

NEWS & VIEWS

Down Syndrome Association Malta

December 2012

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Newspaper Post



The Association

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

SERVICES:

- Parental Support
- Aerobics, 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

MEMBERSHIP:

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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Founded 1981

Member of the



Federazzjoni Maltija tal-Organizzazzjonijiet
Persuni b'Dizabilità (F.M.O.P.D.)

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Għeżież membri u ħbieb,

Din is-sena, eżattament fl-10 t'Ottubru, 2012 Malta rratifikat il-Konvenzjoni tal-Ġnus Magħquda dwar id-Drittijiet ta' Persuni b'Dizabilità.

L-għan ta' din il-Konvenzjoni hu li tippromovi, tippoteġi u tassigura t-tgawdija sħiħa u ugwali tad-drittijiet umani u l-libertajiet fundamentali kollha mill-persuni b'dizabilità kollha, u li tippromovi rispett lejn id-dinjità intrinsika tagħhom.

Persuni b'dizabilità jinkludu dawk li għandhom nuqqasijiet fiżiċi, mentali, intellettuali jew sensorjali fit-tul, li meta jirrelataw ma' ostakoli varji jistgħu jtellfuhom milli jippartecipaw b'mod sħiħ u effettiv fis-socjetà fuq bażi ugwali bħall-oħrajn.

Forsi wieħed jistaqsi x'inhuma d-drittijiet fundamentali (*human rights*)? Kofi Annan, li kien Segretarju Generali tal-Ġnus Magħquda kien qal hekk: *Human rights are what reason requires and conscience demands. They are us and we are them. Human rights are rights that any person has as a human being. We are all human beings; we are all deserving of human rights. One cannot be true without the other* (Id-drittijiet fundamentali huma dak li r-raġuni tinħtieġ u dak li l-kuxjenza titlob. Huma aħna u aħna huma. Id-drittijiet fundamentali huma drittijiet li kull persuna umana għandha. Aħna lkoll persuni umani; aħna lkoll jistħoqqilna d-drittijiet umani. Wieħed ma jistax joqgħod minghajr l-iehor).

Fost dawn id-drittijiet umani nsibu d-dritt għall-ħajja, għall-għixien ta' livell adattat għas-saħħa u l-*well-being* tal-persuna, id-dritt għall-edukazzjoni, għax-xogħol u d-dritt biex wieħed jistrieħ u jirrikrea ruħu.

L-Assoċjazzjoni tagħna ħadmet u għadha qiegħda taħdem biex naraw li persuni *Down syndrome* ma jkunux miċhuda minn dawn id-drittijiet.



Uljedna għandhom id-dritt ikunu mgħallma u mharrġa professjonalment biex ikunu jistgħu jidhlu fid-dinja tax-xogħol. Huma għandhom id-dritt jgħixu ħajja indipendenti fejn u ma min iridu u wkoll li jkollhom fejn jirrikreaw ruħhom u jiltaqgħu ma' shabhom u jagħmlu ħbieb ġodda f'ambjent addattat. Ser nidhlu

fis-sena 2013 u sfortunatament għadna m'aħniex sodisfatti mit-taħriġ għall-adulti tagħna biex ikunu jistgħu jidhlu fid-dinja tax-xogħol; mill-iskemi tax-xogħol issupportjat (*supported employment*); mill-iskemi/ghajnuniet għall-ħajja ndipendenti. Ma nistax ma nsemmix il-frustrazzjoni tagħna għall-fatt li ġa għaddeu kważi sitt snin minn meta bdejna naħdmu u nagħmlu pressjoni fuq l-entitajiet governattivi u l-Gvern biex jgħinna jkun hemm għażla oħra bħala post ta' divertiment addattat għal uljedna. Ir-riżultat għadu wieħed negattiv.

Nappella liż-żgħażaġh kollha Maltin u Għawdxin li ċertament jifhemu x'ifisser ikollok l-għażla biex speċjalment fil-*weekend* tiltaqa' mal-ħbieb u tagħmel ħbieb ġodda f'postijiet ta' rikreazzjoni addattati, biex juru solidarjetà maż-żgħażaġh b'nuqqas intellettuali u jingħaqdu magħna halli nqajjmu kuxjenza għal dan il-bżonn urġenti.

