

NEWS & VIEWS

Down Syndrome Association Malta

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The Association

The Association promotes the interests, developments and inclusion in society of persons with Down Syndrome.

SERVICES:

- Parental Support
- Speech Therapy (by appointment)
- Keep Fit, weekly
- Mass and Tombola, First Friday of month
- Social activities: three times yearly
- Talks and fora
- Christmas Party and Disco
- Book, audiotapes and video library
- “News & Views” magazine: yearly
- Members Newsletter

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Full members:
Annual: €2.50 Life: €25

Associate members:
Annual: €5.00 Life: €35

EDITORIAL CONTRIBUTIONS:

Esperjenzi, artikli u ittri mill-qarrejja għal dan il-magażin huma dejjem milqugħa.

Experiences, articles and letters from our readers to this magazine are always welcome.

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Iż-żmien jgħaddi u ma jistenna 'l hadd. Kulma jibqa huma l-memorji u r-riżultat tal-ħidma. Inħares lura u nara dak li ġara u wettaqna matul din is-sena li kważi waslet fi tmiemha – is-sena 2008. Illum qegħda nara frott il-ħidma tal-Kumitat f'dak li huwa tisbieħ fil-*premises* u wkoll f'dawk l-issues li jolqtu direttament lil uliedna.

Il-*premises* diġa' sar ħafna aktar akkoljenti u sabiħ. Baqa' ħafna xi jsir! Il-finanzi jilgħabu logħoba mportanti fuq kemm nistgħu ngħaġġlu u nagħmlu x-xogħol kollu li jirrikjedi l-post biex finalment inkunu nistgħu ngħidu li l-*premises* huwa lest minn kollox. Hemm bżonn ta' ħafna aktar impenn minn naħa tagħkom il-koll li għandkom għal qalbkom lill-Għaqda tagħna. Inħeġġeġ lil kull min jista' jagħti dak il-ftit biex tiġu 'l quddiem u toffru l-għajnuna tagħkom.

Anke l-*issues* li bdejna u bqajna naħdmu bla heda fuqhom qegħdin, ftit ftit iħallu l-frott mixtieq u meħtieġ. Dan kollu seta' jsir grazzi għall-appoġġ kontinwu tagħkom. Jiena nemmen li jirnexxielna u ser naslu – l-importanti huwa li aħna nibqgħu magħqudin il-koll flimkien, nikbru fin-numru ta' membri, nagħtu l-appoġġ tagħna u nsiru membri attivi – jiġifieri ninvolvu ruħna aktar u nattendu għall-attivitajiet. Dan kollu għandna nagħmluh għax għandna fiduċja f'uliedna. Nagħmluh għal uliedna! Hekk biss tista' l-Għaqda tkompli tikber u tissaħħaħ biex tkun il-vuċi ta' wliedna, biex uliedna jingħataw widen, biex il-ħtiġijiet tagħhom jiġu kkunsidrati, biex inkunu involuti fil-*policy making* u f'diskussjonijiet li jirrigwardaw lil uliedna.

Jiena nemmen li kull wieħed u waħda minnkom, bħali u bħall-Kumitat, tixtiequ titjib ferm aktar f'dak li jolqot lil uliedna. Imxejna 'l

quddiem, imma fadal ħafna aktar xi jsir biex aħna l-ġenituri nserrhu moħħna li uliedna għandhom dak kollu li jinħtieġu – anzi li uliedna jkollhom dak li għandu ħaddieħor, fost oħrajn edukazzjoni kontinwa (*Life Long Learning*), taħriġ, impjeg, servizz residenzjali addattat għall-bżonnijiet individwali tagħhom eċċ. B'dawn il-ħsibijiet fuq moħħna, l-Assoċjazzjoni Down Syndrome ser tibqa' tinsisti u tħabrek biex it-tibdil għall-aħjar fil-ħajja ta' wliedna jsir malajr kemm jista' jkun.



Il-ħajja hija bidla kontinwa u l-eżiġenzi ta' llum huma differenti mill-eżiġenzi tal-bieraħ u dawk tal-lum ser ikunu differenti minn dawk ta' għada. Huwa għalhekk li l-Għaqda trid tibqa' ħajja biex tkun tista' timxi maż-żminijiet. L-Għaqda

hija aħna l-koll. L-Għaqda hija kemm dawk li huma żgħar fl-età, kemm dawk li huma f'età medja u wkoll dawk li għandhom età aktar kbira. Għalhekk l-Għaqda trid tħares l-interessi ta' kulhadd – tal-kappa wiesa ta' etajiet li hemm fi hdanha. Kull *issue* hija mportanti għall-Għaqda għax kull membru huwa mportanti għall-Għaqda.

Filwaqt li niringrazzja lilek, li qiegħed taqra dan il-messaġġ, għall-interess tiegħek, nappellalek biex tibqa' tagħti s-sapport tiegħek biex il-ħidma tiegħi u tal-Kumitat tħalli l-frott għall-benefiċċju sħiħ tal-persuni kollha li għandhom Down syndrome. Niringrazzja wkoll lis-Sinjuri Antoinette Peel u Evelyn Vella, li llum m'għadhomx membri tal-Kumitat tal-Għaqda, għall-ħidma twila tagħhom fi hdan il-Kumitat.

Fl-aħħarnett nixtieq, għan-nom tal-Kumitat, nawgura lilkom l-koll u lill-familji tagħkom il-Milied it-tajjeb u sena ġdida mimlija risq u paċi.

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L-artikli u l-veduti miġjuba f'dan il-magażin mhux bilfors juru l-opinjoni ta' l-Editor jew tal-Għaqda Down Syndrome.

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FRONT COVER

Firas Abushwashi

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Our Son Firas

Firas is our second born son after our daughter Zainab. He was born in Tripoli in June 2000. He has Down syndrome.

When he was six years of age we had to come over here to Malta because of my work. We did not know what we were to find here in Malta with regards to his education. We were a bit nervous at first but, after searching through the internet, I found out that in Malta there was a Down Syndrome Association.

On our arrival we contacted the Association and Marthese Mugliette, the Chairperson of the Association gave us all the required information about the situation in Malta with regards to children who have Down syndrome. We were not only given information but also direct support and help. This means that Mrs Mugliette was always present with us for every meeting we had to make it possible for our son to have a facilitator.

We had also been informed that there were entities (The Eden Foundation and The Equal Partners Foundation) who gave very good services to children like our son. It was suggested to us to check all availabilities and then make our decision. We decided to go for the Eden Foundation's services especially because this is not far from my work place.

Ms. Rosette Pace from the Eden Foundation helped us a lot and always made sure that we are given the necessary relevant information about our son's case. We are really grateful for the work done and is still being done by the Eden Foundation with our son Firas, especially Mr Kenneth Borg who is our son's tutor.

Firas attends Msida Primary school and this is his third year within the Maltese education system. Until last scholastic year Ms Joyce Romano was his facilitator. Firas did really well at school with her help together with that of the Eden Foundation's. All of us worked together for his only benefit and this gave a very good result. Firas is happy and is doing very well at school both academically and socially. All his classmates are his friends and he is always looking forward to go to school. This has made us very proud of him. We must admit that we never realized that he has so many potential and we have realized that being given

the right support and help he has moved on very well. He has made a lot of progress and this thanks to all those involved with his education and of course his same will.

Firas is a happy child and, like his peers, he is always willing to learn new things. He has learnt a lot also from his sister Zainab who is always there for him. They play together and communicate together as every brother and sister do. Firas speaks his own language together with Maltese and English. He is more fluent in Maltese language because he spends all his scholastic hours with his Maltese school friends.

About a year ago Firas had his second sister Rawasi whom he loves so much. He was happy when she was born and always looked for her on his return from school. Like his sister Zainab, he takes care of her in his own way. We love seeing them playing together. We treat the three of them equal and this has helped all of us a lot.

Every day is a challenge for all of us. We are always on the look out for new things and experience Firas has had and this makes all the family feel proud of him. We think we are lucky that we had to come over here to Malta because apart from making new friends we have realized that Firas has gained a lot.

We wish to take this opportunity to thank all those who, directly or indirectly, were involved with Firas especially Ms Marthese Mugliette, Ms Rosette Pace, Mr Kenneth Borg and Ms Joyce Romano. We wish these friends of ours all the very best and God Bless you.



Il-Horse Riding għal Tfal li għandhom Down Syndrome

Il-*horse riding* huwa sport u passatemp popolari ħafna; madankollu għandu ħafna benefiċċji fiżiċi, psikoloġiċi u soċjali, speċjalment għal tfal li għandhom diżabilità mhux severa bħal min għandu *Down syndrome*. Il-*horse riding* jinħtieġ relazzjoni bejn iż-żiemel u t-tifel/tifla u jinkoraġġihom biex jagħmlu hilitom biex ikollhom suċċess fil-*horse riding*.

Huwa importanti li wieħed ikun jaf li kemm-il darba *x-ray* juri li l-persuna konċernata għandha xi nstabilità fil-għonq, din m'għandiex tirkeb iż-żiemel minħabba li jista' jkun perikoluż għaliha. Tfal li għandhom problemi fil-qab għandhom ikunu ċertifikati minn tabib li jistgħu jmorru *horse riding* u dan għandu jsir b'kawtela.

