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Samoopredelitev odraslih oseb z diagnozo avtizem iz Slovenije

Povzetek: Vprašanje poimenovanja posameznika in/ali (manjšinske) družbene skupine je zelo občutljivo in se mu v večini družb, ki upoštevajo načeli spoštovanja in nediskriminatornosti, namenja kar nekaj raziskovalne pozornosti. S poimenovanjem zlasti manjšinskih družbenih skupin se do določene mere (lahko) opredeli tudi njihov položaj v odnosu do večinske skupine oz. nekakšna družbena hierarhija, pa tudi perspektiva, skozi katero se gleda na odločujočo značilnost te skupine (npr. jezik in narodnost, spol, posebne potrebe). Pri tem pa se neredko spregledajo preostale značilnosti, ki prav tako pomembno vplivajo na življenje pripadnikov manjšinskih skupin. V zadnjih letih se v tem kontekstu uveljavlja praksa, da se o poimenovanju povpraša pripadnike proučevane manjšinske skupine, kar je bil osnovni namen raziskave, katere del je predstavljen v prispevku. Odrasle osebe z diagnozo avtizem ($n = 55$) so utemeljile, katera v Sloveniji prepoznana poimenovanja doživljajo kot žaljiva in katera preferirajo. Kvalitativna analiza pokaže, da med anketiranci ni konsenza o najbolj zaželenem poimenovanju, medtem ko z vidika v teoriji prepoznanih paradigem (najprej oseba, najprej identiteta) v odgovorih prevladuje preferenca poimenovanj najprej oseba. Kot najmanj zaželeno poimenovanje so anketiranci opredelili oseba z avtističnimi motnjami, ki je sicer trenutno uradno poimenovanje v slovenski zakonodaji (ZUOPP-1 2011), predvsem ker v poimenovanju poudarja patologijo, motnjo in nakazuje na napako v osebi sami.

Ključne besede: avtizem, samoopredelitev, terminologija, najprej oseba, najprej identiteta

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Znanstveni prispevek

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Uvod

Izraz, ki se uporablja za poimenovanje avtizma in oseb z avtizmom,¹ se že od prvih opisov avtizma v 40. letih prejšnjega stoletja spreminja, v zadnjih letih pa je pogosto osrednja tema razprav in raziskav. Terminologija, ki jo uporabljamo, lahko vpliva na zaznavanje okolice, zakonodajo, dostop do ustrezne pomoči in podpore ter možnost samozagovornišтва (Lei idr. 2021; Vivanti 2020). Poimenovanje je pomembno, saj (so)vpliva na razumevanje avtizma in vzpostavljanje odnosov, kar potrjujejo tudi raziskave, da se namreč osebe z avtizmom v obdobju šolanja, predvsem zaradi nerazumevanja učiteljev in vrstnikov, pogosto počutijo izključene, neredko so tudi žrtve ustrahovanja (Cappadocia idr. 2012; Cunningham 2022). V Sloveniji je bila v Zakonu o usmerjanju otrok s posebnimi potrebami (ZUOPP-1 2011) ta skupina učencev (poimenovana kot otroci z avtističnimi motnjami) relativno pozno prepoznana in pri nekaterih odraslih z avtizmom se kaže, da v času šolanja niso dobili potrebnih oblik pomoči na področju komunikacije in socialnih spretnosti. Negativne izkušnje v odnosih z vrstniki in učitelji v obdobju šolanja pa lahko negativno vplivajo na njihove odnose v odrasli dobi (Rogič Ožek 2023). Predvsem jezik, ki se uporablja v odnosu z osebami z avtizmom, lahko vpliva na dojemanje okolice in s tem poveča ali zmanjša tveganje za omenjene težave (Botha idr. 2023), saj nekatere od teh izhajajo iz nerazumevanja oziroma neprilagojenosti okolja, lahko pa tudi sama strukturiranost okolja že obstoječe težave še dodatno poglobi (Keating idr. 2023).

Prvi sistematični opis značilnosti avtizma oz. »avtistične okvare afektivnega stika« (Kanner 1943) je objavil Leo Kanner, ki je identificiral dve pglavilni značilnosti, in sicer velike težave v socialni interakciji in odpor do sprememb oz. težnjo po ohranjanju enakosti (prav tam). Istega leta je avtizem oz. »avtistično psihopatijo« opisal tudi Hans Asperger, ki je opazoval otroke z nadpovprečno inteligentnostjo in identificiral podobne značilnosti kot Kanner. Leta 1981 je njegov (izvorno v nemščini pisan) članek v angleškem jeziku predstavila Lorna Wing,

1 Termin, ki ga uporabljamo v prispevku, se razlikuje od poimenovanja v zakonodaji. Izbira uporabljenega termina temelji na znanstveni literaturi in raziskavi, predstavljeni v prispevku.

ki je opazovani fenomen poimenovala »Aspergerjev sindrom«, k Aspergerjevim pa je dodala še svoja opažanja in predlagala vključitev spektra in triade primanjkljajev (na področju socialne interakcije, komunikacije in imaginacije) v diagnozo (Hippler in Klicpera 2003).

Kljub drugačnim prvim opisom že v 40. letih je bil avtizem v drugi izdaji *Diagnostičnega in statističnega priročnika duševnih motenj* (v nadaljevanju DSM) Ameriškega psihiatričnega združenja, ki je bil objavljen leta 1968, opredeljen kot infantilna psihoza pod kategorijo otroške shizofrenije. Kannerjeva podlaga za diagnozo je bila vključena šele v DSM-3 leta 1980 kot »otroški avtizem« (Harris 2018), DSM-4, ki je bil izdan leta 1994, pa je avtizem razdelil na štiri kategorije: avtistične motnje, Rettov sindrom, otroško dezintegrativno motnjo in Aspergerjev sindrom. Te kategorije so bile v DSM-5 (2013) odpravljene in začel se je uporabljati nov enoten termin »motnje avtističnega spektra«.

Medtem ko med strokovnjaki diskusija o terminologiji večinoma temelji na tem, kako najbolj učinkovito opisati *stanje*, je vidik oseb, ki jih s tem opisujejo, pogosto spregledan (Vivanti 2020). Tudi to se je v zadnjih letih začelo spreminjati. Ena izmed ključnih sodobnih raziskav, ki je diskusijo prenesla v širši krog, je bila opravljena v Veliki Britaniji med osebami z avtizmom, njihovimi starši in preostaliimi družinskimi člani oz. prijatelji ter strokovnjaki (Kenny idr. 2016). To je bila po dostopnih informacijah prva raziskava, ki je v debato vključila tudi osebe z avtizmom. Pokazala je, da strokovnjaki in starši na poimenovanje gledajo drugače kot te osebe same. Odprla je pot podobnim raziskavam, ki temeljijo na tem, da dajo glas proučevani skupini, da vodi pogovor o lastni identiteti. Izhajanje iz skupine teh oseb glede preference pri poimenovanju samih sebe je pomembno tudi zato, ker nekateri raziskovalci ugotavljajo, da so osebe z avtizmom v vsakodnevni situacijah izključene iz te diskusije; zgodi se tudi, da jim drugi (predvsem učitelji, specialisti in starši) vsiljujejo izraze, ki so po njihovem mnenju najbolj primerni, izkušnje pa imajo tudi s tem, da jih osebe brez avtizma popravljajo pri uporabi določenih izrazov (Keating idr. 2023).

V Sloveniji je ključen termin, prepoznan v zakonodaji, *oseba z avtističnimi motnjami*, ki se uporablja ob postavitvi diagnoze in v šolskem obdobju odločbe (Kriteriji ... 2015). Opredelevitev značilnosti avtističnih motenj, ki se uporablja v Sloveniji, temelji sicer na definiciji zadnje izdaje DSM-5 (2013), pa vendar v samem poimenovanju te skupine nismo prevzeli izraza »motnje avtističnega spektra«, ki je od leta 2013 uporabljen v tem priročniku.

Zgodovinski vidik poimenovanja

Skozi zgodovino so bile osebe, ki so na podlagi različnih značilnosti močno odstopale od večine, pogosto izločene iz družbe. V tem kontekstu je tudi veljalo, da je bilo za označevanje specifičnosti raznih skupin oseb s posebnimi potrebami primarno v uporabi poimenovanje, ki je na prvo mesto postavilo motnjo oz. diagnozo (v nadaljevanju nM – *najprej motnja*). Začele so se pojavljati kritike takega poimenovanja, saj se tako poudarjajo težave, identiteta osebe se enači z motnjo,

poimenovanje pa ima zato negativen prizvok (Dwyer 2022). Konsenz tako v strokovnih krogih kot pri teh osebah samih je, da se taka poimenovanja danes več ne uporabljajo.

Da bi obrnili perspektivo, se je v 70. letih začela uporabljati terminologija, ki se osredotoča na to, da se oseba postavi pred diagnozo (v nadaljevanju nO – *najprej oseba*); s tem se tudi sporoča, da so si osebe z isto diagnozo lahko različne in da je motnja zgolj del identitete, ki pa osebe ne definira v celoti (Dwyer 2022; Vivanti 2020). Preferenca do take vrste poimenovanja sicer ni prišla od oseb z avtizmom, temveč od strokovnjakov (Botha idr. 2023), in se je uveljavila predvsem v strokovnih krogih.

Ta način poimenovanja v zadnjem času vedno pogosteje kritizirajo tako osebe z avtizmom kot tudi nekateri strokovnjaki, predvsem z dveh vidikov. Trdijo namreč, da je avtizem bistven del posameznikove identitete, ki ga ni mogoče ločiti od nje, ter da ob uporabi poimenovanj z osebo na prvem mestu potrdimo stigmo, da je avtizem nekaj slabega in nezaželenega (Bury idr. 2023; Vivanti 2020). Primernejši izrazi po tej paradigmi so tisti, ki na prvo mesto postavijo identiteto (v nadaljevanju nI – *najprej identiteta*). Po zasnovi terminov so ti sicer zelo blizu ali celo enaki poimenovanju nM, po pojmovanju pa so popolnoma drugačni, saj prej negativni konotaciji in s tem stigmati spremenijo pomen in poudarjajo, da bi morale biti osebe z avtizmom ponosne na svojo identiteto in nevrorazličnost (Dwyer 2022; Taboas idr. 2023).