Jalla s-sena 2013 tkun is-sena tar-riżultati tal-ħidma tagħna. Għan-nom tal-Kumitat nixtieqilkom Milied hieni u sena ġdida mimlija ġid, hena u saħħa.

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Editorial



NEWS&VIEWS

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Patrick Umanah
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Views expressed in this magazine may not necessarily be those held by the Editor or by the Down Syndrome Association.

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

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FRONT COVER

From left to right: Maria Mifsud, Gayle Mugliette, Yusi Ratia. At the back: Saami Helle. The 4 participants of VALO project

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It is a well-known fact that the month of December (Christmas month) on our beautiful Islands brings about many magazines, most of them are for commercial adverts while others are on awareness on social issues concerning humanity or the environment. The only magazine that makes a difference is the Down Syndrome Associations' "News & Views". So, you are welcome to our 39th Issue, December, 2012.



This issue draws its point of view from the motto of The European Disability Forum (EDF), the voice of persons with disabilities in Europe: "Nothing about us without us", meaning that no decision concerning disabled people should be taken without disabled people. EDF believes that "a society, in which disabled people are fully included, is a better society for all". Our Association is strongly in agreement with this motto.

May I also take this opportunity to remind our entire members who are still not participating in our activities in March each year when celebrating World Down syndrome Day which focus on aspects of daily living with Down's syndrome. In 2012 we are involved in a project of communication, our new feasibility initiative planned to link with other associations catering for persons with learning disability.

There were talks and media awareness on supported employment for people with Down syndrome in which we want to move away from the idea that there is some associated burden to employ a person who has Down syndrome. Rather, all employers will need to know that persons Down syndrome have a condition that affects their learning and working on a given task.

This means that the person who has Down Syndrome will need a longer period to understand his/her tasks than the other person, as well as a bit more support to ensure the tasks are learnt. Once all tasks and responsibilities are mastered, the performance in the workplace of someone with Down syndrome has been shown to be outstanding and some employers regard them to be good employees.

In this issue, we focus on many issues such as inclusive education, sports (where Liverpool

FC Community Team, through the intervention of the Liverpool Supporters Club, Malta) met and coached, amongst others, some of our members; communication (where Radio Valo – Finnish's Feasibility & Accessibility of People with learning Disability visited Malta in conjunction with Youth in Action Programme; independent healthy living (the Adult Down Syndrome Clinic which started seeing to our members since

August 2012; the perspective of the Supported Employment with Disabled People; the services offered and related articles: on Podiatry and Occupational Therapy.

Other items of great importance are the message and reports from the President's desk detailing on the work and activities of the Association along with the Administrative Report from the General Secretary.

I am sure this year is probably one of the most challenging regarding serious financial situations which have affected our income yet; we appreciate the yearly support of our benefactors and the new members with their membership fees.

I would like to take the opportunity to thank the newly elected two members to the committee who have taken the roles of Assistant Treasure (Ms Joanne Xerri) and PRO (Ms Anna Farrugia).

Finally, may I invite you to join us on Face Book "Down Syndrome Association, Malta". So read on, and hope you will enjoy reading these interesting and empowering articles while together, we can start a wider awareness campaign to implement the already ratified "United Nations Convention on the Rights of Persons with Disabilities" in which our members will benefit. Do know that our Association is just a phone call away should you need any further information or assistance.

Wishing you all Happy Christmas and Happy New Year.

Mr. Patrick Umanah
M.A, B.ED (HONS, B.A (HONS) B.A.

Il-Klinika għall-Adulti li għandhom Down syndrome

Wara sitt snin ta' ħidma, l-Assoċjazzjoni Down Syndrome rnexxiha tilhaq ftehim mal-Ministeru tas-Saħħa sabiex titwaqqaf klinika għas-sorveljanza tas-saħħa tal-adulti Down syndrome. Ma nistax ma nsemmix illi l-maġġor parti tax-xogħol u l-lobbying għamlitu l-id singolari tal-ħabrieċa Presidenta tal-Assoċjazzjoni, is-sinjura Marthese Mugliette li ħadmet bla heda għal din il-kawża nobbli.