Ħafna mill-benefiċċji fiżiċi tal-*horse riding* jirriżultaw mill-mod ta' kif iż-żiemel jiċċaqlaq u l-effett ta' dan fuq ir-rikkieb. Hekk per eżempju meta ż-żiemel ikun miexi, iġieghel lil min ikun riekeb fuqu jagħmel movimenti simili tal-mixi. B'hekk ikun qiegħed jiġi mgħallem is-sensazzjoni ta' kif normalment wieħed jimxi. Meta ż-żiemel jittrottja, r-rikkieb għandu bżonn stabbiltà tajba, bilanċ u koordinazzjoni u għalhekk dan il-moviment huwa utli biex itejjeb dawn l-affarijiet. Il-*horse riding* huwa wkoll mod ideali ħafna biex jissaħħu l-muskoli u biex titjeb il-mod ta' kif wieħed iżomm lulu nnifsu (*posture*). Dan għaliex ir-rikkieb jinħtieġ li jiċċaqlaq kontinwament mal-movimenti taż-żiemel. Il-moviment taż-żiemel ukoll jgħin biex jissaħħu l-muskoli u allura jgħin ħafna lill-persuni li għandhom *Down syndrome* peress li huma għandhom tendenza li l-muskoli tagħhom huma xi ftiit jew wisq dgħajfa aktar minn ta' haddiehor.

Kemm psikoloġikament kif ukoll soċjalment, il-*horse riding* u sport ieħor huma importanti biex jimmotivaw lit-tifel/tifla biex jagħmlu hilitom biex jirnexxu, u jinkoraġixxi lit-tfal li



faċilment jittlifu l-attenzjoni biex jikkonċentraw aktar. It-tfal ikollhom aktar stima tagħhom infushom meta jilhqqu għanijiet, jitgħallmu hilit għodda, jikkonċentraw u jkunu motivati u b'hekk itejbu l-hilit akkademiki tagħhom. Ir-relazzjoni li tiżviluppa bejn it-tifel/tifla u ż-żiemel tgħallim lit-tfal dwar relazzjonijiet sbieħ u dwar ir-responsabbiltà.

Spiss, lezzjoni tal-*horse riding* tikkonsisti f'li wieħed jitgħallem il-pożizzjoni t-tajba ta' kif jirkeb iż-żiemel, il-hilit bażiċi tal-*horse riding* u wkoll xi eżerċizzji li jistgħu jsiru fuq dahar iż-żiemel. Dejjem ikun hemm persuni li jgħinu biex imexxu liż-żiemel u jimxu maż-żiemel u mar-rikkieb biex tkun żgurata l-harsien tas-saħħa. Normalment għalliema professjonali tmexxi l-lezzjoni tal-*horse riding*. Normalment ukoll iż-żiemel ikun ta' statura żgħira jew medja u jkun mans u dhuli.

Studji wrew kemm huwa mportanti l-isport għat-tfal kollha, b'mod partikolari għall-persuni li għandhom *Down syndrome* u dan mhux biss biex itejbu l-abilitajiet fiżiċi tagħhom imma wkoll għall-benefiċċji soċjali u psikoloġiċi.



Ms Gatt hija senior physiotherapist, kwalifikata f'Malta u t-tezi tagħha kienet dwar il-benefiċċju tal-*horse riding* għal tfal li għandhom Down syndrome. Ilha taħdem sitt snin f'dan il-qasam u issa qiegħda taħdem is-CDAU. Sena ilu spicċat masters fil-fiżjoterapija veterinarja u wkoll tagħmel fiżjoterapija fuq l-animali wkoll.

Constipation and Down Syndrome

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Constipation is usually defined as the presence of hard or thick, pasty stools which cause discomfort as they are passed. In severe cases, the child has an inability to pass the hard stool on his/her own.

The direct cause of constipation is not enough water in the stool. This occurs because of the diet not having enough water-retaining elements (fiber) or because the stool is kept in the rectum too long, allowing the colon to reabsorb more water than usual.

In children with Down syndrome, two factors exist to make constipation more likely: low muscle tone and decreased motor activity. Both of these make the colon more likely to retain stool for longer periods, leading to loss of water from the stool.

If left untreated, constipation can lead to (1) rectal fissures: tears in the rectum leading to bright red blood on the surface of the stool and on the toilet paper, but not mixed in with the stool; (2) impaction; (3) stretching of the rectum leading to the loss of the sensation of the need to have a bowel movement. This last problem can further lead to the weakening of the rectal muscles (sphincters) and cause the child to have bowel movement accidents (in medecalese, "encopresis").

The usual treatment of constipation is dietary: increasing fiber, fruits and vegetables. In bottle-fed babies, the introduction of a stool softener is used, such as corn syrup (Karo), malt barley extract (Maltsupex) or lactulose (Duphalac). Lactulose is also

used in children and adults. All of these soften the stool by adding water to the stool. Another way of adding dietary fiber is through products such as Metamucil, Citrucel, or fiber wafers. Increasing the amount of fluids the child drinks is helpful; and in older children, decreasing the amount of constipating foods (milk products, bananas, white rice) may also help.

For babies who are having a hard time passing a stool, the use of glycerin can be helpful. These can be found as solid suppositories or in liquid form (Babylax), and are useful as occasional measure. For severe constipation, your doctor will usually recommend a medicated suppository or enema; please do not use these without consulting your doctor first. Likewise, avoid other laxatives unless your doctor specifically recommends them. The treatment of encopresis is long and involved, and I won't go into that here.

Two special conditions require further mention in children with DS: Hirschsprung disease and hypothyroidism.

Hirschsprung disease is a condition in which a segment of colon directly above the rectum is formed without nerve endings. This condition makes it impossible for that segment to push the stool along into the rectum; the stool backs up just above the rectum and only enters the rectum when enough stool backs up to push the front along (like a train caboose pushing the engine). These babies typically do not pass stool in the first 48 hours of life, and are chronically constipated. Children with DS do

have an increased risk of having Hirschsprung disease, and sometimes it can be very difficult for the doctor to tell the difference between Hirschsprung and the normal stooling pattern of a baby with DS. The diagnosis is made by first performing a barium enema on the child, and if that exam is suspicious, confirmed by a rectal biopsy. Treatment is the removal of the segment of colon without the nerve endings (the length is variable from child to child). The traditional treatment was performed in two stages: the first surgery attached the ending of the colon to a specially made opening (colostomy), and then reattachment of the rectum was performed months later. Now, however, many surgeons are removing the involved segment of colon and reattaching the good colon to the rectum in one procedure. This surgery solves the problem of constipation, though children without long segments of colon may have problems with diarrhea and malabsorption for the rest of their lives. Parents of children with Hirschsprung disease may be interested in a parent organization called the Pull-thru Network at www.pullthru-network.org/.

Constipation is also one of the signs of hypothyroidism, another condition more common in children with DS. Because the signs and symptoms of hypothyroidism can be well hidden in children with DS, a regular thyroid screening blood test is recommended every one to two years, even if the child is growing well.

Len Leshin, M.D., F.A.A.P.

www.ds-health.com

Il-Motivazzjoni Tiegħi biex Ngħallem Tfal Down Syndrome

Għal hafna snin jiena kont nimmudella u hsibt li tkun haġa tajba li ngħaddi l-hiliet li tgħallim l il dawk il-persuni li, minhabba xi kundizzjoni, is-soċjetà tagħna għadha ma waslitx biex tagħtihom l-istess ċans kif tagħti lil haddiehor. Darba, bejni u bejn ruhi, staqsejt għaliex qatt ma rajt persuni li għandhom diżabilità juru l-hiliet tagħhom f'dan il-qasam bħal u ma' haddiehor. Xtaqt li nkun jien li nibda nagħmel xi haġa fir-rigward.

Għalhekk ikkuntatjajt lir-Razzett tal-Hbiberija u dawn min-naħa tagħhom ma wrewx interess. Imbagħad kellim lill-Fondazzjoni Eden li wrew interess però minhabba l-mod tas-sistema ta' kif jagħmlu l-affarijiet dehret li din il-haġa kienet 'il bogħod biex isseħħ.

Kont kważi qtajt qalbi li jirnexxi l-hsieb tiegħi! Darba rajt avviż tal-Assoċjazzjoni Down Syndrome fuq il-gazzetta *The Times* u għamilt sforz u kkuntatjajt lil din l-Assoċjazzjoni. Mill-ewwel wrew interess f'dak li xtaqt inwettag u flimkien ma' Marthese Mugliette, ic-*Chairperson* ta' l-Assoċjazzjoni Down Syndrome, hdimna hafna biex nibdew dan il-proġett u narawh jirnexxi.

Il-lezzjonijiet isiru darba kull hmistax u issa li waqafna ftit għaż-żmien tas-sajf u qiegħda nħares lura lejn dak li diġà għamilna, nistqarr li dawn it-tfal għandhom hafna x'jagħtu però, fl-opinjoni tiegħi, sfortunatament il-fatti juru li l-htigijiet u l-eżiġenzi tagħhom qegħdin ikunu mwarrba u injorati minn ta' madwar. Għandhom hafna talenti u hemm bżonn li jiġu mghejjuna biex juru u joħorġu l-vera kapaċitajiet tagħhom. Huma persuni affezzjonati hafna u kapaċi jagħtu hafna aktar imħabba milli jirċievu.