Koncept *nevrorazličnosti* (*neurodiversity*) je vedno bolj pogosto uporabljan in je nadpomenka ne le izrazu avtizem, temveč tudi drugim oblikam nevrorazličnosti (npr. ADHD, učne težave). V paradigmi avtizem kot *nevrorazličnost* niso poudarjene zgolj težave, temveč tudi močna področja avtizma in različne vrste potreb posameznikov na različnih področjih (den Houting 2019).

Podoben premik v poimenovanju, ki poudarja, kako je poimenovanje pomembno za razumevanje samega sebe kot pripadnika določene skupine oseb, se je pred tem zgodil tudi pri drugih skupinah, denimo invalidnih, slepih, slabovidnih, gluhih in naglušnih oseb (Bias-Free Language 2022). Zato Ameriško psihiatrično združenje (prav tam) poudarja, da ko vemo, kakšno vrsto poimenovanja neka skupina preferira, to uporabljamo kot naše izhodišče. Podobno stališče imajo tudi nekateri raziskovalci na področju poimenovanja skupine oseb z avtizmom (Botha idr. 2023). Kakšno vrsto poimenovanja torej preferirajo osebe z avtizmom?

»Najprej identiteta« ali »najprej oseba«?

Pri oblikovanju terminov se v sodobnosti pojavljata dve primarni paradigmi – poimenovanje z osebo na prvem mestu, torej nO (npr. *oseba z avtizmom*), in poimenovanje z identiteto na prvem mestu, torej nI (npr. *avtistična oseba*). Tako nastali poimenovanji naslavljata problem negativnih konotacij določenih izrazov z dveh različnih zornih kotov: medtem ko prvi poudarja, da je oseba več kot zgolj diagnoza, drugi poudarja, da je diagnoza pomemben del osebe ter mora biti vir spoštovanja in ponosa (Vivanti 2020).

Osebe z avtizmom glede na raziskave v tujini po večini preferirajo izraze nI (npr. Taboas idr. 2023). Kot razlog za preferiranje teh izrazov navajajo utemeljitev, da avtizem ni »dodatek«, ki ga lahko odložijo ali ločijo od svoje osebnosti (Keating idr. 2023). Osebe z avtizmom se na takšen način povežejo v širšo skupnost, značilnosti, ki so pogosto videne kot težave, pa se v konceptu nevrorazličnosti redefinirajo kot del človeške raznolikosti (Bury idr. 2023). Te značilnosti so neredko tudi njihovo močno področje (npr. kategoriziranje, sistematiziranje in poznavanje dejstev) (Lai idr. 2014), kar jih opolnomoči in so nanje lahko ponosni. Obenem s tem prevzamejo moč nad v preteklosti uporabljenimi negativnimi izrazi, kot je značilno tudi za nekatere druge marginalizirane skupnosti. Besedna zveza »oseba z ...« je po večini oblikovana za poimenovanje patoloških ali zdravstvenih značilnosti (npr. oseba z rakom), nasprotniki tovrstnih izrazov zato menijo, da oblika izraza »oseba z avtizmom« namiguje, da je avtizem nekaj slabega, nekaj, kar je treba odstraniti ali ozdraviti (Botha idr. 2023; Keating idr. 2023). Taka oblika poimenovanja se praviloma ne uporablja za opis nevrotipičnosti ali drugih praviloma bolj pozitivno dojemanih lastnosti (npr. ne uporablja se izraz »oseba s tipičnim razvojem«) (Bury idr. 2023). Botha, Hanlon in Williams (2023) se sprašujejo tudi, ali res moramo uporabiti specifičen izraz, da se spomnimo, da je nekdo v prvi vrsti oseba.

Glede na že obstoječe raziskave izraze nI preferira večina oseb z avtizmom, pa vendar obstaja nezanemarljiv delež takih, ki jim te vrste izrazov niso blizu. Nekaterim osebam z avtizmom namreč menijo, da je način izražanja nI ponižujoč in dehumanizirajoč (Bury idr. 2023; Keating idr. 2023). Preferenca do izrazov nO navadno izhaja iz želje posameznikov, da je avtizem prepoznan zgolj kot le en del njihove osebnosti, saj da ne opiše njihove osebnosti v celoti (Keating idr. 2023), medtem pa poimenovanja nI bolj pogosto povezujejo s stigmo, vezano na poimenovanja nM (Bury idr. 2023).

Analize konkretnih poimenovanj

Iz raziskav je razvidno, da ni popolnega konsenza o obliki izrazov, še manj o konkretnem izrazu, ki naj bi se uporabljal (Botha idr. 2023; Kenny idr. 2016). Nekaterim je neki termin najljubši, medtem ko je drugim isti termin najbolj žaljiv. Kljub temu pa je v različnih raziskavah opaziti konsenz pri odmiku od terminov, ki napeljujejo na to, da je avtizem »motnja« (Bury idr. 2023; Keating idr. 2023; Kenny idr. 2016), saj vključevanje tega izraza v terminologijo namiguje, da je s temi osebami nekaj narobe oz. da je njihova »diagnoza« nekaj tragičnega. Poudarjanje motenj je značilnost medicinskega diskurza (Bottema-Beutel idr. 2021; Bury idr. 2023; Lei idr. 2021), toda vsakršnega odstopanja od tipičnega še ne moremo opredeliti kot motečo lastnost, saj je ta percepcija odvisna od socialnega konteksta, kar poudarja tudi koncept nevrorazličnosti. Nekaterim osebam z avtizmom je uporaba besed »nezmožnost« oz. »primanjkljaj« (*disability*) in »motnja« (*disorder*) za opisovanje samih sebe v nasprotju z njihovo identiteto in privede

do dodatnih ovir in nepripravljenosti, da se s svojo diagnozo izpostavljajo drugim (Lei idr. 2021).

Ovira, motnja ali primanjkljaj so izrazi, ki niso nepomembni v procesu oblikovanja identitete posameznika. Jezik in komunikacijski sistemi so eden izmed glavnih dejavnikov, ki vplivajo tudi na kulturno identiteto skupnosti oseb z določenimi ovirami. To pa se ne kaže zgolj v komunikaciji med osebami z določenimi ovirami, motnjami oz. primanjkljaji, temveč tudi v razpravah o njih in z njimi (Kunt in Zászkaliczky 2011). Družbena identiteta tako temelji na ponotranjenju družbenih kategorij in stereotipov, izhaja iz medskupinskih primerjav in iz osebe kot unikatnega individuuma (Razpotnik 2004). Skupine oseb z neko oviranostjo na podlagi svoje oviranosti in socialnega pomena ovir, ki jim ga pripiše družba, oblikujejo lastno identiteto (Forber-Pratt idr. 2017). Tudi avtizem je postal pomemben del družbene identitete in kulture (Botha in Gillespie-Lynch 2022). Raziskave kažejo, da močnejši je občutek, da je avtizem del posameznikove identitete, večja verjetnost je, da bo posameznik preferiral termine nI in jih manj pogosto označil kot žaljive (Bury idr. 2023; Keating idr. 2023). Večjo verjetnost, da bo posamezna oseba neki termin doživljala kot žaljiv, pa prinaša tudi izkušnja negativne uporabe tega termina v preteklosti (Bury idr. 2023).

Eden izmed izrazov, pri katerem je opaziti največ konsenza, je »oseba na (avtističnem) spektru«, ki tudi zaradi predloga *na* daje bolj pozitivno konotacijo, zaradi česar je tudi ena izmed manj žaljivih oblik poimenovanja in celostno gledano med bolj zaželenimi (Botha idr. 2023; Bury idr. 2023). Povezuje poudarek na osebi in raznolikost (Bury idr. 2023), čeprav nekateri opozarjajo, da uporaba besede *spekter* odvzame oz. zmanjša pomen avtizma za delovanje posameznikov, hkrati pa avtizem tudi umetno razdeli na visoko- in nizkofunkcionalnega (Kenny idr. 2016).

Večina do zdaj objavljenih raziskav je bila opravljena na angleško govoreči populaciji, pri čemer se razlike v preferenci do uporabe posameznih terminov kažejo že med različnimi angleško govorečimi državami (Keating idr. 2023), še bolj očitne pa so v drugojezičnih državah in okoljih; npr. osebe z avtizmom iz nizozemsko govorečega okolja v nasprotju z angleško govorečimi osebami preferirajo izraze tipa nO (Bosman in Thijs 2024; Buijsman idr. 2023; De Laet idr. 2023), v francosko govorečem okolju je pa najbolj preferiran izraz (*avtistična oseba* oz. *personne autiste*) lahko dojeman hkrati po paradigmi nO in tudi paradigmi nI (Geelhand idr. 2023; Fecteau idr. 2024). Za bolj celostno razumevanje preference do terminov so potrebne raziskave med posamezniki, ki prihajajo iz različnih jezikovnih in kulturnih okolij (Bottema-Beutel idr. 2021; Bury idr. 2023).

Potreba po raziskavah na tem področju se kaže tudi v slovenskem okolju, saj je ob pregledu terminologije v znanstveni in strokovni literaturi ter na spletnih straneh, namenjenih osebam z avtizmom, opaziti, da so uporabljeni izrazi lahko zelo različni.

Metodologija in zbiranje podatkov

Namen študije

Ker v Sloveniji še ni bila opravljena oz. objavljena raziskava o samoopredelitvi oseb z avtizmom, je bil temeljni namen študije od odraslih z avtizmom pridobiti utemeljena stališča do različnih poimenovanj te družbene skupine v slovenski družbi in ugotoviti razlike v preferencah do izrazov glede na dožemanje avtizma, spol in obdobje prejema diagnoze (podobno tudi npr. Buijsman idr. 2023 in Keating idr. 2023). Posebej nas je zanimalo:

1. Kako osebe z avtizmom dojemajo avtizem?
2. Katera uveljavljena poimenovanja osebe z avtizmom preferirajo in zakaj?
 - 2.1 Ali obstajajo razlike v preferencah do izrazov glede na dožemanje avtizma, spol in obdobje prejema diagnoze?
3. Katera uveljavljena poimenovanja osebe z avtizmom ocenjujejo kot žaljiva in zakaj?
 - 3.1 Ali obstajajo razlike v žaljivosti izrazov glede na dožemanje avtizma, spol in obdobje prejema diagnoze?

Predstavljene analize podatkov so del kompleksnejše raziskave v sklopu doktorskega študija, v kateri smo poleg stališč odraslih z avtizmom do različnih poimenovanj te družbene skupine raziskali še morebitne izkušnje z mikroagresijo in diskriminacijo ter avtostigmatizacijo.