Il-ftehim ġie ffirmat aktar kmieni din is-sena ġewwa l-bini tad-Dipartiment tas-Saħħa fil-Belt Valletta. Dakinhar sehhet ġrajja ġdida fis-servizz tas-Saħħa peress li din hi l-ewwel klinika tax-xorta tagħha. Din il-klinika ser isservi ta' *prototype* li fuqha d-Dipartiment tas-Saħħa jfassal kliniċi oħrajn għas-servizzi t'entitajiet u kundizzjonijiet mediċi oħra.

L-iffirmar tal-ftehim kien segwit minn ħafna xogħol ieħor loġistiku. L-ewwel pass li ttiehed kien li twaqqaf it-Tim Amministrattiv li kien responsabbli għall-ippjanar kollu, mill-bidu sal-aħħar, ta' kif u minn min kellha tithaddem din il-klinika. Dan it-tim li ħadem bla heda fuq bażi volontarja kien magħmul mill-President tal-Għaqda Ms Marthese Mugliette, minn ġenitur membru tal-Għaqda l-Professur Joseph M. Cacciottolo u minni Dr Isabella Borg, ic-*Chief Medical Advisor* tal-istess Għaqda.

Saru intervisti lil tobba li kienu wrew interess f'dan is-servizz sabiex setgħet tintgħażel il-persuna medika li kellha tkun inkarigata mit-tmexxija tal-klinika. Għal din ir-responsabbiltà ġiet magħzula Dr Dorothy Zammit li għandha esperjenza vasta fis-servizzi mediċi tal-iskejjel u wkoll bħala tabiba tal-familja. Sadanittant l-Għaqda kkomunikat ma' professjonisti barranin biex ikun possibbli nkunu nformati x'inhu jsir fir-rigward fuq bażi internazzjonali. Din

il-komunikazzjoni wasslet biex Dr Zammit marret Spanja sabiex tikseb esperjenza ta' kif titmexxa klinika ta' din ix-xorta.

Wara laqgħat li kellna mas-CEO ta' Ċentri tas-Saħħa Primarja s-Sur Edward Borg u t-tim tiegħu, finalment ġew magħzula l-lokalità u l-ġurnata li fiha tinzamm il-klinika. Ġejna wkoll mogħtija infermiera biex tassisti lil Dr Zammit fil-klinika.

Il-Klinika għall-Adulti Down Syndrome twaqqfet fil-poliklinika ta' B'Kara. L-iskop ewlieni tal-klinika hu li jsir *screening* mediku lil kull individwu Down syndrome, mill-età ta' 16-il sena 'l fuq, fuq bażi annwali jew aktar spiss, dejjem skont il-bżonn tal-individwu. Il-għan hu li waqt *check-up* mediku ġenerali, Dr Zammit tkun tista' tinduna mill-ewwel b'xi problemi mediċi li jista' jkun hemm u b'hekk tkun tista' tirreferi lill-individwu għand professjonisti oħra skont il-bżonn. Fost affarijiet oħra, il-klijenti jiġu rreferuti għall-*check-ups* tas-smiġħ u tal-vista u wkoll testijiet tad-demem li jinkludu dawk taz-zokkor u tat-*thyroid*. Jingħata wkoll tagħrif dwar in-nutrizzjoni biex jiġi evitat il-piż żejjed u mard li jiġi minn piż żejjed. Għal kull vista jinżammu *r-records* mediċi li kopja tagħhom tingħata lill-ġenituri jew lill-*carer*. B'hekk it-tabib tal-familja tal-klijent ikun jista' jiġi nformat mill-istess klijent dwar dak kollu li jirriżulta mill-vista. Għan ieħor hu li l-bżonnijiet tal-ġenituri u tal-*carers* ikunu identifikati u jingħata s-sapporport meħtieġ.