Jien nista' ngħallimhom abilitajiet li permezz tagħhom iżidu l-istima fihom nfushom partikolarment billi jtejbu l-kunfidenza tagħhom waqt l-immudellar u quddiem udjenza. Għandi grupp ta' tmien (8) żgħażaġh li l-etajiet tagħhom ivarjaw bejn il-ħdax (11) u l-erba' u għoxrin (24)



sen. Ilkoll għandhom livelli ta' maturità u ta' abilità differenti. Għalhekk huwa aktar ta' sfida kbira għaliha biex noħroġ l-aħjar f'kull wieħed u waħda minn dan il-grupp. S'issa hemm ġuveni wieħed biss li jagħmel parti minn dan il-grupp u nixtieq hafna li dan in-numru jikber!

Abilitajiet speċifiċi li għallimthom s'issa huma kif jipprezentaw lilhom infushom bil-kunfidenza quddiem udjenza, kif jagħmlu u jkollhom kuntatt viżwali ma persuni oħra u dan peress li huma jkunu ftit mistħija u wkoll kif itejbu l-lingwa u l-kunfidenza fihom nfushom.

Nittama li nżidilhom l-abilitajiet billi nkompli ntejbilhom kif iżommu l-pożizzjoni tagħhom (*posture*), inżidilhom il-livell ta' koncentrazzjoni fuq biċċa xogħol speċifika u nittama wkoll li nressaq il-grupp aktar lejn xulxin biex nassigura preżentazzjoni finali ta' ċertu livell.

Jiena nara l-futur immedjat ta' dawn iż-żgħażaġh pożittiv hafna. Għalkemm għandhom firxa wiesja ta' abilitajiet u livelli differenti ta' maturità, jiena nispera li jirnexxili nwassal lill-grupp kollu biex jaħdem f'armonija waħda. Nistqarr li dan il-grupp qiegħed jgħinni nsir aħjar fil-mod ta' kif ngħallem kif ukoll qiegħed jgħinni nkun aktar paċenzjuża u nagħti każ il-htigijiet ta' dawk ta' madwari. Nittama li nara lil dawn iż-żgħażaġh juru l-abilitajiet tagħhom flimkien ma żgħażaġh oħra fil-kamp tal-immudellar. B'hekk huma wkoll ikunu mgħotija l-opportunità li juru t-talenti tagħhom bħal, ma' u daqs l-oħrajn.

Doris Bonello

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Fuq Wara: Dorianne Mifsud, Christine Farrugia, Doris Bonello, Roselyn Bonello, Maria Gauci u Sylvana Cassar.



Esperjenza Pożittiva

Ix-xitwa l-oħra, kelli l-opportunità li nagħmel esperjenza ma' żgħażaġh li għandhom Down Syndrome li kienu jiltaqqu għal 'Talent Group'. B'dew isiru sensiela ta' *sessions* li fihom kienu jippartecipaw dawn iż-żgħażaġh u b'hekk jesploraw it-talenti tagħhom u anke jiskopru xi talenti moħbija.

L-ewwel sensiela tas-*sessions* kienet tikkonsisti f'*posture sessions* li jinkludi l-immudellar. Is-sehem tiegħi f'dawn is-*sessions* kien li nagħti daqqa t'id lill-għalliema Doris: ngħin lil dawn iż-żgħażaġh x'hin isibu diffikultà f'xi pass li jridu jagħmlu.

Din l-esperjenza bdiet b'kumbinazzjoni, meta kont mistiedna nakkompanja lill-kuġina tiegħi għat-tieni *session*. Jien ma kontx naf x'hemm jistennieni, imma nista' ngħid li minn dakinhar 'l quddiem ma tliftx *session* waħda. Kont vera nistenna bil-herqa dawn is-*sessions* u nista' ngħid li llum li waqfu jsiru minhabba s-sħana tas-sajf, qed nimmissjahom u nistenna li nerġġhu nibdewhom wara s-sajf. Kienet xi haġa li fl-istess ħin naqta' mir-rutina tax-xogħol. Jiena *occupational therapist* u x-xogħol tiegħi jinvolvi hafna enerġija sew fiżikament kif ukoll mentalment. Għalhekk

is-*sessions* kienu għaliha wkoll ħin ta' rilassament minbarra li l-attività hija haġa li niehu pjaċir nagħmilha.

Matul dawn ix-xhur, rajt lil dawn iż-żgħażaġh 'jikbru'. Dejjem kienu jagħmlu l-almu tagħhom biex dak li kienet tgħallimhom Doris jagħmluh mill-aħjar li jistgħu. Id-determinazzjoni ta' dawn iż-żgħażaġh kienet timpresjonanti. Aħna l-adulti kemm-il darba naqtgħu qalbna meta ma jirnexxilniex f'xi haġa u nagħmlu stop. Imma jiena rajt li dawn iż-żgħażaġh, anke jekk ikollhom jirrepetu għal mitt darba, dawn ma jaqtgħux qalbhom imma jistinkaw sakemm jirnexxilhom jagħtu l-aħjar 'performance' tagħhom. U nista' ngħid li din kienet sodisfaċenti.

Barra minn hekk, ħareġ il-karattru ta' dawn iż-żgħażaġh. Saħansitra, kien hemm min kien mistħi u aktar beda jinfetaħ ma' l-oħrajn. Imma l-aktar li vera kien jolqotni kien is-sodisfazzjon u l-ferħ li kien jidher fuq wiċċhom meta, wara kull *session*, kienu juru lill-ġenituri tagħhom dak li kienu tgħallmu għid.

Din l-esperjenza għallmitni hafna u tkompli tikkonfermali dak li jien dejjem emmint: li kull persuna, indipendentement għandhiex diżabilità/kundizzjoni jew le, xi ftit jew wisq għandha x'toffri imma jista' jkun li jkollha bżonn min jgħinha tisfrutta dak li hemm internament. Għalhekk minn hawnhekk nixtieq inhegġeġ biex aktar persuni jibdew jattendu dan it-'Talent Group' għax hu ta' benefiċċju sew fiżikament u mhux inqas soċjalment.

Charmaine Xerri



World Telecommunication and Information Society Day

Nhar is-Sibt 17 ta' Meju, 2008, l-*International Telecommunication Union* fakkret il-Jum Dinji tat-Telekomunikazzjoni u Informazzjoni (*World Telecommunications and Information Society Day*). It-tema għal din is-sena kienet ddedikata għall-persuni b'diżabilità – *Connecting Persons with Disabilities: ICT Opportunities for All*.

Din il-ġurnata giet imfakkra wkoll hawn Malta fuq bażi nazzjonali u dan billi dakinhar l-Onorevoli Ministru għall-Infrastruttura, Trasport u Komunikazzjoni gie fiċ-Ċentru tagħna jara lill-membri tagħna li jattendu l-programm REACH jagħmlu użu mill-*computers* li ġentilment ġew mogħtija lilna mill-Ministeru tiegħu. Preżenti għal din il-kommemorazzjoni kien hemm ukoll is-Sur Micallef, Chairman, *Malta Communications Authority*.

Kemm l-Onorevoli Ministru kif ukoll is-Sur Micallef spjegaw u aċċennaw dwar l-importanza tal-użu tal-*computers* fiż-żminijiet tal-lum b'mod partikolari mill-persuni li għandhom diżabilità. Il-*computer* jiftaħ ħafna toroq u huwa mod tajjeb u modern ta' kif uliedna jistgħu jimxu 'l quddiem fit-tagħlim tagħhom.

Huwa għal dan l-iskop li l-Assoċjazzjoni tagħna setgħet tibbenefika minn din l-għotja sabiha. Grazzi għal din l-għotja, it-tagħlim fil-programm REACH setgħa jitjeb għall-benefiċċju ta' dawk li jieħdu sehem. Barra minn hekk dawn il-*computers* qegħdin ukoll għall-użu tal-bqija tal-membri tagħna kollha u dan permezz tal-*evening classes* li bdejna riċentament fil-*premises* tagħna.



Il-Ministru Austin Gatt, Joseph Vassallo, is-Sur Philip Micallef, Francesco Galea u ċ-Chairperson Marthese Mugliette.



Is-Sur Manuel Gellel, Joseph Vassallo, il-Ministru Austin Gatt, Francesco Galea, iċ-Chairperson Marthese Mugliette, Joe Borg Bonello (Kumitat) u Charles Vassallo (Viċi Chairman).

Informazzjoni Utli għalik

L-Allowance għal Tfal b'Diżabilità

Ġenituri li għandhom tfal b'diżabilità, kemm dik mentali kif ukoll fiżika, huma intitolati għall-*allowance* tad-diżabilità. Dan wara li jiġi kkonfermat minn *panel* mediku.

L-*allowance* tad-diżabilità mhijiex *means tested*. Jiġifieri s-somma hija ta' €16.30 (Lm7) fil-ġimgħa għal kull wield b'diżabilità.

Il-formola ta' l-applikazzjoni trid tkun mimlija u ffirmata miż-żewġ ġenituri jekk ikun il-każ. Ir-rapport mediku, li huwa nkluż fl-applikazzjoni, għandha tkun mimlija minn tabib li jiċċertifika id-diżabilità tat-tifel/tifla.

Iċ-ċittadini locali u dawk kollha Ewropej li għandhom permess ta' residenza hawn u wkoll iċ-ċittadini Ewropej oħra li ġejjin mill-pajjiżi li huma membri fil-European Social Charter u li jissodisfaw il-kriterja jistgħu japplikaw.