Raziskovalna metoda

Izvedena je bila empirična raziskava, ki je temeljila na kombinaciji deskriptivne in kavzalne neeksperimentalne raziskovalne metode. Podatke smo zbirali s spletnim anketnim vprašalnikom, ki je bil oblikovan na podlagi tujih študij (Bury idr. 2023; Keating idr. 2023; Kenny idr. 2016) in je zajemal vprašanja, vezana na všečnost in žaljivost izrazov, ki se uporabljajo v slovenskem prostoru, ter preferenco oz. ranžirno vrsto izbranih terminov. Termini so bili, podobno kot v nekaterih že objavljenih raziskavah (Keating idr. 2023; Kenny idr. 2016), izbrani tako, da so zastopali obe relevantni paradigmi (nO in nI) in se primarno uporabljajo v strokovni, zlasti medicinski sferi (npr. oseba z avtističnimi motnjami, oseba z motnjo avtističnega spektra, oseba na avtističnem spektru, oseba z Aspergerjevim sindromom) ter tudi neformalno znotraj določenih krogov in društev (avtist, aspi, avtistična oseba, oseba z avtizmom).

Raziskovalni vzorec

Na povabilo k sodelovanju v raziskavi se je odzvalo 97 ljudi, v končno analizo smo vključili 55 anketirancev (izključili smo tiste, ki niso odgovorili na vsa vprašanja oz. niso opredelili, da imajo diagnozo avtizem), kar glede na predvidevanje, da je v Sloveniji cca 200 odraslih z diagnozo avtizem (po oceni, da je prevalenca avtizma po svetu 1 % (Lai idr. 2014)), pomeni 27,5 % osnovne populacije. Z vidika spola so prevladovalе ženske, saj jih je bilo več kot polovica ($n = 31$ oz. 56,4 %), moških je bilo manj ($n = 21$ oz. 38,2 %), nekaj sodelujočih pa se spolno ni želelo opredeliti ($n = 3$ oz. 5,4 %). Anketiranci so bili v povprečju stari 30,16 leta ($SD = 1,636$). Večina jih je diagnozo prejela že kot polnoletna oseba, v povprečju pa v starosti 21,23 leta ($SD = 1,674$). Najpogosteje so bili njihovi starši tisti, ki so prvi prepoznali, da imajo morda avtizem ($n = 17$ oz. 31,0 %), neredko pa so to prepoznali sami ($n = 15$ oz. 27,3 %). Pri vprašanju o pridobljeni izobrazbi je šest anketiranih iz skupine najmlajših izbralo zaključeno OŠ (10,9 %), med preostalimi pa štirje poklicno (7,3 %), šest strokovno (10,9 %), 19 gimnazijo (34,6 %), osem visokošolsko (14,5 %), osem univerzitetno izobrazbo (14,5 %), trije so imeli znanstveni magisterij in eden doktorat (1,9 %). Polovica anketirancev živi s starši ($n = 28$ oz. 50,9 %), četrtina sama ($n = 14$ oz. 25,5 %), desetina (10,9 %) oz. šest z lastno družino in trije s sostanovalci (5,4 %); trije (5,4 %) so izbrali odgovor »Drugo« (npr. s sestrama v študentskem domu, s sestro in očetom).

Postopek zbiranja podatkov

Zaradi težje dostopnosti izbrane populacije (odrasli z avtizmom) smo povabilo k sodelovanju poslali na različne naslove: koordinatorjem za študente s posebnimi potrebami treh slovenskih univerz (Ljubljana, Maribor, Koper), različnim društvom (Bravo, Aspi, Društvo študentov invalidov Slovenije, Modri december), skupinam za osebe z avtizmom na Facebooku in posameznikom, za katere smo vedeli, da sodijo v izbrano populacijo, s prošnjo, da k sodelovanju povabijo še preostale, ki jih poznajo. Vprašalnik v elektronski obliki je bil dostopen v aplikaciji 1KA tri mesece (od 10. februarja do 10. maja 2024) in je vključeval 19 vprašanj (izbirnega, odprtega in kombiniranega tipa).

Obdelava podatkov

Numerične podatke, pridobljene z anketnim vprašalnikom, smo obdelali kvantitativno, na nivoju deskriptivne in inferenčne statistike (frekvence, odstotki, srednje vrednosti, t-test). Odgovore na odprta vprašanja iz anketnih vprašalnikov pa smo analizirani kvalitativno deduktivno oz. hermenevtično v skladu s postavljenimi raziskovalnimi vprašanji (Mesec 2023; Vogrinc 2013).

Rezultati in interpretacija

Primanjkljaj, motnja, nevrorazličnost?

Na kombinirano vprašanje, kaj je za njih avtizem, jih je velika večina ($n = 36$ oz. 65,5 %) odgovorila, da je to nevrorazličnost. Nekaj udeležencev je izbralo odgovor, da je avtizem motnja (14,5 %). Najmanj se jih je opredelilo, da je to bolezen (1,9 %) ali ovira (3,6 %), nihče pa se ni opredelil, da je avtizem primanjkljaj. Osem anketirancev je izbralo odgovor »Drugo«, navajali so naslednje odgovore: »a way of being; avtizem je od zunaj družbeno nesprejemljiv, od znotraj pa ga sploh ni«, »več zgoraj naštetega, odvisno od posameznika«, »posebnost«, »drugačen pogled na svet«, »ni nič od naštetega«, »ne vem, kako bi opredelila, zagotovo pa ne bi uporabila zgoraj navedenih izrazov«, »prednost«.

Zaželenost in žaljivost uporabe izbranih terminov v slovenskem prostoru

Udeleženci so izraze, ki se za poimenovanje oseb z avtizmom uporabljajo v slovenskem prostoru, na sedemstopenjski Likertovi lestvici označili glede na to, kako so jim všeč (1 – sploh mi ni všeč, 7 – zelo mi je všeč). V Preglednici 1 so izrazi razvrščeni glede na aritmetično sredino, na prvem mestu je izraz, ki je bil anketirancem v povprečju najbolj všeč.

Št.	Termin	M	SD	Strinjanje (1 – sploh mi ni všeč / 7 – zelo mi je všeč)						
				1	2	3	4	5	6	7
1	oseba na avtističnem spektru	4,56	1,893	7 12,7 %	3 5,5 %	5 9,1 %	5 9,1 %	13 23,6 %	16 29,1 %	6 10,9 %
2	oseba z avtizmom	4,40	2,157	8 14,5 %	7 12,7 %	5 9,1 %	3 5,5 %	11 20,0 %	9 16,4 %	12 21,8 %
3	oseba z motnjo avtističnega spektra	4,27	1,986	9 16,4 %	4 7,3 %	6 10,9 %	4 7,3 %	13 23,6 %	14 25,5 %	5 9,1 %
4	avtistična oseba	4,25	2,084	9 16,4 %	6 10,9 %	5 9,1 %	5 9,1 %	9 16,4 %	14 25,5 %	7 12,7 %
5	aspi	4,20	2,138	12 21,8 %	3 5,5 %	4 7,3 %	7 12,7 %	7 12,7 %	16 29,1 %	6 10,9 %
6	oseba z Aspergerjevim sindromom	4,16	2,115	11 20,0 %	4 7,3 %	6 10,9 %	4 7,3 %	11 20,0 %	12 21,8 %	7 12,7 %
7	avtist	4,04	2,194	10 18,2 %	9 16,4 %	5 9,1 %	4 7,3 %	8 14,5 %	10 18,2 %	9 16,4 %
8	oseba z avtističnimi motnjami	3,29	1,941	12 21,8 %	13 23,6 %	8 14,5 %	4 7,3 %	8 14,5 %	7 12,7 %	3 5,5 %

Preglednica 1: Izrazi glede na všečnost (Likertova lestvica)

Z vidika vsečnosti lahko ugotovimo, da so na prvih treh mestih poimenovanja, ki jih v teoriji uvrščamo v skupino poimenovanj nO in naj bi bila bolj pogosta izbira strokovnjakov (Botha idr. 2023), ki proučujejo osebe s to diagnozo, kot samih oseb z avtizmom. Glede na aritmetično sredino je najmanj všečno poimenovanje oseba z avtističnimi motnjami, ki pa je v Sloveniji formalno sprejeto. Statistično pomembno razliko ($p = 0,010$) smo ugotovili pri izrazu oseba z avtizmom, ki je anketirancem, ki avtizem dojemajo kot motnjo, bolezen, oviro ali primanjkljaj ($M = 5,55$, $SD = 0,93$), bolj všeč kot tistim, ki ga dojemajo kot nevrorazličnost ($M = 4,28$, $SD = 2,26$). T-test je pokazal, da ni bilo statistično pomembnih razlik med spoloma (moški in ženski) glede vsečnosti izrazov, prav tako ne med anketiranci, ki so diagnozo dobili pred dopolnjenim 18. letom ali po tem.

Udeleženci so termine na sedemstopenjski Likertovi lestvici označili tudi glede na žaljivost (1 – sploh ni žaljiv, 7 – zelo je žaljiv). V Preglednici 2 so izrazi razvrščeni glede na aritmetično sredino, na prvem mestu je povprečno najbolj in na zadnjem povprečno najmanj žaljiv izraz.

