community Health Workers program), Establish a program of community workers (Community Autism Workers), kaasoo horseedka waalidku ay waxbari karaan waalidka kale, siiyaan macluumaad la xiriira dhigaallada/agabyada, u doodaan, ka caawiyaan dhex jibaaxa hab-dhiska caafimaadka, iyo inay waalidkana ugu xiraan dhigaallada/agabyada.
- Xaqiijiyaan in shaqaalaha bulshadu yihiin kuwo leh awood xirfadeed, luqad iyo dhaqan ahaanba diyaarsan yihiin.
- Bulsho kasta xubnahoodu ay ka mid yihiin go'aameysika dhammaan hawl-gallada, fursadaha deeqaha, iyo guddiyada dejiya nidaamka arrimaha la xiriira autismka.

Tajo jeedinta 2 (Recommendation 2)

In bulshada dhexdeeda laga abuuro xaruun dhigaal/agab

- In bulshooyinka gudahooda lagu maal-galiyo xaruumo dhigaal/agabyo, si fududna macluumaadka lagu heli karo.
- In la taageero horumarinta xaruun autism oo u gaar ah bulshada Soomaaliyeed, bartilmaameed iyo munaasiba u ah adeegyada naafada aadka u daran.
- In xaruumaha laga shaqaaleysiyo shaqaalo daqan iyo afba ku haboon bulshadaha ay khidmadaha siiyan si buuxdana u yaqaan fahamsanna autism-ka iyo higaalladiisa/agabyadiisa.

Talo jeedinta 3 (Recommendation 3)

La abuuro agabyo/dhigaallo lagu sameeyo guddiyo tala-wadaag ee qoysaska.

- La maal-galiyo hay'adaha bulshada si loogu qabto guddiyo talo-wadaag joogto ah bulshooyinkaasi dhexdooda.
- La caddeeyo lana kaabo xaruumo ehel u ah dhaqanka iyo luqadda adeeg bixiyeyaasha ka sokow.

Talo jeedinta 4 (Recommendation 4)

In la xoojiyo hab-dhiska (capacity in the system) si loo helo adeegyada dhaqan xasaasiga ah loona yareeyo waqtiga badan ee la sugo ageegyadaasi.

- In lagu kaabo guddi horumariya adeeg-bixiyeyaasha autism-ka ayna ka mid yihin shaqaalaha bulshada.
- In la yagleeyo hab-dhis lagu xisaabiyo muddo sugida ama inta ay ka qaadato bulshooyinka dhaqamada kala duwan inay helaan agab.
- In loo sameeyo shaqaale heer degmo ah ee ku takhasusay autism-ka, isla markaasna garan kara hiddaha, dhaqan iyo afka dadka ay u adeegayaan, isla markaasna kaabad u noqon kara shaqalaha autismaka bulshada (Community Autism Workers).
- In la xadido mudada sugitaanku ku eg yahay, lana eego, lana qiimeeyo horumarka.
- In takhaatiirka lagu wacyi galiyo baaritaanka munaasibka ah iyo qiimaynta autism-ka.

- In la sameeyo darraasad tijaabo fara-galin/soo dhix-gal sida “Su’alaha Saxan ee Mashruuca (‘Right Question Project’) si loo wanaajiyo xiriirka ka dhixeeya xirfadleyaasha iyo waalidka.
- In xaruunta bulshada la keeno adeegyada baaritaanka amiinka hore ee wareega (mobile screening services), ayna weheliyaan shaqaale dhaqanka iyo luqaddaba si wanaagsan u garanaya.
- In la eego farqiga/sinnaan la’anta u dhixaysa adeegyada, ayna ka mid in loo qaleeyo carruurta caymiska guud ku jira (publicly insured children).
- in la xaqijiyo in dugsiyada leeyihii mug ay bixin karaan adeegyo leh tayo iyo adeegyo caddayn/markhaati ku-salaysan) ee carruurto autism-ka qabta (evidence based services to children with autism).
- In la kordhiyo shirarka loo qabto waalidka iyo dugsiga iyadoo turjubaanno la adeegsanayo.
- In si buuxda loogala xisaabtamo hab-dhiska dugsiga tayada iyo habbooni/ku fillaanta adeegyada autism-ka ee ay bixiyaan.

Talo jeedinta 5 (Recommendation 5)

In xil loo helo oo la xuso mashaakilaadka iyo kharajka la xiriira daryeelka caafimaadka.

- In la eegyo saamaynta dib u qaabaynta daryeelka caymiska autism-ku ku leeyahay adeegsiga adeegyada carruurta bulshada kala dhaqammada duwan.
- In la xaqiqiyo adeegyo cayiman/gaar ah oo dhammaystiran ee autism sida “Dheefta Caafimaadka Lagama maarmaanka ah” ee isku beddelashada Caafimaadka (Essential Health Benefits in health exchanges).
- in lagu daro daryeelka caafimaadka carruurta aan sharciga lahayn (Medical coverage).
- In laga caawiyo ku diiwaan gelinta macluumaadka dheefta (enrollment and benefit information) taasoo loo arko kuwo la aamini karo kuwo aan laga cabsanayn/baqayn (non threatening), sida, u soo celinta kharajka Shaqaalaha Bulshada Autism-ka ka shaqeeya(Community Autism Workers).