Il-klinika fethet il-bibien għall-ewwel darba nhar is-Sibt 11 t'Awwissu, 2012. Minn dakinhar 'il hawn, kull nhar ta' Sibt, din il-klinika baqgħet tilqa' fiha lill-klijenti adulti Down syndrome. S'issa kellna *feedback* sodisfaċenti u inkoraġġanti ħafna mill-ġenituri li diġà ħadu lil uliedhom għall-vista. Ahna nittamaw u nheggu lill-persuni adulti



Ms Marthese Mugliette, President u Dr Natasha Azzopardi Muscat, CMO iffirmaw il-ftehim. Fuq wara Dr Isabelle Borg, Chief Advisor tal-Għaqda, l-Onor. Ministru Dr Joe Cassar, Dr Kenneth Grech, Segretarju Parlamentari, is-Sur Malcolm Vella Haber, Segretarju Privat.

kollha li għandhom Down syndrome, sew Maltin kif ukoll Għawdxin, biex jagħmlu użu minn dan is-servizz. L-appuntament jista' jsir jew mill-ġenituri, jew b'ittra mit-tabib tal-familja, jew mill-*carers* t'istituzzjonijiet fejn ikun qed jgħix l-individwu, jew

mill-Assoċjazzjoni stess. Wieħed jista' jċempel fuq in-numri tat-telefon 21494960 / 21235158 jew jibgħat *email* fl-indirizz elettroniku dsc.mhec@gov.mt.

Dr Isabella Borg
Chief Advisor

Kummenti tal-Ġenituri

I take the opportunity to hail the very good work done by all concerned at the Adult Down Syndrome Clinic. The enthusiastic and proactive stance of all involved in the set up and operation of this clinic has been greatly appreciated by parents and carers of Down syndrome persons. The services being provided are second to none. This initiative would not have been possible without the collaboration of your association and the Primary Health Care to whom we extend our gratitude for making our lives so much easier and we encourage you to continue in your unwavering vocation of caring for these people. Thank you.

Evelyn Vella (Ġenitur)

Reċentament, aħna l-ġenituri ta' Christine Farrugia, fost ħafna oħrajn, ġejna mistiedna nieħdu t-tifla tagħna d-downs' clinic fiċ-ċentru tas-saħħa f'Birkirkara. Din il-klinika fethet apposta biex it-fal tagħna li għandhom id-Down Syndrome, jiġu eżaminati ta' kull sena ħalli jekk ikun hemm xi haġa f'saħħithom li mhix sejra sew, tingħata trattament. F'din il-klinika, iżommu rekords tat-testijiet li jsirulhom, permezz tal-kompjuter, u dan it-tagħrif ikollhom aċċess għalih dawk biss li jsegwu s-saħħa ta' dawn iż-żgħażaġh. Wara s-CDAU ma kellna mkien fejn nirreferu liż-żgħażaġh tagħna rigward saħħithom. Għalhekk aħna l-ġenituri nappoġġjawha ħafna din il-klinika u nisperaw li din il-klinika tkompli tibqa' tkun ta' ġid għal uliedna. Grazzi u prosit.

Angela u Domenic Farrugia (Ġenituri)

F'Settembru għamilna użu minn servizz ġdid li ħadmet ħafna għalih id-Down Syndrome Association. Dan huwa s-servizz tad-Down's clinic għal dawk il-persuni b'Down Syndrome li għandhom 'il fuq minn 16-il sena. Sibna li dan is-servizz huwa effiċjenti u jaħdem flimkien mal-oqsma l-oħra li t-tifel tagħna qed juża ġol-isptar. Hriġna sodisfatti u nisperaw li s-servizz jibqa' jtitjeb.

Louisa Grech, omm Ben Grech (20 sena) (Ġenitur)

ara aktar kummenti f'paġna 16

Supported Employment with Disabled People

Mike Evans

Mike Evans is a Chartered Fellow and Graduate of the Chartered Institute of Personnel and Development. He was Manager of the Employment Disability Unit of Dundee City Council in Dundee, Scotland from 1991 to 2011 and was President of the European Union of Supported Employment (EUSE) from 2007 until 2011. He was also Chairman and a founding member of the Scottish Union of Supported Employment. He is a co-author of the EUSE Quality Standards Guide which has played an influential role in the delivery of Supported Employment in many projects throughout Europe. He was also the Co-ordinator of the EUSE Leonardo Partnership which produced the European Supported Employment Toolkit which he co-authored and edited. This Toolkit has now been translated into six languages and is widely used throughout Europe, Australia and South America.

Mike is now a consultant and provides training and guidance for employment projects across Europe. He has recently written a Good Practice Guide for employers on the island of Jersey and also was the lead EUSE officer in the EU Study of Supported Employment in Europe.