Št.	Termin	M	SD	Žaljivost (1 – sploh ni žaljiv / 7 – zelo je žaljiv)						
				1	2	3	4	5	6	7
1	avtist	3,65	2,192	12 22,2 %	10 18,5 %	5 9,3 %	4 7,4 %	10 18,5 %	7 13,0 %	6 11,1 %
2	oseba z avtističnimi motnjami	3,55	1,864	8 14,5 %	11 20,0 %	12 21,8 %	5 9,1 %	10 18,2 %	4 7,3 %	5 9,1 %
3	avtistična oseba	3,04	1,721	14 25,5 %	11 20,0 %	8 14,5 %	9 16,4 %	8 14,5 %	4 7,3 %	1 1,8 %
4	aspi	3,02	1,890	12 21,8 %	18 32,7 %	5 9,1 %	10 18,2 %	3 5,5 %	1 1,8 %	6 10,9 %
5	oseba z motnjo avtističnega spektra	2,91	1,808	15 27,3 %	12 21,8 %	11 20,0 %	7 12,7 %	4 7,3 %	2 3,6 %	4 7,3 %
6	oseba z avtizmom	2,82	1,690	16 29,1 %	12 21,8 %	10 18,2 %	5 9,1 %	8 14,5 %	3 5,5 %	1 1,8 %
7	oseba z Aspergerjevim sindromom	2,75	1,777	17 30,9 %	12 21,8 %	12 21,8 %	5 9,1 %	4 7,3 %	1 1,8 %	4 7,3 %
8	oseba na avtističnem spektru	2,75	1,680	13 23,6 %	17 30,9 %	13 23,6 %	4 7,3 %	2 3,6 %	3 5,5 %	3 5,5 %

Preglednica 2: Izrazi glede na žaljivost (Likertova lestvica)

Iz Preglednice 2 je očitno, da so se kot najmanj žaljiva poimenovanja izkazala tista, ki jih lahko uvrstimo v paradigmo nO. Primerjava preglednic pa pokaže, da so anketiranci najbolj žaljivi poimenovanji (avtist, oseba z avtističnimi motnjami) opredelili tudi kot najmanj všečni, najmanj žaljivo poimenovanje (oseba na avtističnem spektru) pa kot najbolj všečno.

Statistično pomembna razlika ($p = 0,021$) se je pokazala pri izrazu *oseba z avtističnimi motnjami*, saj je bil za anketirance, ki avtizem dojemajo kot nevrorazličnost ($M = 3,83$, $SD = 1,83$), ta bolj žaljiv kot za tiste, ki avtizem dojemajo kot motnjo, bolezen, oviro ali primanjkljaj ($M = 2,73$, $SD = 1,10$), kar je v skladu s konceptom nevrorazličnosti, ki poudarja, da ni vsakršno odstopanje tudi motnja. Isti izraz je tudi bolj žaljiv ($p = 0,007$) za tiste, ki so diagnozo pridobili kot odrasli ($M = 4,23$, $SD = 1,86$), v primerjavi s tistimi, ki so jo pridobili kot mladoletne osebe ($M = 2,71$, $SD = 1,69$). Izraz *oseba z motnjo avtističnega spektra* ($p = 0,001$) je za osebe, diagnosticirane v otroštvu, manj žaljiv ($M = 1,94$, $SD = 1,14$) kot za tiste, diagnosticirane v odraslosti ($M = 3,52$, $SD = 1,98$), enaka ugotovitev velja za izraz *oseba z avtizmom* ($p = 0,019$; $M_{mlad.} = 2,00$, $SD_{mlad.} = 1,50$ in $M_{odr.} = 3,16$, $SD_{odr.} = 1,70$). Moškim so v primerjavi z ženskami statistično pomembno bolj žaljivi izrazi *oseba z avtizmom* ($p = 0,021$; $M_M = 3,48$, $SD_M = 1,86$ in $M_{\bar{z}} = 2,32$, $SD_{\bar{z}} = 1,40$), *avtistična oseba* ($p = 0,003$; $M_M = 3,90$, $SD_M = 1,58$ in $M_{\bar{z}} = 2,48$, $SD_{\bar{z}} = 1,59$) in *oseba na avtističnem spektru* ($p = 0,017$; $M_M = 3,38$, $SD_M = 1,43$ in $M_{\bar{z}} = 2,32$, $SD_{\bar{z}} = 1,64$).

Rangiranje izbranih terminov glede na preferenco in žaljivost

Ker nas je zanimalo tudi, kako utemeljujejo svoje izbire, smo anketirance v nadaljevanju zaprosili, da navedene izraze oz. poimenovanja razvrstijo glede na preferenco oz. zaželenost uporabe in glede na žaljivost, nato pa svojo izbiro tudi utemeljijo.

V Preglednici 3, kjer so izrazi razvrščeni po aritmetičnih sredinah glede na ranžirni vrsti (manjša aritmetična sredina pomeni povprečno bolj preferiran oz. bolj žaljiv izraz), je opaziti, da so bolj zaželeni izrazi praviloma opredeljeni kot manj žaljivi in obratno, ne pa nujno kot povsem nasprotni (podobno kot Bury idr. 2023). Čeprav nekaterih izrazov udeleženci v raziskavi niso preferirali, jih niso nujno opredelili kot bolj žaljive.

Preferenca				Žaljivost			
Št.	Termin	M	SD	Št.	Termin	M	SD
1	oseba z avtizmom	3,58	1,834	1	oseba z avtističnimi motnjami	3,37	2,101
2	oseba na avtističnem spektru	3,77	1,888	2	avtist	3,59	2,679
3	oseba z Aspergerjevim sindromom	3,98	2,198	3	avtistična oseba	4,34	2,352
4	oseba z motnjo avtističnega spektra	4,19	2,559	4	aspi	4,37	2,268
5	avtistična oseba	4,44	2,116	5	oseba z motnjo avtističnega spektra	4,56	2,292
6	avtist	4,89	2,710	6	oseba z avtizmom	4,98	2,006
7	aspi	5,02	2,366	7	oseba na avtističnem spektru	5,02	1,712
8	oseba z avtističnimi motnjami	5,83	1,779	8	oseba z Aspergerjevim sindromom	5,33	2,337

Preglednica 3: Primerjava ranžirnih vrst izbranih izrazov glede na preferenco in žaljivost

V Preglednici 3 je pri *preferenci* očitna usmerjenost naših anketirancev na poimenovanja nO, saj so kar štiri od petih poimenovanj, ki uporabljajo besedno zvezo *oseba z/na ...*, na prvih štirih mestih. Kvalitativna analiza utemeljitev izbir je pokazala, da je večina tistih, ki so kot najbolj zaželeno poimenovanje izbrali *oseba z avtizmom*, to utemeljila z *značilnostjo izraza* (kode: najbolj nevtralen, enostaven, kratek, strokovno sprejemljiv), ki se *ne osredotoča na motnje* in *ne določa osebe*, temveč navede le eno od njenih lastnosti.

Tudi anketiranci, ki so na prvo mesto uvrstili izraz *oseba na avtističnem spektru*, navajajo podobne utemeljitve, ki smo jih ravno tako uvrstili v kategorijo *značilnost izraza* (kode: širše poimenovanje, najbolj nevtralen, kratek, dovolj spoštljiv), k čemur so dodali še *poudarek na spektru* (npr. »poudari, da se avtizem izraža na zelo različne načine«, »ne opredeli, kaj je bolj ali manj avtistično«, »najboljši približek izrazu oseba na spektru avtizma«) in poudarjali *nevšečnost motnje v poimenovanju*.

Tisti, ki so kot najbolj zaželen izraz izbrali *osebe z Aspergerjevim sindromom*, so to utemeljevali tudi z *značilnostjo izraza*, ki »nima nobene negativne konotacije, ni predolg«, in ker je bila to *njihova diagnoza*.

Poimenovanje oseba z motnjo avtističnega spektra so nekateri izbrali kot najbolj zaželeno zlasti zaradi *značilnosti pojava* (kode: motnje širokega spektra, ne posplošuje) in zaradi *učinka izraza* (kode: všečen, najbolj diskreten, najboljše zveni).

Avtistična oseba je poimenovanje, ki so ga nekateri anketiranci utemeljevali kot najbolj zaželenega, ker *ne poudarja patologije* (npr. »ne napoveduje patologij, manjvrednosti, ne vabi k pootročevanju in ne razvršča«, »ne trdi, da si motnja, bolezen«) in ker je *avtizem del osebe* (npr. »oseba je v celoti avtistična«, »avtizem je del mene, ne v slabem smislu«). Nekateri so poudarjali *značilnosti izraza* (npr. »pridevnik dobra izbira za opis nevrotipa«, »kratek in enostaven«, »opiše, a ne definira«) in *druge utemeljitve* (npr. »daje možnost živeti po svojih odločitvah«, »tudi izraz avtist_ka je glede na kontekst lahko posmehljiv, poniževalen, žaljiv«).

Za izraz *avtist* so se odločali predvsem zaradi *značilnosti izraza* (kode: kratko, razumljivo, vsi drugi so slabši, se lahko uporablja v (ne)uradnem jeziku) in ker omogoča *neločevanje osebe od avtizma* (npr. »potrjuje paradigmo nevrodivezitet in s tem tudi identiteto človeka«, »ker je avtizem del mene, se mi zdi ločevanje oseba z ... neprijetno«, »ker opisuje to, kar sem«), pa tudi, ker *ne poudarja patologije* (npr. »ni bolezen ali motnja«, »nismo defektni, samo drugačni«, »motnja sporoča, da je z mano nekaj narobe«), temveč gre le za *drugačno doživljanje sveta*.

Odnos do poimenovanja *aspi* so večinoma utemeljevali z *značilnostmi izraza* (kode: simpatičen, kratek, novejši, modernejši, najbolj nevtralen, lepo zveni) in s tem, da *ne vključuje besed avtizem, bolezen, motnja*.

Pri izbiri najbolj zaželenega poimenovanja oseba z avtističnimi motnjami pa od anketiranca nismo prejeli utemeljitve.

Nadalje so anketiranci izraze razvrstili po *žaljivosti* (v Preglednici 3), nato pa utemeljili, zakaj so izbrani izraz označili kot najbolj žaljiv. Nekateri anketiranci ($n = 8$) ponujenih izrazov niso rangirali z argumentacijo, da se jim noben izraz ne zdi žaljiv oz. so žaljivi lahko vsi glede na ton glasu. Glede na aritmetično sredino sta najvišje na lestvici izraza oseba z avtističnimi motnjami in avtist. Utemeljitev izbire najbolj žaljivih izrazov so bile razvrščene v kategorije.

Pri rangiranju izrazov po *žaljivosti* so kot razlog za izbiro termina oseba z avtističnimi motnjami navedli, da izraz »motnja« *nakazuje na napako v osebi* (npr. »je nekaj, za kar se predpostavlja, da moti [...], da se jo da popraviti«, »namiguje, da je z mano nekaj narobe«). Pogosto so tudi utemeljevali, da reflektira *negativno konotacijo avtizma* (npr. »oseba, stigmatizirana s strani okolice«), pa tudi, da je izraz žaljiv in poskuša *ločiti identiteto od osebe* (npr. »kot da je avtizem [...] nekaj, kar imaš in lahko odložiš«).