Il-Proċedura

L-applikazzjonijiet jistgħu jingabru:

- Mill-uffiċċji distrettwali
- Billi ċċempel SPIC fuq in-numru tat-telefon 159 tista' wkoll tapplika on line fuq il-website <http://www.welfare.ie/forms/da1.pdf>

L-applikazzjonijiet iridu jintbagħtu lid-Dipartiment tas-Sigurtà Soċjali 38, Triq l-Ordinanza, Valletta.

Il-Kapital (flus, kontijiet fil-bank, proprjetà) f'isem il-persuna b'Diżabilità

Il-kapital li persuna jista' jkollha fuq isimha m'għandux limitu. Jiġifieri persuna b'diżabilità jista' jkollha kwalunkwe ammont fuq isimha imma huwa l-interessi ta' dan il-kapital li jiġi kkunsidrat. Dawn l-interessi m'għandhomx jaqbu l-*minimum wage* ta' bħalissa li hija ta' €142.39 (Lm61.13) fil-ġimgħa. Il-kapital li jintret ma jaffetwax il-pensjoni imma huma l-interessi / renta li tiġi mill-kapital li jagħmel l-effett għax huma dawn li jiġu kkunsidrati. (*informazzjoni miġbura mid-Dipartiment tas-Sigurtà Soċjali*)

Ir-Registrazzjoni għax-xogħol

Dawk il-membri *Down syndrome* li bħalissa qegħdin fuq ir-registru tal-ETC u kull ġimgħa huma meħtieġa biex imorru jirreġistraw għax-xogħol huma mgħarrfa li jekk qegħdin isibu xi problema dwar din is-sistema (il-*weekly registration*) għandhom iċċemplu lil Ms Dorianne Powney fuq 22201407 (ETC) għall-għajnuna fir-rigward. (*informazzjoni miġbura mill-ETC*)

Mill-Kalendarju tal-Assoċjazzjoni



Bhas-snin l-oħra l-Assoċjazzjoni Down Syndrome fakkret il-Jum Dinji tad-Down Syndrome li jaħbat fil-21 ta' Marzu. Din is-sena, minhabba li din il-ġurnata ħabtet eżatt fil-Ġimgħa l-Kbira, saret quddiesa fid-29 ta' Marzu, 2008 fil-kappella tad-Dar tal-Providenza. Din il-quddiesa ġiet offruta b'suffraġju tal-membri Down syndrome u tal-familjari qrib membri tagħna li hallew din id-dinja. L-iskop ta' din il-quddiesa kien ukoll biex nagħtu l-opportunità lil dawk l-imsieħba membri residenti fid-Dar tal-Providenza biex jingħaqdu magħna f'din l-attività. Qaddes din il-quddiesa Patri M. Borg Bonello, id-Direttur Spiritwali tagħna filwaqt li l-grupp mmexxi mis-Sinjuri J. Curmi u S. Xuereb ħadu hsieb tal-kant waqt il-quddiesa.



Fil-31 ta' Jannar, 2008 l-Assoċjazzjoni Down Syndrome ipprezentat kopja tal-Pakkett Informattiv għall-Ġenituri lill-Onor. Dr. L. Deguara, ex Ministru għas-Saħħa u lil Dr. F. Bartolo, Amministratur, Mater Dei. Din iċ-ċerimonja saret fil-iSptar Mater Dei minn fejn dawn il-pakketti ser jingħataw lill-ġenituri l-ġodda ta' wlied Down syndrome.

Is-Sinjura K. Hignett flimkien ma wliedha li jissapportjaw ferm lill-Assoċjazzjoni tagħna żaru ċ-Centru tagħna waqt waħda mill-lezzjonijiet tat-Talent Group mmexxi mis-Sinjorina D. Bonello.



Nhar it-8 ta' Diċembru 2007, is-Sinjorina C. Azzopardi min-National Euro Changeover Committee, iltaqgħet ma' dawk il-membri tagħna li wrew interess biex flimkien ma' wliedhom ikunu jaflu dwar il-bidla tal-lira maltija għall-ewro.



Nhar is-7 ta' Diċembru 2007, is-Sinjura K. Hignett flimkien mas-Sur L. Degabriele, għan-nom tat-Trelleborg Sealing Solutions Malta pprezentaw lill-Assoċjazzjoni tagħna 4 laptops għall-użu waqt il-program REACH flimkien mad-donazzjoni finanzjarja mill-Kumitat fi hdan l-istess kumpanija l-Kumitat Qlub Ġenerużi.

Nhar il-5 ta' Novembru, 2007 L-Assoċjazzjoni tagħna, bħal fis-snin ta' qabel, aċċettat l-inviti tal-Fondazzjoni Eden biex nieħdu sehem f'xi attivitajiet tagħhom matul d-Down Syndrome Awareness Week li tiġi mfakkra minnhom. Waħda mill-attivitajiet li għaliha attendejna kienet il-laqgħa li saret mal-Eċċellenza Tiegħu Mons. P. Cremona, Arcisqof ta' Malta.



J. Gauci, G. Mugliette, C. Vassallo – Kumitat J. Vassallo, M. Mugliette – Chairperson, l-Eċċ. Tiegħu Mons. P. Cremona, l-Arcisqof ta' Malta, J. Borg Bonello – Kumitat, M. Mifsud, Helen Mifsud – Kumitat.

Joint Stiffness and Gait Pattern Evaluation in Children with Down Syndrome

By Mr. Ray Bezzina, Senior Principal, Physiotherapy Department

Hypotonia, ligament laxity and motor alterations are characteristic for patients with Down syndrome.

Down syndrome is the most common non inherited cause of mental impairment and occurs in one out of one thousand live births as a result of the presence of all or a portion of an extra copy of chromosome 21.

There are a number of medical problems that are associated with the syndrome, including cardiac and respiratory conditions. Motor disability is widespread among individuals with Down syndrome. It includes longer motion and reaction times, balance and postural deficits and co contraction of agonist and antagonist muscles.

These deficits may have a casual link to delays in achieving motor development milestones in children. The delay in motor development in Down syndrome is linked to the generalised muscle hypotonia and ligament laxity that is characteristics of the condition.

Early physiotherapy focuses on facilitating motor control and coordination in order to achieve developmental milestones. Once walking is established, regular physiotherapy is usually discontinued.

There are however, numerous reports suggesting that children with Down syndrome begin to develop orthopaedic problems early in childhood and would benefit from specific biomechanical assessment and management.

Castille et al. reported that walking in children and adolescents with Down syndrome was characterised by a pattern

with external rotation of the hips, increased knee flexion and valgus and external rotation of the tibia.

In children, pes planovalgus (*flat foot*) with marked pronation of the foot was observed, which could impact on postural stability and ambulation.

Foot deformity and resulting impeded function has been described as lever arm dysfunction in patients with neuromuscular disorders. In adolescents and adults with Down syndrome, hallur valgus, hammer toe deformities, plantar fasciitis, and early onset of foot arthritis associated with severe flat feet were also observed, which impair ambulation and cause further dysfunction.

Children with Down syndrome show ligament laxity, resulting from the connective tissue disorder, that characterises the condition. Muscle hypotonia is another characteristic of these patients. The combination of these problems impedes dynamic joint stabilisation and explains the increased incidence of musculo-skeletal deformities.

Children need to compensate for their muscle and ligament dysfunction in order to cope with daily activities and maintain function. Gait (*manner of walking*) becomes unsteady, and the increased cautiousness during walking may lead to low velocity and short strides.

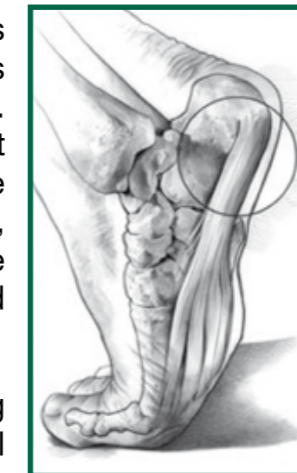
Gait alterations indicate a general functional muscle weakness. The increased joint stiffness that was observed may represent a compensatory mechanism to muscle weakness.

Studies show a difference in joint stiffness patterns between the hip and the ankle

joint. Overall joint stiffness was increased at the hip but was decreased at the ankle joint. While hypotonia and ligament laxity are thought to be the hallmarks of Down syndrome, these features may not be observed at every joint and under all conditions.

Also 'postural stiffness' during standing and higher overall stiffness for adults with Down syndrome are compared to normals. It may be that these patients increase postural stability by increasing cocontraction.

Studies show increased hip joint stiffness,



pes planovalgus (flat foot)

and ankle joint stiffness was reduced. Typically in patients with Down syndrome, the foot is highly unstable and deformed. This additional hypermobility may mask the true magnitude of joint stiffness at the ankle. The functional problem of foot instability may further contribute to the lack of push-off force produced by these patients.

It is highly recommended that patients with Down syndrome should be assessed regularly for biomechanical dysfunctions, by qualified professionals, to address in an appropriate way such conditions.

Perfect

As my children were born,
I wanted them to be perfect.

When they were babies,
I wanted them to smile and be content playing with their toys.
I wanted them to be happy and to laugh continually
instead of crying and being demanding.
I wanted them to see the beautiful side of life.