Supported Employment is a method of working with disabled people and other disadvantaged groups to access and maintain paid employment in the open labour market. This method of working is a proactive policy in accordance with the United Nations Convention on the Rights of People with Disabilities.

The concept, principles and values of Supported Employment are based on the early work from North America which demonstrated that people with significant learning disabilities including those with Down Syndrome, could perform a variety of complex tasks, highlighting the potential and capabilities of people with learning disabilities/Down Syndrome to participate in paid work in the open labour market. Due to the success of Supported Employment assisting people with learning disabilities to access and maintain employment, the model was developed and expanded to include all areas of disability and disadvantage.

In the late 1980's, the model transferred across the Atlantic to Europe and a number of disability organisations in various European countries successfully

piloted Supported Employment projects funded mainly under European Union programmes such as Helios and Horizon. The European Union of Supported Employment (EUSE) was formed in 1993 and has developed its structure since that time.

The definition of Supported Employment in Europe is recognised as:
"Providing support to people with disabilities or other disadvantaged groups to secure and maintain paid employment in the open labour market"

Supported Employment is completely consistent with the concepts of empowerment, social inclusion, dignity and respect for individuals. Within Europe, agreement has been reached on the values and principles that should be present at all Supported Employment stages and activities and adhere to full citizenship rights of individuals:

Individuality – Supported Employment regards each individual as unique, with his / her own interests, preferences, conditions and life history

Respect – Supported Employment activities are always age appropriate, dignifying and enhancing

Self-determination – Supported Employment assists individuals to improve their interests and preferences, express their choices and define their employment / life plan according to personal and contextual conditions. It promotes the principles of self-advocacy by service users

Informed Choice – Supported Employment assists individuals to understand their opportunities fully so they can choose consistently within their preferences and with an understanding of the consequences of their choices

Empowerment – Supported Employment assists individuals to make decisions on their lifestyle and participation in society. Individuals are centrally involved in the planning, evaluation and development of services

Confidentiality – The Supported Employment service provider considers information given by individuals to them as confidential. The service user has access to his/her personal information gathered by the provider and any disclosure is at the discretion of and with the agreement of the individual

Flexibility – Staff and organisational structures are able to change according to the needs of service users. Services are flexible and responsive to the needs of individuals and can be adapted to meet specific requirements

Accessibility – Supported Employment services, facilities and information are fully

accessible to all people with disabilities. The values and principles of Supported Employment are supported by a 5-stage process/methodology that has been identified and acknowledged as a European model of good practice which can be used as the framework within Supported Employment.

Stage 1 Engagement – Underpinned by the core values of accessibility to ensure informed choices are made

Stage 2 Vocational Profiling – Ensuring empowerment to the individual throughout the process

Stage 3 Job Finding – Self-determination and informed choice are key values in Supported Employment

Stage 4 Employer Engagement – Accessibility, flexibility and confidentiality are key values to be nurtured through this process

Stage 5 On/Off Job Support – Flexibility, confidentiality and respect are the key components to successful support measures. Support measures particularly refer to when the individual is in paid employment and are delivered through the provision of an Employment Support Worker/Job Coach

The European Union of Supported Employment promotes the concept of Supported Employment as a vehicle/methodology to assist disabled and disadvantaged people access their right to work.

Whilst there are slight variations of the definition across the world, there remain three consistent elements that are

Occupational Therapy and Down Syndrome

fundamental to the European Supported Employment model:

1. Paid Work - Individuals should receive commensurate pay for work carried out – if a country operates a national minimum wage then the individual must be paid at least this rate or the going rate for the job
2. Open Labour Market – People with disabilities should be regular employees with the same wages, terms and conditions as other employees who are employed in businesses/organisations within the public, private or voluntary sectors
3. On-going Support - This refers to job support in its widest concept whilst in paid employment. Support is individualised and is on a needs basis for both the employee and the employer

Therefore from a perspective of people with Down syndrome, Supported Employment adopts a person-centred approach that places the individual at the heart of the process. Supported Employment offers informed choice and support throughout the process not only to the individual but also to employers, potential work colleagues and of course the individual's family.