Žaljivost izraza *avtist* so utemeljevali s tem, da je izraz po njihovem mnenju pogosto uporabljen kot žaljivka (npr. »ker sem bila pogosto priča, da se je [...] uporabljala kot zmerljivka v podobnem smislu kot npr. idiot«), pa tudi, da je izraz razumljen negativno, *negira vidik, da je nekdo najprej oseba, in izraža, da je napaka v osebi*.

Za izraz *avtistična oseba* so utemeljili, da je žaljiv, ker *na prvo mesto ne postavi osebe* (npr. »kot da bi avtizem določal to osebo in ni nič drugega kot nek avtist«).

Izbiro izraza *aspi* kot najbolj žaljivega so utemeljili predvsem z *zgodovinskim kontekstom* (povezave z nacizmom) in *uporabo izraza kot žaljivke*. Tudi izraz *oseba z motnjo avtističnega spektra* je bil na prvo mesto žaljivosti postavljen z razlogom, da *motnja nakazuje na napako v osebi* (npr. »spominja me na čase, ko sem mislila, da sem sama kriva/res jaz motena/nekaj počnem narobe«) in *ločuje identiteto od osebe*. Izraz *oseba z avtizmom*, je bil izbran z utemeljitvijo, da ločuje identiteto od osebe in se uporablja kot žaljivka, *oseba na avtističnem spektru*, ker nakazuje, da ima oseba več težav, in *oseba z Aspergerjevim sindromom* zaradi zgodovinskega konteksta in ločevanja na visoko- in nizkofunkcionalni avtizem.

Zaključek

Podobno kot izhaja iz raziskav v tujini, je tudi v slovenskem prostoru opaziti, da ni konsenza o uporabi enega izraza. Ameriško psihiatrično združenje (Bias-Free Language 2022) v takem primeru predlaga uporabo kombinacije poimenovanj z identiteto in osebo na prvem mestu.

Kvalitativna analiza utemeljitev preferenčnih izrazov v celoti pokaže, da naši anketiranci preferirajo poimenovanja nO, zato tudi v prispevku uporabljamo izraz, ki sodi v to paradigmo. Rezultati so v nasprotju z ugotovitvami ključnih raziskav na tem področju, sicer opravljenih na angleško govoreči populaciji, in podobni ugotovitvam na nizozemsko govoreči populaciji (Bosman in Thijs 2024; Buijsman idr. 2023; De Laet idr. 2023). To potrjuje, da na dožemanje preference poimenovanj pomembno vpliva tudi jezikovno in kulturno okolje (Bury idr. 2023; Fecteau idr. 2024; Keating idr. 2023). V naši raziskavi je bilo ugotovljeno, da je najmanj zaželeno poimenovanje *oseba z avtističnimi motnjami*, ki pa je trenutno uradno poimenovanje v Sloveniji (ZUOPP-1 2011), predvsem se zaznava kot nezaželeno, ker v poimenovanju poudarja patologijo, motnjo in nakazuje na napako v osebi sami. To je skladno z ugotovitvami podobnih raziskav v tujini, da primarna dilema pri poimenovanju torej ni, ali na prvo mesto postavimo osebo ali identiteto, temveč v tem, ali v poimenovanju poudarjamo patologijo ali ne (Bury idr. 2023; Fecteau idr. 2024; Keating idr. 2023).

V naši raziskavi so bile potrjene ugotovitve že opravljenih raziskav v tujini glede dileme pri uporabi izraza *oseba z Aspergerjevim sindromom* (Geelhand idr. 2023; Kenny idr. 2016), saj nekateri ta izraz preferirajo zaradi nevtralne konotacije oz. ker je to njihova diagnoza, in pri izpeljanki *aspi*, ki da je kratka, simpatična, nevtralna in ne vključuje neposredno besede *avtizem* (Keating idr. 2023). Po drugi strani pa omenjajo razdiralnost uporabe tega izraza, saj sam po sebi implicira višje funkcioniranje (Keating idr. 2023; Lei idr. 2021) in zgodovinski kontekst v povezavi z nacizmom, kar spodbuja negativno razumevanje izraza (Keating idr. 2023).

Na podlagi naših ugotovitev in skupka ugotovitev raziskav v tujini podajamo predloge za rabo terminologije v Sloveniji. Ustrezni so tako izrazi, ki na prvo mesto postavljajo osebo, kot tisti, ki na prvo mesto postavljajo identiteto, pri čemer se v komunikaciji, zakonodaji, drugih formalnih dokumentih in strokovnih smernicah skušajmo odmakniti od poudarjanja patologije (npr. motnje, pri-

manjkljaji). Pozorni moramo biti tudi na to, kako govorimo o osebah brez avtizma v istem kontekstu z osebami z avtizmom (npr. »zdrava kontrola« in »normalna populacija«), saj lahko tudi tako damo avtizmu negativno konotacijo (npr. osebe označimo kot »nezdrave« ali »nenormalne«) (Bottema-Beutel idr. 2021). Pri opisovanju razlik oseb z avtizmom glede na osebe brez avtizma ne smemo govoriti samo o njihovih primanjkljajih, temveč tudi o močnih področjih v primerjavi z osebami brez avtizma (Lei idr. 2021). Priporočljivo je še izogibanje terminom, kot sta visokofunkcionalni in nizkofunkcionalni avtizem (Bottema-Beutel idr. 2021; Keating idr. 2023), na kar so opozarjali tudi naši anketiranci. Kako bomo govorili o avtizmu, je tudi odvisno od konteksta (npr. strokovnjak staršu, oseba z avtizmom drugi osebi) (Kenny idr. 2016). Pozorni moramo torej biti na to, kako bo naš izraz vplival na dožemanja v okolici, šolskem prostoru in drugem kontekstu (Kenny idr. 2016), saj osebe z avtizmom lahko stigmatiziramo predvsem s *pogledom* na njih, ne nujno s specifičnim izrazom, ki ga uporabimo (Botha idr. 2023). Najpomembneje je, da se ljudje v okolici ne bojijo, kateri izraz bodo uporabljali vpričo oseb z avtizmom, saj to lahko privede do še večje izoliranosti, ker se bodo morda zaradi strahu pred »napako« tem osebam v celoti izogibali (Keating idr. 2023). Naše glavno vodilo naj bo, da vedno primarno upoštevamo preferenco osebe, s katero in o kateri govorimo (Bury idr. 2023; Dwyer 2022; Keating idr. 2023; Kenny idr. 2016).

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SELF-IDENTIFICATION OF ADULTS DIAGNOSED WITH AUTISM IN SLOVENIA

Abstract: Naming an individual or a minority group is a very sensitive issue. In most societies that follow the principles of respect and non-discrimination, this issue is paid considerable attention in research. The language we use to describe minority groups can define their positions vis-à-vis the majority and establish a social hierarchy, as can the perspectives through which the defining characteristics of a particular group are viewed (e.g., language, nationality, gender and special needs). Characteristics that also have a significant impact on the lives of minority group members are often overlooked. In recent years, it has become commonplace to include the views of the members of the minority group under study concerning their language preferences. This aspect has been the main topic of our research, part of which is presented in this article. In our study, adults diagnosed with autism (n = 55) explained which terms used to refer to them in Slovenia they find offensive and which ones they prefer. The qualitative analysis found no consensus among the participants regarding preferred terms. Concerning the two main paradigms described in the article (person-first language and identity-first language), there was a predilection for person-first terminology. The participants identified the term person with autistic disorders as the least desirable, even though this is currently the official wording adopted in Slovenian legislation, mainly because it emphasises pathology and points to a flaw in the person.

Keywords: autism, language preferences, terminology, person-first language, identity-first language

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Self-identification of adults diagnosed with autism in Slovenia

Abstract: Naming an individual or a minority group is a very sensitive issue. In most societies that follow the principles of respect and non-discrimination, this issue is paid considerable attention in research. The language we use to describe minority groups can define their positions vis-à-vis the majority and establish a social hierarchy, as can the perspectives through which the defining characteristics of a particular group are viewed (e.g., language, nationality, gender and special needs). Characteristics that also have a significant impact on the lives of minority group members are often overlooked. In recent years, it has become commonplace to include the views of the members of the minority group under study concerning their language preferences. This aspect has been the main topic of our research, part of which is presented in this article. In our study, adults diagnosed with autism ($n = 55$) explained which terms used to refer to them in Slovenia they find offensive and which ones they prefer. The qualitative analysis found no consensus among the participants regarding preferred terms. Concerning the two main paradigms described in the article (person-first language and identity-first language), there was a predilection for person-first terminology. The participants identified the term *person with autistic disorders* as the least desirable, even though this is currently the official wording adopted in Slovenian legislation, mainly because it emphasises pathology and points to a flaw in the person.

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Introduction

The terms used to refer to autism and people with autism¹ have been changing since the first descriptions of autism in the 1940s. Recently, they have often been a central topic of informal, professional and academic discussion. The terminology we use can affect our perception of the environment, legislation, access to appropriate help and support, and the possibility of self-advocacy (Lei et al. 2021; Vivanti 2020). Terminology (co)determines our understanding of autism and the relationships of people with autism. This is substantiated by research showing that people with autism often feel excluded in school, mainly due to poor understanding from teachers and peers, and are frequently bullied (Cappadocia et al. 2012; Cunningham 2022). In Slovenia, this group of students has been recognised relatively late in the Placement of Children with Special Needs Act (ZUOPP-1 2011), where they are identified as “children with autistic disorders.” Furthermore, research shows that in the country, some adults with autism do not receive the necessary support in schools with regard to communication and social skills. Negative relationships with peers and teachers during school years can negatively impact the relationships these individuals build in adulthood (Rogič Ožek 2023). The language used when talking about people with autism can influence society’s perception of them and increase or decrease the risk that these difficulties will occur later in life (Botha et al. 2023). This is because some of these challenges arise or are amplified as a result of maladaptation and the structure of the environment (Keating et al. 2023).

The first systematic description of autism, or “autistic disturbances of affective contact” (Kanner 1943), was published in 1943 by Leo Kanner, who identified two main characteristics: great difficulties in social interaction and the resistance to change (or the insistence on the preservation of sameness). In the same year, “autistic psychopathy” was described by Hans Asperger, who observed children with above-average intelligence and identified similar characteristics to Kanner. In 1981, Asperger’s article (originally written in German) was published in En-

1 The term adopted in this article differs from that of Slovenian legislation. It was chosen based on the literature and the research presented here.

glish by Lorna Wing, who used the term “Asperger’s syndrome” and added her own observations to those of Asperger. Wing proposed the inclusion of a spectrum and a triad of impairments (impairment of social interaction, communication and imagination) in the autism diagnosis (Hippler and Klicpera 2003).