As they grew older,
I wanted them to be giving instead of selfish.
I wanted them to skip the terrible twos.
I wanted them to stay innocent forever.

As they became teen-agers,
I wanted them to be obedient and not rebellious, mannerly and not mouthy.
I wanted them to be full of love, gentle and kind-hearted.
"Oh, God, give me a child like this" was often my prayer.
One day He did. Some call him with special needs... I call him Perfect!!

- author unknown -



Ringrazzjamenti

Mrs. K. Hignett, rappreżentanta tat-Trelleborg Sealing Solutions Malta u tal-American Int. Women's Association flimkien ma' wliedha, is-Sinjura M. Mugliette, Chairperson u s-Sur D. Farrugia, ġenitur membru u mpjegat mat-Trelleborg Sealing Sol. Malta.



Lill-KMPG li anke din is-sena vverifikaw il-kotba u l-kontijiet finanzjarji minghajr hlas.

Lis-Sinjuri Jessica Curmi u Stephanie Xuereb li flimkien mal-grupp tagħhom reġġu użaw il-hin tagħhom biex, fiż-żmien tal-Milied ġabru fondi għall-Assoċjazzjoni tagħna permezz tal-carol singing.

Lill-istaff tal-Kumpanija Trelleborg Sealing Solutions Malta li permezz tal-Kumitat Qlub Ġenerużi matul din is-sena taw għotjiet finanzjarji biex intaffu l-piż finanzjarju għat-tisbiħ tal-premises.

Lill-Kumpanija Trelleborg Sealing Solutions Malta li tatna erba' laptops biex il-klijenti tal-program REACH setgħu jibdew jagħmlu użu minnhom waqt il-hin edukattiv tagħhom.

Lill-American International Women's Association li anke matul din is-sena, għal aktar minn darba, għinuna finanzjarjament biex inkomplu naghmlu t-tibdil neċessarju fil-premises tagħna għall-benefiċċju tal-membri kollha tagħna.

Lill-Familja Hignett għas-sapport u l-għajnuna kbira, kontinwa u f'waqta li tati lill-Assoċjazzjoni tagħna.

Lill-Kumpanija Medelec Switchgear Ltd li hadet hsieb l-ispejjeż kollha tax-xogħol u x-xogħol li sar fir-rigward tat-tisbieħ ta' l-aperturi interni kollha.

Lill-Kumpanija Just Paints għall-għajnuna kbira tagħhom fuq il-kontijiet taż-żebgħa.

Lill-familja Stanley Mifsud, membri tagħna, li offritilna d-drapp tal-purtieri l-godda u s-sopraporti.

Lill-Onor. Ministru Dr. A. Gatt, Ministru għall-Infrastruttura, Trasport u Komunikazzjoni għall-għotja sabiħa ta' tmien computers biex b'hekk il-membri kollha tagħna jkunu jistgħu jġu mharrġa bl-inqas piż u xkiel possibbli għalihom.

Lis-Sinjura Doris Bonello, li mgħejjuna mis-Sinj Charmaine Scerri, fuq bażi volontarja tagħllem lil xi membri żagħżagħ tagħna kif jimxu fuq catwalk.

Lis-Sinjuri Esther Gauci u Helen Mifsud, ġenituri membri tagħna, li ġentilment offrew li jhitsu l-purtieri l-godda.

Lill-kumpanija Bad Boy Cleaners li offrewlna t-tindif tal-'premises' b'xejn wara li tlesta x-xogħol kollu.

Lis-Sur Kenneth Poulson, membru assoċjat mal-Għaqda tagħna li tana printer, scanner, fax għall-użu tal-uffiċċju tagħna.

Diskors Amministrattiv tas-Segretarju Ġenerali

4 t'April 2008

Din is-sena jerġa' jmiss li nivvutaw għall-membri godda fil-Kumitat biex immexxu l-Għaqda. Kull sentejn l-Għaqda trid tghaddi minn proċess biex jittla' Kumitat ġdid li l-membri jisperaw ikollu l-enerġija u mezz finanzjari w importanti hafna, persuni biex jiehdu fuqhom l-inkariku biex imexxu l-Għaqda 'l quddiem għal ġid tat-tfal tagħna.

Biex inżommu l-Għaqda hajja hemm bżonn l-impenn tal-membri kollha. Għalhekk kull sena naghmlu appelli sabiex nies godda jersqu 'l quddiem, kemm jekk jahsbu li jistgħu jagħtu kontribut fit-tmexxija tal-Kumitat kif ukoll biex joffru ruħhom bhala helper meta jkun hemm bżonn. Hemm bżonn li membri b'ideat godda jsibu posthom fil-Kumitat, anki jkunu lesti jiehdu post il-membri tal-Kumitat li ilhom iservu bosta snin.

It-teżorer sejjer jghidilna li l-Għaqda mhix tiġbor flus biżżejjed biex immexxu 'l quddiem is-servizzi billi nissussidjaw 50% mill-miżata tas-sessjonijiet. Infatti s-servizz tal-fizjoterapija kellu jieqaf minhabba li l-konkorrenza kienet ftit wisq biex niġġustifikaw l-ispejjeż involuti. Barra minn hekk hemm l-ispejjeż tal-magazin, il-party u d-disco tal-Milied u biex inżommu ċ-Centru fi stat tajjeb. Il-flus bil-mod jidhlu għax hemm konkurrenza kbira mill-NGO's fuq il-pubbliku u l-entitajiet.

Naghmlu appell lill-membri kollha biex nuru aktar interess fl-Għaqda, nipparteċipaw aktar fi hdanha u fl-okkażjonijiet li jkollna, biex hekk nagħtu kuraġġ akbar u rieda soda biex il-Kumitat ikompli bil-hidma tiegħu biex l-Għaqda tkompli tikber.

Fl-ewwel laqgħa tal-Kumitat, wara li kien ġie mahtur fl-2006, iċ-Chairperson kienet uriet ix-xewqa li l-Għaqda taħdem fuq issues li jolqtu direttament lil uliedna. Wiehed irid jghid ix-xewqa saret realta' u tul l-ewwel u t-tieni sena ta' dan il-Kumitat kienu diversi l-issues li l-Għaqda semmgħet il-vuċi tagħha għan- nom tal-membri kollha.

Attivitajiet

L-Għaqda organizzat diversi attivitajiet li dejjem intlaqgħu tajjeb hafna mill-membri u minn min jattendi.

Fis-6 ta' Mejju 2007 giet organizzata harġa ta' ġurnata, li kienet tikkonsisti f'quddies fil-knisja

ta' Selmun. Wara saret ikla buffet fir-Ramla Bay Hotel Complex. Bhas-soltu Mrs Peel ma naqsitx li torganizza tombola, waqt li t-tfal u anke l-kbar, kellhom l-opportunità li jużaw is-swimming pool, sakemm sar il-hin għat-te. Bhas-soltu, il-persuni li għandhom Down syndrome kienu halsu prezz issussidjat.

Fit-18 ta' Lulju 2007, għall-attività tas-sajf, giet organizzata ġurnata fl-iSplash and Fun Park. Id-domanda għal din il-harġa dejjem tkun popolari bil-membri li jattendu jiehdu hafna pjaċir. Is-sidien offrew il-post għall-prezz speċjali ta' Lm8 inkluż l-ikel għall-membri. Tfal membri/persuni li għandhom Down syndrome ġew issussidjati mill-Għaqda u l-prezz kien ta' Lm 3.50.

L-Għaqda hadmet hafna biex ma' Ms. Claire Azzopardi, rappreżentanta tal-Uffiċċju Bidla għall-Ewro, ikun possibli ntellgħu attività bla hlas fid-8 ta' Diċembru 2007 filgħodu għall-membri biex jingħata l-opportunità diretta lill-membri kollha u lill-familji tagħhom biex jitgħallmu dwar l-użu ta' l-ewro. Il-membri li attendew għal din il-laqgħa ngħataw pakkett tal-flus tal-plastik, stickers u folder.

Il-party tal-Milied sar it-Topaz Hotel Bugibba fit-23 ta' Diċembru 2007 fejn bhas-soltu tqassmu r-rigali tal-Milied lill-membri. Meta wiehed jattendi din l-attività forsi ma jahsibx kemm tinvolvi xogħol għall-organizzazzjoni tal-party. Bhas-soltu r-rigali ntraw mill-ġenituri stess. Din is-sistema tassigura li t-tfal jiehdu rigal li verament jiehdu gost bih. Lil dawk il-ġenituri li wrew l-irċevuta tar-rigal, l-Għaqda tathom hames liri bhala sussidju. Din is-sena, ukoll biex evitajna problemi fuq l-ikel, servejna platti ta' l-ikel lil kull persuna, mhux finger foods. Il-persuni li għandhom Down syndrome ġew issussidjati mill-Għaqda u halsu biss Lm1.

Attività oħra f'dawn iż-żminijiet tal-Milied kienet id-disco għat-tfal li sar fid-Deporres Hall tas-Sliema fid-29 ta' Diċembru 2007. Barra d-disco kien hemm ukoll riċeviment żgħir. Sfortunament din id-darba nzerta l-maltemp, li żamm lil hafna nies milli jattendu.