I was recently invited to Malta by Minister Chris Said to assess the situation in Malta regarding the service provision and opportunities for people with disabilities to access the open labour market.

Whilst I did not find a Supported Employment programme or any similar model in Malta, I did see some extremely important measures that would complement and enhance any Supported Employment initiative that may be developed in Malta namely:

- There is a legal employment quota in Malta
- There are wage subsidies available to employers who employ a person with a disability
- There is the opportunity for a disabled person to retain their welfare benefits whilst also receiving wages for employment.

During my recent visit I held some very positive discussions with key stakeholders including: Minister Said, KNPD, ETC, Agenzija Sapport and a range of Maltese NGOs including the Down Syndrome Association.

I would conclude this article by encouraging all the readers to work together to develop a Maltese Supported Employment programme that conforms to the basic values and principles outlined in this article.

Michael J Evans
Chartered Fellow CIPD
Dundee, Scotland
November 2012

Bernardette Ellul Felice

I qualified as an Occupational therapist in 1993. Ever since I have been seeing children and adults with various difficulties like Down Syndrome, Autism, Global Developmental Delays and more as my private work.

My full time work with the government was at St.Vincent De Paule Residence for 10 years and now I am At Sir Paul Boffa Hospital and have been here for the past 9 years. My role at SPBH is as Head of Department and visit Mater Dei once a week to cover Rainbow ward.

In the Private sector I started off with the Eden Foundation for 7 years and then moved to freelance work and nowadays its mostly freelance and cover as well referrals from Equal Partners.

In 2011 I Qualified as an I.T.E.C Massage therapist and I use this in combination to my Occupational Therapy for my Clients. I find that massage therapy compliments a lot Occupational therapy and helps me give a more holistic therapy session to my clients.



Probably most parents and carers of persons with Down Syndrome have heard and experienced an Occupational Therapist. The scope of my article is to try and make our role more clear and explain better what we can do.

Sometimes the role of the Occupational Therapist gets confused with many other professions and this is due to the fact that OT is versatile and uses all means possible to help achieve the targeted skill in question.

The Occupational Therapist is in the life of the person with Down Syndrome from birth up to the point when the person is independent to his/her full potential.

At Birth the Occupational Therapist will provide the necessary activities and tasks that will stimulate the child to achieve the milestones according to age and according to the child's ability. Many a time parents set their own timing as regards their child's progress. This causes unnecessary stress and tension. In reality the child should be allowed to attain his/ her developmental milestones at his / her own pace.

It is of utmost importance that the child reaches a particular skill when the child is ready. Our job is to create experiences for the child, thus facilitating the attaining this particular skill but this surely does not mean or contemplate pushing the child over the limits.

In the 19 years that I have been practising OT I have experienced children that were able to put on shoes alone at the age of 3 and also much later like at the age of 10 or older. The most important thing is for the parent/carer to be persistent, if the OT has made it clear that the child has no difficulty to put on his / her shoes than discipline is important and we need to be patient to give enough time for the child to carry out the particular skill. For this to succeed the child has to be left to carry out this skill every time he/she needs to do it throughout the day. This is very important since if we give up and on a particular day and we decide to do the task ourselves for the child, we would be passing on the message that it is ok not to put on the shoes and let others do it for you. This will be contradictory in the person's mind and we surely would not want that.

Youth in Action Programme – Feasibility Visit in partnership with Lyhty ry

Persistence and Discipline are very important. I have seen children at 15 turning from completely dependent to becoming independent. We have a habit of branding a child incapable for life of performing certain tasks. It often happens that a child finds difficulty in carrying out an activity at one stage in his life and at a later stage, develops capabilities to perform that same task.

If we want to see change in our children, we need to be the once that make the change first.

The Occupational Therapist will be able to help the parents and carers choose the appropriate expectations for the person with down syndrome according to their ability not age.

Bernadette Ellul Felice
Occupational Therapist
79539472
jesperhoney@yahoo.com



Christine Farrugia bil-medalji li rebhet

Prosit Christine!

F'Ottubru li għadda, Christine, flimkien ma' seba' atleti oħra, marru Ċipru jirrappreżentaw l-iSpecial Olympics Malta fil-Bowling European Games li saru hemmhekk.