Despite these early descriptions, autism was defined as “infantile psychosis” under the category of childhood schizophrenia in the second edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American Psychiatric Association, which was published in 1968. Kanner’s basis for diagnosis was only included in the third edition of the DSM (in 1980) as “infantile autism” (Harris 2018). The fourth edition of the DSM, published in 1994, organised autism into four subgroups: autistic disorder, Rett disorder, childhood disintegrative disorder and Asperger syndrome. These subgroups were removed in the fifth edition of the DSM (2013), where a new unified term – “autism spectrum disorder” – was introduced.

Among professionals, the terminological discussion is mainly based on how to describe the condition most effectively. The perspectives of the persons being described are often overlooked (Vivanti 2020). This has started to change in recent years. One of the earliest pieces of research that widened the discussion was a study conducted in the United Kingdom among people with autism, their parents, other family members, friends and experts (Kenny et al. 2016). To the best of our knowledge, this was the first study that included people with autism in the terminological debate. It showed that the preferences of experts and parents regarding terminology differed from those of the people with autism. This study opened the way for similar research by allowing people with autism to lead the conversation about their identity. Using language that originates from their perspectives is of utmost importance for individuals with autism as some scholars have found that these individuals are excluded from discussions that concern them in everyday situations. Another problem is that people without autism – teachers, specialists and parents – impose their language preferences on them and correct them when they use certain terms (Keating et al. 2023).

In Slovenia, the term adopted in the relevant legislation is “person with autistic disorders,” which is used in diagnoses and statements pertaining to students with special needs (Kriteriji za opredelitev vrste in stopnje primanjkljajev, ovir oz. motenj otrok s posebnimi potrebami 2015). The characteristics of these “autistic disorders” are based on the definition of the latest edition (the fifth) of the DSM (2013); however, in Slovenian legislation, the term “autistic spectrum disorder,” which has been used in the DSM since 2013, has not been adopted.

The history of terminology

Throughout history, people who greatly deviated from the typical based on various characteristics were often excluded from society. In these instances, terminology that put disorders or diagnoses first (pathology-first language) was primarily used. Eventually, criticisms of this approach arose because it focused

on weaknesses; with it, a person's identity was equated with a disorder, which created negative connotations (Dwyer 2022). Regarding autism, the consensus among both professionals and people with autism is that this type of language is no longer in use.

In the 1970s, terminology that puts the person before the diagnosis (person-first language [PFL]) began to be used to signal that people with the same diagnosis can differ and are not defined solely by autism (Dwyer 2022; Vivanti 2020). The preference for this type of terminology did not emerge from people with autism but from experts (Botha et al. 2023), and it has been used mainly by professionals.

Recently, this terminology has increasingly been criticised by people with autism and some experts, who have claimed that autism is a key part of an individual's identity, which cannot be separated from the person, and that using PFL connotes autism as something negative and undesirable (Bury et al. 2023; Vivanti 2020). Based on this criticism, an appropriate terminology places identity first (identity-first language [IFL]). In the latter, the terms used are very similar (or even the same) as those used in pathology-first language. However, in evaluative terms, they are entirely different because they change the meaning of previously negative connotations, emphasising that people with autism should be proud of their identity and neurodiversity (Dwyer 2022; Taboas et al. 2023).

The concept of neurodiversity is increasingly mentioned in this field. It is an umbrella term used not only for autism but also for other forms of neurodiversity, such as ADHD and dyslexia. The neurodiversity paradigm highlights not only the difficulties people with autism face but also their strengths and different needs in various areas (den Houting 2019).

A comparable shift in terminology has previously occurred also for other subgroups, such as disabled, Deaf and hard-of-hearing, and blind and visually impaired people (Bias-Free Language 2022). Therefore, the American Psychiatric Association (Bias-Free Language 2022) now states that when we know what type of terminology a particular group prefers, we should honour it as a sign of respect. Some scholars have a similar position concerning the linguistic approach used to talk about people with autism (Botha et al. 2023). So, what type of terminology do people with autism prefer?

Person-first or identity-first language?

As mentioned, two primary approaches regarding the language used to describe autism appear – PFL (e.g. “person with autism”) and IFL (e.g. “autistic person”). Despite the seemingly contradictory views, both approaches address the problem of negative connotations, but they do so from two different angles – while PFL emphasises that a person is more than just their diagnosis, IFL maintains that the diagnosis is an integral part of the person and should be respected (Vivanti 2020).

According to current research, people with autism mostly prefer IFL terms (e.g., Taboas et al. 2023). As a reason for their preference, they explain that autism is not an “accessory” that can be put away or separated from the individual (Keating et al. 2023). With this terminology, people with autism are connected to a wider community, and characteristics often seen as difficulties are redefined via the concept of neurodiversity as part of natural human diversity (Bury et al. 2023). These characteristics are often also seen as strengths (e.g., categorisation and systematisation abilities, as well as knowledge of facts) (Lai et al. 2014). This empowers them and gives them pride. Furthermore, it enables them to gain control over negative terms used in the past, as other marginalised communities have also done. The words “person *with*” are mainly used to indicate pathological or medical characteristics (e.g., a person with cancer). Therefore, those who oppose PFL believe that saying “person *with* autism” suggests that autism is something negative that must be removed or cured (Botha et al. 2023; Keating et al. 2023). Also, this type of language is generally not used to describe neurotypical people or generally positively perceived characteristics (e.g., the phrase “person with typical development” is not used) (Bury et al. 2023). Botha, Hanlon and Williams (2023) also question whether we really need to use a specific term to remember that someone is, first and foremost, a *person*.

According to existing research, the majority of people with autism prefer IFL, but there is still a significant proportion of those who do not relate to this type of language. Indeed, some people with autism believe that the terms based on IFL are derogatory and dehumanising (Bury et al. 2023; Keating et al. 2023). The preference for PFL usually comes from the desire for autism to be recognised as only one part of their personhood (Keating et al. 2023). This shows that IFL is sometimes associated with the stigma of pathology-first language (Bury et al. 2023).

Analysis of specific terms

There is no evidence of a consensus regarding the terminology to be used in the case of autism (Botha et al. 2023; Kenny et al. 2016). Some people prefer using one term, while others find the same term offensive. However, in various studies, we can observe a trend of moving away from terms that suggest that autism is a “disorder” (Bury et al. 2023; Keating et al. 2023; Kenny et al. 2016) as the use of this word implies that something is wrong with them and that the diagnosis is something tragic. Emphasising disorders is a feature of a medical model (Bottema-Beutel et al. 2021; Bury et al. 2023; Lei et al. 2021), but not all differences are disrupting and can be determined by the environment, which is emphasised also by the concept of neurodiversity. For some people with autism, words such as “deficit” and “disorder” are not in line with their self-identities and lead to additional obstacles and reluctance to disclose their diagnoses to others (Lei et al. 2021).

“Disorder” and “deficit” are terms that can significantly impact the formation of an individual’s identity. Language and communication systems are key aspects that influence the cultural identity of groups with disabilities. This is evident not only in communication among persons with disabilities but also in discussions about and with them (Kunt and Zászkaliczky 2011). Social identity is formed by the internalisation of social categories and stereotypes, intergroup comparisons and the person as a unique individual (Razpotnik 2004). Certain disability groups form their identities based on their disabilities and the barriers created for them by society (Forber-Pratt et al. 2017), which is also typical for the group of people with autism (Botha and Gillespie-Lynch 2022). Research shows that the stronger the perception that autism is part of an individual’s identity, the more likely someone is to prefer IFL terms and not label them as offensive (Bury et al. 2023; Keating et al. 2023). Also, it is more probable that an individual will consider a certain term offensive if they have witnessed it being used negatively in the past (Bury et al. 2023).

One of the best-received terms in the community is “person on the (autism) spectrum,” which has a more positive, less offensive connotation due to the preposition “on” (Botha et al. 2023; Bury et al. 2023). This term emphasises both the person and the diversity within the group (Bury et al. 2023). However, some commentators suggest that the use of the word “spectrum” diminishes the impact of autism on the individual and that it artificially divides autism into high- and low-functioning varieties (Kenny et al. 2016).

Most of the research published so far has been conducted in English-speaking countries. The differences among autism-related language preferences are already evident in different English-speaking cultures (Keating et al. 2023), and they are even more apparent in non-English-speaking countries and environments. For example, unlike English-speaking people, Dutch-speaking individuals with autism prefer PFL (Bosman and Thijs 2024; Buijsman et al. 2023; De Laet et al. 2023). In French-speaking environments, the preferred term (autistic person [*personne autiste*]) can be viewed from both the PFL and IFL perspectives (Geelhand et al. 2023; Fecteau et al. 2024). For a more comprehensive understanding of these preferences, research conducted among individuals from different linguistic and cultural backgrounds is necessary (Bottema-Beutel et al. 2021; Bury et al. 2023). The need for this kind of research is also evident in Slovenia, where the terminology in scientific and professional works, as well as on websites dedicated to people with autism, shows that various terms are used.

Methodology

Purpose of the study

Thus far, no studies have been published in Slovenia on the language preferences of adults with autism. Therefore, our primary aim was to document the

attitudes of these individuals towards the terminology used to refer to them in Slovenian society. We were particularly interested in the following questions:

- How do people with autism perceive autism?
- Which established terms do people with autism prefer and why?
- Are there differences in language preferences based on the perception of autism, gender and age at diagnosis?
- Which established terms do people with autism consider offensive and why?
- Are there differences in opinions regarding perceived offensiveness based on the perception of autism, gender and age at diagnosis?

The analysis presented here is part of a broader doctoral research project. In addition to investigating the language preferences of adults with autism, potential experiences of microaggression, discrimination and self-stigmatisation were also investigated.

Research method

This study was conducted using descriptive and causal non-experimental methods. Data was collected through an online questionnaire, which was based on studies carried out outside Slovenia (Bury et al. 2023; Keating et al. 2023; Kenny et al. 2016). It included questions regarding participants' opinions about certain terms and rankings of these terms based on preference and offensiveness. Drawing on previous studies (Keating et al. 2023; Kenny et al. 2016), the terms were chosen to represent both PFL and IFL. The terms in questionnaire are primarily used in professional and medical settings (e.g., person with autistic disorders, person with autism spectrum disorder, person on the autism spectrum and person with Asperger's syndrome) and informally in specific subgroups and associations (autist[ic],² Aspie, autistic person and person with autism).