Fis-sitt Simpożju Internazzjonali tad-Down Syndrome, il-Bord tad-Down Syndrome

International (DSI) u dak tal-*European Down Syndrome Association (EDSA)* iddeċidew li l-21 ta' Marzu għandha tibda tissejjaħ bħala l-ġurnata tad-*Down syndrome*. Il-ġurnata u x-xahar intgħażlu hekk għax id -*Down Syndrome* hija assoċjata mat-tliet (3) koppji tal-kromożoma 21 (*trisomy 21*). Għalhekk hađu l-21 bħala l-ġurnata u t-tielet xahar tas-sena. Id-DSI u l-EDSA kienu talbu lill-membri tagħhom biex kull sena jiċċelebraw din il-ġurnata dinjija f'pajjiżhom.

Minhabba li l-21 ta' Marzu haġbat il-Ġimgħa l-Kbira, il-Kumitat haġeb li għal din is-sena din il-ġurnata tiġi ċċelebrata fid-29 ta' Marzu 2007 permezz ta' quddies fil-Kappella tad-Dar tal-Providenza Siġġiewi. Il-quddies saret b'suffraġju għall-persuni *Down syndrome* u jew qraba qrib haġna (ġenituri u aħwa) ta' persuni membri li għandhom *Down syndrome* li hallew din id-dinja.

Wieħed forsi jgħid li l-lotterija l-kbira hija l-unika attività bl-iskop ewlieni ta' ġbir ta' flus. Biex l-Għaqda tkompli tissussidja s-servizzi tagħha, torganizza l-attivitajiet soċjali fosthom il-*party* u d-*disco* tal-Milied. Biex isiru dawn l-attivitajiet, is-servizzi u joħrog il-magazin, l-Għaqda jkollha bżonn ferm iżjed fondi għax l-ispejjeż huma kbar u dejjem jiżdiu minn sena għall-oħra. Dawn il-flus jingabru minn donazzjonijiet u mil-lotterija li nagħmlu kull sena. Sfortunament hemm problemi biex insibu *sponsors* għar-riġali, barra li l-konkorrenza għal din il-lotterija qed tonqos, barra li jkun hemm diversi lotteriji oħra fiż-żmien il-Milied. Għaldaqstant il-Kumitat kien iddeċieda li l-lotterija tal-2007 ma ssirx biex nippruvaw nagħmlu waħda fil-bidu tas-sajf jew għall-Għid, imma ukoll ma' saritx. Peress li issa ġejna mistiedna biex nieħdu parti, f'Gunju ta' din is-sena, fil-lotterija tal-*Lions Club (Host)*, din il-lotterija sejra sservi bħala l-lotterija tal-Għaqda.

Barra minn dawn l-attivitajiet, wieħed ma jridx jinsa' l-Quddies ta' kull l-ewwel Ġimgħa tax-xahar fiċ-Centru, fejn wara wieħed ikun jista' jieh u l-kafe' u l-pastizzi u jilgħab it-tombola.

Servizzi tal-Għaqda

L-*speech therapy* isir kull hmistax fiċ-Centru nhar ta' Tnejn mill-professionisti Rita Micallef u Joe Agius. Dawn is-sessjonijiet huma mportanti haġna fl-iżvilupp tat-tfal u huma mezz kif it-tfal jitgħallmu jkommunikaw, jaħsbu, u jieħdu deċiżjonijiet li jistgħu jolqtu lilhom infushom.

Minhabba n-nuqqas ta' konkorenza mill-membri għall-fiżjoterapija, l-Kumitat ha deċiżjoni li għal issa jitwaqqfu dawn is-sessjonijiet. Pero', jekk 'il quddiem insibu li jerġa' jkun hemm domanda għal dan is-servizz nergħu nippruvaw noffruh dejjem skond il-ħtieġa u l-finanzi tal -Għaqda għax is-servizz irid ikun sostenibbli.

Minhabba li s-Sinjura Alison Galea, l-għalliema tal-*Keep Fit* kienet infurmatna li ma setgħetx tkompli tagħmel lezzjonijiet peress li hija kienet qiegħda tistenna tarbija, fuq rakkomandazzjoni ta' l-istess Alison Galea, postha haġitu is-Sinjura Antoinette Caruana. Il-*Keep Fit classes* isiru kull nhar ta' Ġimgħa fl-iskola *Guardian Angel*. Dawn is-sessjonijiet huma miftuħa għall-membri kollha tagħna: zghar, kbar, subien u bniet. Il-hlas għal dawn is-sessjonijiet huwa Lm10 (€23.30) għas-sena kollha li minnhom titħallas l-għalliema tal-*Keep Fit* u l-iskola tal- *Guardian Angel*. Minn dan is-servizz ma jsir l-ebda qliegh għall-Għaqda anzi huma ssussidjat bil-bosta mill-Għaqda.

Il-Programm Reach

L-adulti li għandhom *Down syndrome* qegħdin jiffaċċjaw problema fl-edukazzjoni tagħhom. Fil-preżent, wara li jispiċċaw il-Form 5 fl-iskejjel regolari, uliedna li għandhom *Down syndrome* u li jkunu għadhom mhumiex maturi biżżejjed u, aktar minn hekk, għad m'għandhomx dawk il-*life skills* meħtieġa għall-ħajja adulta, m'għandhomx fejn ikomplu jitgħallmu. Preżentament l-istat m'huwa joffri l-ebda servizz jew programm li huwa mfassal għall-bżonnijiet tal-adulti li għandhom *Down syndrome* biex ilaħħaqhom għall-iżvilupp shih tagħhom qabel ma jibdwu jiġu ppreparati għad-dinja tax-xogħol. Quddiem dan in-nuqqas ta' servizzi offruti, l-Assoċjazzjoni *Down Syndrome*, b'kollaborazzjoni mal-Fondazzjoni Eden, bdiet programm pilota ta' sentejn bħala tranżizzjoni mis-sekondarja għat-taħriġ fl-impjieg. Dan il-programm issa qiegħed fit-tieni sena u qiegħed isir ma' numru żgħir ta' membri tagħna fiċ-Centru hawn il-Belt. Bhal issa n-numru tat-tfal fil-programm tela' għal tmienja. Dan il-programm qiegħed jiġi ffinanzjat mill-ġenituri ta' min qiegħed jibbenifika minn dan is-servizz u mill-*Eden Foundation*. L-Assoċjazzjoni kienet applikat u giet aċċettata biex tibbenifika mill-fondi li ngabru għall-Istrina fl-edizzjoni tal-Milied 2006. Wara li l-flus mill-Istrina waslu għand l-Assoċjazzjoni, huwa mistenni li issa tgħid lill-

ġenituri billi nissussidjaw parti mill-flus li jkollhom joħroġu għal dan is-servizz.

Servizz Ġdid

Il-Kumitat iddeċieda li nibdwu servizz fejn wiegħed jiġi mgħallem kif iżomm il-qagħda ta' persuntu, kif jimxi sewwa, il-kontroll tar-ras u l-gisem u oħrajn. Dan is-servizz qed jingħata minn persuna dedikata u li għandha esperjenza fid-drama u fil-moda. Għal dan is-servizz it-tfal li jistgħu jippartecipaw huma kemm subien u kemm bniet minn 12-il sena 'l fuq. Bhal issa qed jattendu tmien persuni.

Premises

Il-holma tal-Kumitat hija li barra li jkollna Centru tagħna, dan jiġi wkoll irrangat kemm jista' jkun malajr biex inkunu f'pożizzjoni li noffru aktar servizzi u jkun aktar akkoljenti.

Din is-sena komplejna b'dan ix-xogħol imma baqa' haġna xi jsir u qegħdin nippruvaw insibu min jaħdmilna ix-xogħol kollu li hemm bżonn mill-aktar fis possibli. Peress li l-Assoċjazzjoni ma sabitx minn jaħdem bħala volontarjat, issa l-Għaqda sejra jkollha thallas lil min tqabba biex jagħmel ix-xogħlijiet kollha li hemm bżonn. Bhalma tistgħu taraw sar xogħol, il-katusi ta' wara ġew irrangati, l-imwejjed godda waslu, imma jonqos biex inbiddu s-siġġijiet, sar tindif ġenerali biex inneħhu l-affarijiet li m'għandniex użu għalihom iżjed, imma b'dan ir-rigward ukoll baqa' xogħol xi jsir.

Bhalma tistgħu taraw il-kamra fejn konna nagħmlu t-terapija saret il-*computer room*. Dawk it-tmien *computers* għotja mingħand il-Ministeru tal- IT li kien taħt l-Onor. Dr Austin Gatt, bhalissa qegħdin jintużaw mill-programm REACH. Għandna l-hsieb li l-*computers* jiġu ntużati anki minn dawk il-membri li sejr in jieħdu parti fi program ta' hidma biex wieħed jitgħallmu il-komputer. Dan isehh meta nsibu persuna addattata biex tgħallmu il-*computers* lill-membri tagħna.

Forsi wieħed jista' jara mwaħħal ġewwa inkwatru mal-ħajt it-talba tal-Għaqda tat-*Tapestry*. Dan huwa xogħol ta' Antoinette Peel, li għogħbha tagħti dan ix-xogħol lill-Assoċjazzjoni. Għandnom tal-membri ngħidulha grazzi.