F'dan it-tournament ħadu sehem erbatax-il pajjiż fosthom - Ċipru, il-Greċja, Ingilterra, Ġermanja, Danimarka.

L-atleti kollha rebħu medalji ta' deheb, fidda u bronż.

Christine wkoll rebħet medalji, waħda tad-deheb, u tnejn tal-bronż. Nagħti prosit kbira lil Christine u lil sħabha u nawgurawlihom ħafna suċċessi. Prosit Christine. Keep it up.

Ms. Angela Farrugia (Omm Christine)

VALO – Visibility and Accessibility of People with Learning Disabilities is the title of the second project the Down Syndrome Association benefited from through the 'Youth in Action' Programme.

The activity of this project was a feasibility visit by our partners from Helsingin lyhytaikaiskoti ja tuopaja Lyhty ry, Finland. Lyhty, is a non-profit Association which provides living, education and work activity services for adults with learning disabilities. Lyhty is located in Helsinki, Finland and was founded in 1993. Lyhty provides service for approximately 100 individuals plus their families. Lyhty owns four buildings and houses. The staff consists of 45 professionals who provide service around the clock. On top of this, the staff includes ranging amount of non-professionals, civil servants and volunteers. The service philosophy of Lyhty was originally based on nursing philosophies but nowadays the Association is creating its own mix of philosophy and services through research.

The Down Syndrome Association established contact with "Lyhty ry" through the Maltese European Union Programmes Agency. On discovering more about the organisation, their journalistic media exercises seemed ideal within a Maltese context, thus discussions started on how this practise could also be carried out in Malta.

The project aimed at providing an opportunity to empower disadvantaged youths equipping them with the tools necessary to live a fuller and more participative citizenship within their Society. The fact that the European Year (2011) was dedicated to combating poverty and social exclusion, was considered idyllic for hosting this initiative since these priorities

are very much in line with those of the participating organisations.

This feasibility visit was conducted to see whether Malta could set up an internet radio station similar to the Radio VALO concept in Finland as well as the sharing of best practices in the running of both organisations. This feasibility visit offered a golden opportunity to illustrate and demonstrate a success story and how the lessons learnt from the experience of "Lyhty ry" can be emulated in Malta with hopefully as much success.

Furthermore the participants had an opportunity to interact with their peers from another country, shared reciprocal learning in formal and informal contexts on their cultures, way of life, countries and experiences and the opportunities available to them. This project offered the organisations an opportunity to share best practices in regards to the most efficient operational and administrative procedures of their respective organisations.

In other words the final objective of this visit was that of stimulating the respective growth of the organisations concerned both vertically and horizontally:

Vertically through the upgrading and improving of the ways the organisations function as well as the services and opportunities they offer to their members.

Horizontally through the broadening of each other's list of contacts as well as strengthening international cooperation, thus fostering a wider network of organisations sharing an equal interest. More international cooperation will also translate in added strength and leverage to the organisations concerned.

Training Session with Liverpool Football Club Community Team

The 3 day activity started on the 19th March, 2012 and ended on the 21st March, 2012. The participants for this project were Gayle Mugliette and Maria Mifsud from Malta and Saami Helle & Yusi Ratia from Finland. The support persons for this project were Ms Marthese Mugliette, Ms Helen Mifsud, Mr Markus Vahala and Mr Kalle Pajamaa.

This visit was just the beginning! Our next step is for the maltese participants to visit Lyhty and physically experience what is actually being done there. This will be followed by another visit where Maltese supporters for the project will be taught how to teach our members journalistic media exercises and how to set up a local internet radio station for our members' benefit and use.

I am very positive about this unique project (locally) as this is an ideal opportunity for our members to gain confidence in themselves and start talking publicly about themselves and for themselves. The success of this project depends on all of us – whoever is reading this article. The Maltese supporters to work on this project



21st March, 2012 – World Down Syndrome Day
Participants with Hon Minister Dr Chris Said

have not yet been identified and so, if you think you can be one of these supporters, kindly contact us at your earliest for more information.

I wish to take this opportunity to thank the 4 participants - Gayle, Maria, Saami and Yusi - and Lyhty ry, especially Mr Markus Vahala for his continuous support and help which was and still is instrumental for the success of this project.