Participants

In total, 97 people responded to our invitation to participate in the research, and 55 respondents were included in the final analysis; those who did not answer all the questions or did not specify that they had a diagnosis of autism were excluded. Assuming that there are approximately 200 adults with autism in Slovenia (based on the estimate that the prevalence of autism worldwide is 1% [Lai et al. 2014]), 55 participants represent 27.5% of the population. More than half of the participants were women ($n = 31$, 56.4%); less than half were men ($n = 21$, 38.2%). Some participants did not wish to identify their gender ($n = 3$, 5.4%). The mean age of the participants was 30.16 years ($SD = 1.636$). Most of them were diagnosed as adults, at an average age of 21.23 years ($SD = 1.674$). Their parents

2 There is no direct translation for the term "autistic" in the Slovene language. The most similar term used in Slovenia is "avtist," which was adopted in this study.

were usually the first ones to recognise that they might have autism ($n = 17$, 31.0%); quite often, the participants recognised it themselves ($n = 15$, 27.3%). In terms of education, six participants from the youngest group had completed primary school (10.9%); four had finished vocational school (7.3%); six had completed technical school (10.9%); 19 had finished *gimnazija* school (34.6%); eight had completed professional college (14.5%); eight were university graduates (14.5%); three had master's degrees, and one had a doctorate (1.9%). Half of the participants lived with their parents ($n = 28$, 50.9%); a quarter lived alone ($n = 14$, 25.5%); six (10.9%) lived with their families; three (5.4%) lived with roommates, and three (5.4%) chose to answer 'other' (e.g., with their sisters in the student dormitory and with their sister and father).

Data collection

Accessing the selected population was difficult. Therefore, we addressed the invitation to participate to various groups and individuals, including the coordinators for students with special needs of three Slovenian universities (Ljubljana, Maribor and Koper), various associations (Bravo, Aspi, The Society of Disabled Students of Slovenia and Modri December), Facebook groups for people with autism and individuals who we knew belonged to the selected population, whom we also asked to invite other people with autism to participate. The online questionnaire was available via the 1KA software for three months (10 February–10 May 2024), and it consisted of 19 questions (close-ended, open-ended and combined questions).

Data processing

The numerical data was processed quantitatively, using descriptive and inferential statistics (frequencies, percentages, mean values and t-tests). In accordance with our research questions, qualitative analysis of the open-ended questions was performed based on a deductive/hermeneutic approach (Mesec 2023; Vogrinc 2013).

Results

Deficit, disorder or neurodiversity?

When asked how they viewed autism, the vast majority of respondents ($n = 36$, 65.5%) answered that they saw it as an instance of neurodiversity. Few of them said that autism was a disorder (14.5%), and very few defined it as a disease (1.9%) or a handicap (3.6%). No one described autism as a deficit. Eight participants chose to answer "other," and they provided the following answers: "A way of

being; autism is socially unacceptable on the outside, but it does not exist on the inside”; “Several of the above answers, depending on the individual”; “Uniqueness”; “A different view of the world”; “None of the above”; “I don’t know how to define it, but I certainly wouldn’t use the terms above”; and “An advantage.”

Preferred and offensive terms

The participants rated the terms used in Slovenia to describe people with autism on a 7-point Likert scale (1 = strongly dislike, 7 = strongly like). In Table 1, the terms are arranged based on their means (from higher to lower), with the higher scores indicating greater preference.

No.	Term	M	SD	Likability (1 = strongly dislike, 7 = strongly like)						
				1	2	3	4	5	6	7
1	Person on the autism spectrum	4.56	1.893	7 12.7%	3 5.5%	5 9.1%	5 9.1%	13 23.6%	16 29.1%	6 10.9%
2	Person with autism	4.40	2.157	8 14.5%	7 12.7%	5 9.1%	3 5.5%	11 20.0%	9 16.4%	12 21.8%
3	Person with autism spectrum disorder	4.27	1.986	9 16.4%	4 7.3%	6 10.9%	4 7.3%	13 23.6%	14 25.5%	5 9.1%
4	Autistic person	4.25	2.084	9 16.4%	6 10.9%	5 9.1%	5 9.1%	9 16.4%	14 25.5%	7 12.7%
5	Aspie	4.20	2.138	12 21.8%	3 5.5%	4 7.3%	7 12.7%	7 12.7%	16 29.1%	6 10.9%
6	Person with Asperger’s syndrome	4.16	2.115	11 20.0%	4 7.3%	6 10.9%	4 7.3%	11 20.0%	12 21.8%	7 12.7%
7	Autist(ic)	4.04	2.194	10 18.2%	9 16.4%	5 9.1%	4 7.3%	8 14.5%	10 18.2%	9 16.4%
8	Person with autistic disorders	3.29	1.941	12 21.8%	13 23.6%	8 14.5%	4 7.3%	8 14.5%	7 12.7%	3 5.5%

Table 1. Preferred terms.

Note. *M* = mean, *SD* = standard deviation.

As shown above, the three terms with the highest levels of preference are terms that use PFL and are said to be favoured by professionals (Botha et al. 2023) rather than people with autism. The least preferred term was “person with autistic disorders,” which is the official definition in Slovenia. A statistically significant difference ($p = 0.010$) was found for “person with autism,” with the participants who perceived autism as a disorder, disease or handicap ($M = 5.55$, $SD = 0.93$) liking this term more than those who perceived autism as a form of neurodiversity ($M = 4.28$, $SD = 2.26$). T-tests found no statistically significant differences

between the genders and between the participants who were diagnosed before the age of 18 and those who were diagnosed after it.

The participants also rated the terms on a 7-point Likert scale according to their perceived offensiveness (1 = not at all offensive, 7 = very offensive). In Table 2, the terms are arranged based on their means (from higher to lower), with the higher scores indicating greater offensiveness.

No.	Term	M	SD	Offensiveness (1 = not at all offensive, 7 = very offensive)						
				1	2	3	4	5	6	7
1	Autist(ic)	3.65	2.192	12 22.2%	10 18.5%	5 9.3%	4 7.4%	10 18.5%	7 13.0%	6 11.1%
2	Person with autistic disorders	3.55	1.864	8 14.5%	11 20.0%	12 21.8%	5 9.1%	10 18.2%	4 7.3%	5 9.1%
3	Autistic person	3.04	1.721	14 25.5%	11 20.0%	8 14.5%	9 16.4%	8 14.5%	4 7.3%	1 1.8%
4	Aspie	3.02	1.890	12 21.8%	18 32.7%	5 9.1%	10 18.2%	3 5.5%	1 1.8%	6 10.9%
5	Person with autism spectrum disorder	2.91	1.808	15 27.3%	12 21.8%	11 20.0%	7 12.7%	4 7.3%	2 3.6%	4 7.3%
6	Person with autism	2.82	1.690	16 29.1%	12 21.8%	10 18.2%	5 9.1%	8 14.5%	3 5.5%	1 1.8%
7	Person with Asperger's syndrome	2.75	1.777	17 30.9%	12 21.8%	12 21.8%	5 9.1%	4 7.3%	1 1.8%	4 7.3%
8	Person on the autism spectrum	2.75	1.680	13 23.6%	17 30.9%	13 23.6%	4 7.3%	2 3.6%	3 5.5%	3 5.5%

Table 2. *Offensive terms.*

Note. *M* = mean, *SD* = standard deviation.

Table 2 clearly shows that the least offensive terms were those that use PFL. A comparison of Tables 1 and 2 reveals that the participants identified the most offensive terms (autist[ic] and person with autistic disorders) as the least preferred choices and the least offensive term (person on the autism spectrum) as the most preferred choice.

A statistically significant difference ($p = 0.021$) was found for the term “person with autistic disorders,” as the participants who saw autism as a form of neurodiversity ($M = 3.83$, $SD = 1.83$) found the term more offensive than those who perceived autism as a disorder, disease or handicap ($M = 2.73$, $SD = 1.10$). This finding aligns with the concept of neurodiversity, which emphasises that not every difference is a disorder. The same term is also perceived as more offensive ($p = 0.007$) by those diagnosed in adulthood ($M = 4.23$, $SD = 1.86$) compared to

those diagnosed as minors ($M = 2.71$, $SD = 1.69$). “Person with autism spectrum disorder” ($p = 0.001$) was less offensive for the participants diagnosed before turning 18 ($M = 1.94$, $SD = 1.14$) than for those diagnosed in adulthood ($M = 3.52$, $SD = 1.98$). The same applies to the term “person with autism” ($p = 0.019$; $M_{(under\ 18)} = 2.00$, $SD_{(under\ 18)} = 1.50$ and $M_{(over\ 18)} = 3.16$, $SD_{(over\ 18)} = 1.70$). Compared to the female respondents, the male respondents found “person with autism” ($p = 0.021$; $M_{(male)} = 3.48$, $SD_{(male)} = 1.86$ and $M_{(female)} = 2.32$, $SD_{(female)} = 1.40$), “autistic person” ($p = 0.003$; $M_{(male)} = 3.90$, $SD_{(male)} = 1.58$ and $M_{(female)} = 2.48$, $SD_{(female)} = 1.59$) and “person on the autism spectrum” ($p = 0.017$; $M_{(male)} = 3.38$, $SD_{(male)} = 1.43$ and $M_{(female)} = 2.32$, $SD_{(female)} = 1.64$) significantly more offensive.

Term rankings based on preference and offensiveness

As we were also interested in how the participants arrived at their choices, we asked them to rank the terms based on preference and offensiveness and explain their rankings.

In Table 3, where the terms are sorted by mean according to the ranking type (the lower scores indicate greater preference or offensiveness), we see that the more preferable terms were ranked as less offensive and vice versa. However, preference and offensiveness were not the opposite ends of a continuum (see also Bury et al. 2023). Although the participants did not prefer some terms, they did not necessarily identify them as offensive.