Magazine

Il-magazin taħt id-direzzjoni ta' John Peel, Alister

Cachia bħala editur u l-Bord Editorjali tkompla b' determinazzjoni kbira. Nixtieq infakkar fil-bżonn kbir li jeżisti biex nirċievu xi esperjenzi, ritratti u / jew xi artikli sabiex jiġu ppubblikati fil-magazin. Jekk ikollkom bżonn ta' xi għajnuna, il-membri tal-Kumitat lesti jgħinukom b'xi kitba u / jew intervista, jekk hemm bżonn fid-dar tagħkom stess.

Il-magazin jiġi ppubblikat b'diffikultà kbira. Kull haġa tal-magazin tiswa €980 barra €290 pustagġi. 50 fil-mija tan-nefqa għall-posta tingħatha lura mill-Kummissjoni Nazzjonali Persuni b'Diżabilita wara applikazzjoni. Il-flus biex jithallas dan il-magazin iridu jiġu mill-ġbir ta' fondi, għax reklami, biex intaffu l-ispejjeż tiegħu, m'għadniex insibu. Wieħed irid jiftakar illi l-Gvern jagħti biss sa Lm300 (€698.81) għall-proġetti zghar. Dawn il-flus, li l-Għaqda tapplika għalihom kull sena, jintużaw biex jithallsu spejjeż amministrativi.

Laqgħat

Iċ-Chairperson haġet sehem f'dawn il-laqgħat, seminars

18 ta' April 2007 – seminar fiċ-Centru Hidma Soċjali "Nistharrġu Aspetti Differenti mill-Familji Maltin Illum". indirizzata mill-Onor. Ministru D. Cristina. Iċ-Chairperson pubblikament staqsiet biex issir riċerka fuq persuni b'nuqqas intelletwali għax kienet tal-fehema li għandhom l-istess diffikultajiet, bhal diskriminazzjoni u nuqqas ta' servizzi.

23- 25 ta' April 2007 – It-tielet Kungress Internazzjonali organizzat mill-Ministeru għall-Familja u Solidarjeta Soċjali, Mediterraneo Senza Handicap, Dar tal-Providenza, Caritas Malta, KNPD u l-Federazzjoni Maltija tal-Organizzazzjonijiet ta' Persuni b'Diżabilita. It-tema magħżula kienet "Towards a New Humanism – Ethics and Disability".

Għal dan il-Kungress iċ-Chairperson għamlet preżentazzjoni ta' seba' minuti "The Current Situation of the Education of Persons who have Down syndrome in Malta" li kienet ta' nteress għal bosta nies preżenti. Kopja tal-preżentazzjoni li sejra tiġi ppubblikata fid-dokument tal-Kungress ġie mqassam lil dawk preżenti

25 ta' April 2007 – flimkien mal-Viċi Chairman Charles Vassallo, PRO Pio Fenech u Helen

Top Questions on Down Syndrome and Sexuality

Mifsud attendiet il-laqgħa konsultattiva mall-Prim Minister Dr. L. Gonzi f'Kastilja, it-tema kienet l-impjeg.

27 ta' April 2007 – focus grupp organizzat mid-Dipartiment tal-Infommazzjoni tas-Saħħa bil-kollaborazzjoni tal – *European Public Health Institute (Loegd) Germany*.

7 ta' Mejju 2007 – laqgħa tal- *Malta Resource Centre*, Gżira bħala partċipanti fil- Focus Grupp tas-Saħħa u bħala membri tal-*European Anti Poverty Network (EAPN)*.

11 ta' Mejju 2007 – iċ-Chairperson giet intervistata minn Ms. Cynthia Busuttill tat- Times of Malta. L-artiklu sejjer jiġi ppublikat fil-bidu ta' Gunju.

23 ta' Mejju 2007 – konsultazzjoni pubblika mall-Prim Ministru Dr. L. Gonzi.. It-tema kienet 'Inkomplu Intejbu l-Pensjonijiet'

24 ta' Mejju 2007 – Chairperson, flimkien ma' Bro. Austin Gili, Manuel Gellel, Claire Ebejer u rappreżentanta oħra tal- *Eden Foundation* iltaqgħu mas-Sur Anthony Degiovanni, Direttur tal- Adult Education u s-Sur Tyson Borg (EDuc. Dept).

28 ta' Mejju 2007 – il-kuntratt tar-REACH program gie ffirmat miċ-Chairperson M. Mugliette, mis-Segretarju A. Gauci u mit-Teżorer A. Wetz għan nom tal-Assoċjazzjoni u minn Bro. Austin Gili għan-nom tal- *Eden Foundation*. Il -kuntratt gie ffirmat quddiem l-avukat tal-Għaqda Dr. R. Tufigno fl-uffiċċju tiegħu l-Belt.

30 ta' Mejju 2007 – il-laqgħa konsultattiva mall-Prim Ministru bit-tema 'Uliedna Jirnexxu Lkoll'.

1 ta' Ġunju 2007 – laqgħa ma' Bryan Magro, Ministeru għall-Familja u Solidarjetà Soċjali, Marcel Pisani u Joyce Mifsud għall-Aġenzija Sapport biex jiddiskutu t-tranzizzjoni mill-iskejjel speċjali għall- ATC's.

11 ta' Gunju 2007 – iċ-Chairperson flimkien ma' Helen Mifsud (membru tal-Kumitat), iltaqgħu ma tliet familiji Għawdxin li għandhom tfał *Down syndrome, facilitators*, rappreżentanta tal-*Gozo Federation* u Chev. F. Gatt, Kordinatur tal- Kulleġġ ta' Għawdex. Wara l-laqgħa iċ-Chairperson flimkien ma' Helen Mifsud hađu l-opportunità biex immorru s-sala tal-maternità fl-Isptar Ġenerali ta' Għawdex biex jiltaqgħu mal-istaff.

19 ta' Gunju 2007 – iċ-Chairperson attendiet 'the Presidents' meeting' imsejha mill- Federazzjoni (MFOPD).

30 ta' Gunju 2007 – L-ewwel laqgħa tas-Sapport Grupp ta' Għawdex li saret fil-bini tal-NGO's fix-Xewkija Għawdex. Iċ-Chairperson attendiet.

27 ta' Lulju 2007 – iċ-Chairperson attendiet għall-laqgħa tas-sotto kumitat minn EAPN. Bit-tema "Employment and Challenges Opportunities for Persons Experiencing Social Exclusion and Poverty".

20 ta' Settembru 2007 – iċ-Chairperson attendiet laqgħa għall-familji organizzata mill-program tar-Reach

5 ta' Novembru 2007 – iċ-Chairperson flimkien ma' Charles Vassallo, Helen Mifsud u Joe Borg Bonello attendew attività mtella' mill-*Eden Foundation* waqt il-gimgha 'Down Syndrome Awareness Week'.

5 ta' November 2007 – laqgħa ma' Fr. Scerri, il-persuna responsabbli mill-iskejjel tal-Knisja, fuq il-problemi tat-tfał li jattendu l-iskejjel tal-Knisja u s-servizz tal-facilitators.

10 ta' November 2007 – iċ-Chairperson attendiet il-konferenza mtella' mill- *Eden Foundation* bit-tema 'Down Syndrome- A Practical Approach to meet needs of the Individual'. Iċ-Chairperson għamlet preżentazzjoni qasira fuq l-Għaqda..

12 ta' Novembru 2007 – iċ-Chairperson flimkien ma' Helen Mifsud kellhom laqgħa ma' Dr. Vella, il-Kap tal-*Employment Training Centre (ETC)*, fuq persuni *Down syndrome, training*, impiegi, registrazzjoni għall -impjegi, l-Għawdxin u l-fondi tal-EU.

Konklużjoni

Nixtieq nagħlaq billi nringrazzja lilkom preżenti talli ġejtu illum u lill-membri kollha tal-Kumitat u lill-*helpers* għall-hidma tagħhom fi hđan l-Għaqda. Fl-aħħarnet nixtieq nringrazzja wkoll lis-Sur Peel għax-xogħol siewi li baqa' jwettaq fi hđan l-Għaqda u l-għajnuna kontinwa li jagħti lill-Kumitat.

Antoine Gauci
segretarju

Attention Down Syndrome Support Groups: If you'd like to reprint all or part of this Q&A in your newsletter or post it to your website, please feel free to do so with proper attribution to Ms. Couwenhoven, her book, and Woodbine House.

<http://www.woodbinehouse.com/DSandSexTop10questions.asp> - here's the link..

Terri Couwenhoven, M.S., certified sexuality educator, parent, and author of the forthcoming book, Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality, offers thoughtful answers to parents' frequently asked questions about Down syndrome and sexuality.

Will my child with Down syndrome have the same feelings, thoughts, urges desires, and needs around sexuality as other people do?

Yes. We are just now at a point in time in our society when we are accepting sexuality as a healthy and positive aspect of life, particularly for individuals with Down syndrome and other intellectual disabilities, who have experienced horrible oppression throughout history. Speak with any parent who has an older son or daughter with Down syndrome and they will tell you their child experiences the same feelings, desires and needs as other people do in the area of sexuality. Just as there are ranges in sex drive in the general community, there are among individuals with Down syndrome as well. Your son or daughter will have sexual feelings and crushes, want to develop meaningful connections with others, wonder if they are lovable, want to date, and perhaps even find someone to deeply love and share a life with.

My child is only four years old. I can't think of any sexuality issue I need to address at such a young age.

Unfortunately in our society we tend to think about sexuality in rather limited, narrow ways. At the core of healthy sexuality is a sense of feeling valued, loved, lovable and safe and your earliest

interactions with your child influence these feelings. Snuggling, nurturing touch and affection, and gentle caresses are initial ways children begin to understand they are important human beings. As your child becomes more mobile and verbal, you become his interpreter and teacher as he explores, watches, and attempts to understand the world around him. Your child, for example, learns what it means to be a girl or boy by watching what girls do, what toys they play with, how they interact with others. At very young ages you're introducing language and sharing messages about your child's body (if certain parts of the body are avoided that's a message as well) and how to get along with others (social skills). Much of this learning lays the foundation for learning about sexuality throughout the lifespan.

My daughter has difficulty understanding the concept of modesty. How do I teach this?

Typically developing children under the age of five often have an undeveloped sense of modesty. If you've ever been around kids this age you know they love to strip off their clothes and run around naked whenever they get a chance. This lack of modesty is normal and healthy in early childhood. Early in elementary school, however, these same children become more private and modest about their bodies.

Children with Down syndrome and other intellectual disabilities have more difficulty understanding this concept and usually require extra help and instruction. Some of this instruction can be done through modeling (remember kids with Down syndrome are great imitators), so you may have to evaluate if and how modesty is modeled in your home. You could encourage older family members to use a robe or towel to cover the body when moving through public areas of your home, teach your child how to close doors when toileting or bathing, or recommend family members change clothes in designated private areas (rather than the middle of the living room). Beyond modeling, teaching modesty involves helping your child:

- Discriminate between when she has clothes on and when she doesn't (i.e, teach vocabulary like *dressed* and *undressed*, *naked* and *clothed*)
- Identify designated private spaces in your home
- Understand social rules that apply to private body parts (e.g., 'private body parts need to be covered in public places or when other people are around')

Although my daughter is twelve, she functions at a second grade level. I doubt she has the emotional maturity or cognitive

ability to understand what is happening to her body.

I hear this statement often and as a sexuality educator, I do understand your concerns about comprehension. One of my toughest jobs is figuring out how to modify sexuality information so it is more understandable and then evaluating whether or not it has been understood. The developmental age your child is functioning at is critical in figuring out how sexuality education materials can be altered so your daughter has a better chance at understanding what you're teaching. If your daughter reads at a second grade level, for example, instructional sheets need to be at that level. For non-readers, pictures will need to be used. Most parents have good insights on teaching strategies that work for their own child.

Related to preparing your daughter for puberty, there are a couple of issues. First, the initiation of puberty is not dependent on social or emotional maturity or many of us would've never matured! It is a biological process that will happen whether your child is emotionally ready or not. Your job is to help your child understand these changes so she can be informed and as prepared as possible to handle things as best as she can. Second, if you repeatedly refer to your child exclusively in the developmental context, you help others view your child as 'child-like' rather than as a maturing individual. Most of the time when individuals with Down syndrome are treated like same-aged peers, they begin to understand expectations and it increases their ability to develop emotional maturity (albeit more slowly). Progress, not speed, is what's important. Third, once your daughter is out and about in the community, there are pretty rigid societal expectations for age-appropriate behavior, especially in the area of sexuality. People who

are not familiar with your child will expect her to behave close to her chronological age (how she looks) regardless of developmental age. If your daughter (who is 12) is hugging people indiscriminately, she is violating the rights of others and jeopardizing her own safety. All of these are reasons to work at providing information and developing skills that support age-appropriate behavior.

My child is approaching puberty and the whole idea of trying to help him understand what will happen to him is overwhelming. How do I approach this?

Keep in mind that the physical and emotional changes that accompany *pubescence* (the process of changing) happen gradually over three or four years so preparation can occur slowly over time. Once you or your child begins to notice physical changes, it's a good time to begin discussions. Some early signs of physical changes in females include breast budding, height increases, and pubic hair. Enlargement of the scrotum and testicles, height increases or hair under the arms and pubic area are early signs your son is beginning to change. Use these concrete signs as a way to introduce the topic of puberty. For example, 'My, you've gotten a lot taller this year. You must be starting puberty? do you know what that means? Puberty is a time when your body changes and begins to look more adult-like.? Or, ?Have you noticed the hair under your arms? That's one of the changes that helps you know your body is starting to change and look more like an adult. Do you want to know what else will happen?? Once your child can anticipate changes and knows these changes are normal and healthy, ongoing teaching about different aspects of puberty can occur over time as things happen. Be sure to use pictures that help illustrate body changes on the inside and

outside and always incorporate social rules that encourage social appropriateness. For example, 'Even though these changes are normal and happen to everyone, they're private so not all people feel comfortable talking about them. You can always talk to me, or _____ if you have questions, need help, or want to talk.?'

I'm thinking my daughter will be getting her period within the year. My physician is advocating use of the pill. Is this what everyone does? How well do girls with Down syndrome handle periods?

Like educators, physicians and/or health care providers typically follow a set of rules that encourage least restrictive practices and approaches when making decisions. In other words, your physician should be supporting you in making decisions that *minimize risks for your daughter and maximize self-determination*. The assumption that your daughter will be incompetent in this area of her life is unfair, especially considering she hasn't even started menstruating. A least restrictive approach in this situation might be to begin with some good, concrete teaching that will prepare her handling her periods and then see how she does. Some girls will do well right from the get go, others will need more time to adjust to having a period and understand the responsibilities that go along with menstruating. I have found that because it is quite normal to have irregular periods in the first year of menstruating, girls with Down syndrome might have a harder time getting into a pattern or groove. For example, if your daughter gets her first period and then doesn't have another one for four months, it's hard to remember all the details for using a pad. Once periods are coming more regularly, self-care skills often improve.

My experience has been that most girls with mild and moderate cognitive disabilities do quite well handling their periods with understandable instruction, advance preparation, and sometimes behavioral management techniques. Of course, there are girls who will have more difficulties handling their periods or have more significant physical symptoms, reducing the quality of life for them and perhaps the parents. In these situations, hormonal or surgical options may be suggested. Health care providers often suggest hormonal options such as the pill first, then surgical options if there are: challenging behaviors triggered by the hormonal cycle that jeopardize your child's safety or the safety of others, health conditions that are exacerbated by the hormonal cycle (e.g., seizures, diabetes), gynecological conditions that have remained unresponsive to other less invasive treatments, difficulties managing self-care even with good training and support, or specific requests by the patient (your daughter) after making an informed choice, to suppress or eliminate menstruation.

Since entering puberty my 13 year old son has shown an increased interest in masturbation, particularly at inappropriate times and places. His siblings are extremely uncomfortable and embarrassed by this behavior. How do I handle this?

Individuals with intellectual disabilities often have more difficulty understanding the concept of privacy and consequently are more likely to masturbate at inappropriate times and places. There are many reasons for this. Lack of privacy (often due to increased supervision) may distort your child's understanding of when and where it might be okay to

masturbate. Or parents' extreme discomfort with the behavior leads to quick attempts at eliminating the behavior (which doesn't usually work too well) and prevents parents from moving into the teaching mode. Inconsistency in how others handle the behavior in different settings may create confusion (e.g., different messages at school and home) as well. Regardless of the reason, your son needs to understand that masturbation is a private behavior. Begin by providing a clear definition for what it means to be in private. You could define a private place as a space where 'you are alone and no one can see you'. Your son, especially at this age, should have a private place he can go to unwind and do private things. Once you've identified the place for him (usually the bedroom or bathroom with the door closed) create pictures of your son's private place or label the rooms with visual cues that make sense for your child. Make sure others in your family are respecting his privacy and vice versa. When your son masturbates in public areas of the home, use calm but clear messages. For example, 'rubbing your penis is private, so you need to go to your private space.' Repeat and reinforce over time.

Some families I work with report intervals of time when masturbating seems more intense and difficult to handle. We know that hormones being released during puberty can create powerful sensations that spark renewed interest and enthusiasm for masturbation. These periods do subside over time but can be correlated with testosterone surges occurring during puberty. This happens to all males but usually individuals with Down syndrome need more help understanding what is happening to their bodies along with strategies for handling their feelings in socially acceptable

ways. Many females also begin to masturbate around this time, though rates are lower than for males.

My son tells me he only wants to date 'normal' girls and refuses to even consider dating a girl with Down syndrome or other intellectual disability. Why is this?

This is a hard question with multiple layers of complexities, but also a very common experience as younger generations of individuals with Down syndrome are growing up in inclusive settings. Sometimes this attitude evolves from living in a culture that devalues individuals with intellectual disabilities. The milder the cognitive disability, the more aware your child will be of the prejudices, stereotypes, negative treatment and pejorative attitudes towards people with disabilities in our society. As a result, your child may view dating a 'normal' person as a more appealing and acceptable option. In other situations, individuals with Down syndrome (or other intellectual disabilities) who grow up being told they are 'just like everyone else,' are treated 'just like everyone else' so their expectations are 'just like everyone else's.' In other situations, the disability is not talked about, or more often, not understood, so your son or daughter will need help understanding his or her own disability and what that means uniquely for him or her. In other instances individuals with intellectual disabilities have limited opportunities to be with others who are like them. When provided with opportunities to interact with other people with disabilities, your son may recognize the value of dating another person with a disability. If, over time, your son remains negative about others who are like him or struggles with identity issues, seek counseling services.

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