Preference				Offensiveness			
No.	Term	M	SD	No.	Term	M	SD
1	Person with autism	3.58	1.834	1	Person with autistic disorders	3.37	2.101
2	Person on the autism spectrum	3.77	1.888	2	Autist(ic)	3.59	2.679
3	Person with Asperger's syndrome	3.98	2.198	3	Autistic person	4.34	2.352
4	Person with autism spectrum disorder	4.19	2.559	4	Aspie	4.37	2.268
5	Autistic person	4.44	2.116	5	Person with autism spectrum disorder	4.56	2.292
6	Autist(ic)	4.89	2.710	6	Person with autism	4.98	2.006
7	Aspie	5.02	2.366	7	Person on the autism spectrum	5.02	1.712
8	Person with autistic disorders	5.83	1.779	8	Person with Asperger's syndrome	5.33	2.337

Table 3. Comparison of term rankings.

Note. M = mean, SD = standard deviation.

Regarding preference, Table 3 clearly shows the participants' inclination towards PFL, as four out of the five terms that include the words "person with/on" are in the first four places. The qualitative analysis of the reasoning behind these choices showed that the majority of those who picked "person with autism" as the most preferred term did so due to the characteristics of the term (codes: the most neutral, simple, short and professionally acceptable). This term does not focus on deficits and does not define the person; it represents only one aspect of their personality.

The participants who ranked "person on the autism spectrum" first gave similar explanations, which we collapsed in the theme "characteristics of the term" (codes: broad terminology, most neutral, short and respectful enough). The participants added that this term emphasised the idea of the spectrum (e.g., "It emphasises that autism is expressed in very different ways" and "It does not define what is more or less autistic") and that they disliked the notion of disorder.

Those who preferred "person with Asperger's syndrome" justified their choice based on the characteristics of the term, which "has no negative connotations and is not too long," and the fact that it was their diagnosis.

Some participants chose "person with autism spectrum disorder" as the most desirable term mainly due to its characteristics (codes: broad spectrum disorders and avoids generalisation) and impact (codes: likeable, most discreet and best sounding).

"Autistic person" was selected by some as their preferred option because it did not emphasise pathology (e.g., "It does not implicate pathologies and inferiority," "It does not infantilise and does not classify" and "It does not refer to autism as a disorder or disease") and because for them, autism was part of the individual (e.g., "The person is fully autistic" and "Autism is a part of me, but not in a bad way"). Some respondents stressed the characteristics of the term (e.g., "This adjective is a good choice to describe the neurotype," "It's short and simple" and "It describes but does not define") and other justifications (e.g., "It gives the freedom to live according to one's decisions" and "Depending on the context, the term autistic can be derisive, humiliating and insulting").

"Autist(ic)" was chosen as the most preferred term mainly due to the characteristics of the term (codes: short; clear; all the others are worse; and can be used in [un]official terminology) and because it did not separate the person from autism (e.g., "It affirms the neurodiversity paradigm and human identity," "Because autism is a part of me, I find the separation of 'person with' unpleasant," and "It describes who I am"). This term was also picked because it did not emphasise pathology (e.g., "It does not mention a disease or disorder," "We are not defective, just different" and "'Disorder' indicates that there is something wrong with me") but signalled a different way of experiencing the world.

"Aspie" was mostly chosen because of its characteristics (codes: cute, short, newer, more modern, most neutral and nice sounding) and because it did not mention autism, disease and disorder.

The participant who opted for "person with autistic disorders" did not explain their choice.

The respondents also ranked the terms according to their perceived offensiveness (Table 3) and elaborated on their evaluations. Some of them ($n = 8$) refused to perform this ranking, arguing that none of the terms were offensive or that all of them could be offensive, depending on the tone of voice. According to the means, the most offensive terms were “person with autistic disorders” and “autist(ic).” The participants’ reasons were coded and collapsed into themes.

“Person with autistic disorders” was considered the most offensive term because the word “disorder” was seen as indicating a fault in the person (e.g., “It is something that is assumed to cause disorder or can be fixed” and “It suggests that there is something wrong with me”). Many participants also often reasoned that the term reflected the negative connotation of autism (e.g., “A person is stigmatised by the environment”), that it was offensive and separated the person from their identity (e.g., “As if autism was something that you have and can put away”).

“Autist(ic)” was deemed offensive because it had often been used as an insult (e.g., “I have often witnessed it being used as a derogatory term – for example, in a similar sense to ‘idiot’”) and because it is perceived negatively. According to the respondents, this term negates the fact that someone is first a person, and it implies a fault in the person.

The participants believed that “autistic person” was offensive because it did not put the person first (e.g., “As if autism defines a person, and they are nothing but autistic”).

“Aspie” was seen as the most offensive term due to its historical connection to Nazism and its use as an insult. Some respondents ranked “person with autism spectrum disorder” as the most offensive term because “disorder” indicated a fault in the person (e.g., “It reminds me of the times when I thought it was my fault,” “It suggests that I am disturbed” and “It implies that I am doing something wrong”). This term also conveyed that autism was separate from a person’s identity.

On average, the least offensive terms were still considered to be offensive by some participants. “Person with autism,” was chosen because it suggested that autism was separate from the person’s identity and was used as a slur, “person on the autistic spectrum,” because it implied that the person had several difficulties, and “person with Asperger’s syndrome,” because of its historical context and the division into high- and low-functioning autism.

Discussion and conclusion

Our findings show that in Slovenia, as in other cultural and linguistic settings, there is no consensus regarding the terminology that should be used to describe people with autism. When this is the case, according to the American Psychiatric Association (Bias-Free Language 2022), both IFL and PFL approaches are appropriate, and a combination of the two should be employed.

Our qualitative results clearly indicate that the participants preferred PFL terms, which is why we used a term from that approach in our article. Our find-

ings contradict those of studies conducted among English-speaking individuals, and they are similar to those of research carried out among Dutch-speaking individuals (Bosman and Thijs 2024; Buijsman et al. 2023; De Laet et al. 2023). This confirms that language preferences are significantly influenced by linguistic and cultural environments (Bury et al. 2023; Fecteau et al. 2024; Keating et al. 2023). We found that the least desirable term was “person with autistic disorders,” which is currently the official designation used in Slovenian legislation (ZUOPP-1 2011). The main reason for this was that the term was seen as emphasising pathology and disorder and that it indicated a fault in the individual. This is consistent with the findings of similar studies conducted outside Slovenia, according to which the key terminological dilemma is not whether we use PFL or IFL but whether we emphasise pathology in our language (Bury et al. 2023; Fecteau et al. 2024; Keating et al. 2023).

Our research confirms the results of other studies concerning the dilemma of using the term “person with Asperger’s syndrome” (Geelhand et al. 2023; Kenny et al. 2016). Some people prefer this term due to its neutral connotation or because it was their diagnosis; they also like the shortened version “Aspie,” which is short, neutral and does not mention the word “autism” (Keating et al. 2023). However, other individuals point to the divisiveness of this term, which implies higher functioning (Keating et al. 2023; Lei et al. 2021) and is connected to Nazism, giving it a negative connotation (Keating et al. 2023).

Based on our findings and previous research, we wish to make some suggestions regarding the terminology used to refer to autism in Slovenia. Both PFL and IFL terms are appropriate. However, we should strive to move away from emphasising pathology (e.g., disorders and deficits) in day-to-day communication, legislation, formal documents and professional guidelines. We must also be mindful of how we talk about people without autism in relation to those with autism (e.g., “healthy controls” and “normal population”) as this can negatively connote autism (e.g., some individuals might be labelled as “unhealthy” or “abnormal”) (Bottema-Beutel et al. 2021). When describing the differences between people with autism and people without autism, we should not talk only about the former’s difficulties; we should also highlight their strengths (Lei et al. 2021). It is also recommended to avoid terms such as “high-functioning autism” and “low-functioning autism” (Bottema-Beutel et al. 2021; Keating et al. 2023) should be avoided. How we talk about autism also depends on the context (a professional talking to a parent, a person with autism talking to another person, etc.) (Kenny et al. 2016). Therefore, we must pay attention to how our terminology will affect perceptions of society, the school environment and other settings (Kenny et al. 2016), as people with autism can be stigmatised more by the way they are *perceived* than by the specific terms we use (Botha et al. 2023). Most importantly, in their broader networks, people should not be afraid of the terms they employ, as this could result in even greater isolation for people with autism if those without this condition avoid them altogether for fear of making “mistakes” (Keating et al. 2023). The main rule should always be to respect the preference of the person with

whom and about whom we are talking (Bury et al. 2023; Dwyer 2022; Keating et al. 2023; Kenny et al. 2016).

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SAMOOPREDELITEV ODRASLIH OSEB Z DIAGNOZO AVTIZEM IZ SLOVENIJE

Povzetek: Vprašanje poimenovanja posameznika in/ali (manjšinske) družbene skupine je zelo občutljivo in se mu v večini družb, ki upoštevajo načeli spoštovanja in nediskriminatornosti, namenja kar nekaj raziskovalne pozornosti. S poimenovanjem zlasti manjšinskih družbenih skupin se do določene mere (lahko) opredeli tudi njihov položaj v odnosu do večinske skupine oz. nekakšna družbena hierarhija, pa tudi perspektiva, skozi katero se gleda na odločujočo značilnost te skupine (npr. jezik in narodnost, spol, posebne potrebe). Pri tem pa se neredko spregledajo preostale značilnosti, ki prav tako pomembno vplivajo na življenje pripadnikov manjšinskih skupin. V zadnjih letih se v tem kontekstu uveljavlja praksa, da se o poimenovanju povpraša pripadnike proučevane manjšinske skupine, kar je bil osnovni namen raziskave, katere del je predstavljen v prispevku. Odrasle osebe z diagnozo avtizem ($n = 55$) so utemeljile, katera v Sloveniji prepoznana poimenovanja doživljajo kot žaljiva in katera preferirajo. Kvalitativna analiza pokaže, da med anketiranci ni konsenza o najbolj zaželenem poimenovanju, medtem ko z vidika v teoriji prepoznanih paradigem (najprej oseba, najprej identiteta) v odgovorih prevladuje preferenca poimenovanj najprej oseba. Kot najmanj zaželeno poimenovanje so anketiranci opredelili oseba z avtističnimi motnjami, ki je sicer trenutno uradno poimenovanje v slovenski zakonodaji (ZUOPP-1 2011), predvsem ker v poimenovanju poudarja patologijo, motnjo in nakazuje na napako v osebi sami.

Ključne besede: avtizem, samoopredelitev, terminologija, najprej oseba, najprej identiteta

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