**Marthese Mugliette
President**



21st March, 2012 – World Down Syndrome Day
Some committee members together with our Finnish partners met with H.E. Mr Anton Tabone



On the 21st March 2012, World Down Syndrome Day, the Down Syndrome Association received an invitation from Mr James Vella, Secretary of the Liverpool Supporters Club Malta.

The club was to host representatives of the Liverpool Football Club Community Team and our members were invited to participate and benefit from a training session offered by these Liverpool professionals.

This information about the LFC Community Team is quoted from the Liverpool FC website:

Led by Community Coaching co-ordinator Bill Bygroves, who is also Liverpool FC's club chaplain, the Liverpool Football Club Community Team works very closely with the local community and are involved in a whole host of various activities both locally and world wide.

Bill Bygroves works alongside former professional footballer Owen Brown and they lead a very dedicated and enthusiastic team working with the community. There are community coaches including Head Coach Eddie Sullivan, Disability Liaison Officer Jodi Unsworth and Admin Co-ordinator Tracy Boden. There are three full-time and two part-time coaching community staff.

The community department work closely with young children and visit local schools throughout



Mr Bill Bygroves (in red) first from the left and his team

Podiatry and Down Syndrome. The need for Proper Foot Care

the Merseyside region giving assemblies. The mottoes chosen by the Liverpool FC Community team are Kick Drugs into Touch, Give bullying the boot, Show racism the red card, Better than being a good footballer is being a good person and You'll Never Walk Alone.

Football wise, the community team take youngsters for general football coaching in mainstream schools, after school clubs, community centres, special needs schools and adult day care centres.

Unfortunately, on the day of the training session, it rained throughout the day. Luckily the rain stopped just a few minutes before the session began. The weather kept some persons who were interested to attend this training session at home and thus lost such an opportunity! The group was made up of persons with intellectual disabilities amongst which persons who have Down syndrome. The coaches Mr Bill Bygroves, Mr Eddie Sullivan, Mr John Shaw and Mr Mark Chester were great with our children. It was a privilege to meet these professional persons who find time to share valued time with persons in the community, particularly with persons with disability.

Apart from being one of their mottoes, **You'll Never Walk Alone** is also the official anthem of Liverpool Football Club. I cannot, not include the anthem's lyrics in my article as it has a very beautiful message :

**When you walk through a storm hold your head up high
And don't be afraid of the dark.
At the end of a storm is a golden sky
And the sweet silver song of a lark.
Walk on through the wind,
Walk on through the rain,
Tho' your dreams be tossed and blown.
Walk on, walk on with hope in your heart
And you'll never walk alone,
You'll never, ever walk alone.**

**Walk on, walk on with hope in your heart
And you'll never walk alone,
You'll never, ever walk alone.**

Thank you Mr James Vella of Liverpool Supporters Club Malta for choosing our Association to benefit from such a special initiative. Thank you also to Mr Bygroves, Mr Sullivan, Mr Shaw and Mr Chester for spending time with our children and thus making this event a memorable experience.

**Marthese Mugliette
President**

Kummenti tal-Ġenituri

Bhala ġenitur u membru tal-Għaqda nixtieq nuri s-sodisfazzjon tiegħi għall-ftehim li sar bejn l-Għaqda u l-Ministeru tas-Saħħa sabiex wara tant żmien twil, l-adulti tagħna qed igawdu milli jkollhom vista fil-klinika tad-Down Syndrome ġewwa l-poliklinika ta' B'Kara. Dan hu pass għaqli hafna għax hekk evitajna l-outpatient tal-isptar. Fil-fehma tiegħi nixtieq u nissuġġerixxi li minflok kull sena jsir għall-inqas tliet darbiet fis-sena. Ir-raġuni hi għaliex li uliedna huma suġġetti għal hafna mard bħall-qalb, Tyroid, Aborzita, Diabetics u kollesterol. Għalhekk nirrikmanda għal testijiet tad-demem għal kontra dawn l-affarijiet li jistgħu jinstabu u jolqtuhom. Dan jistgħu jinqalgħu minhabba li hafna minnhom ma jaħdmux u iżjed ma jikbru jonqos l-eżerċizzju. Għalhekk nappella lill-Ministru tas-Saħħa sabiex minflok vista waħda, isirulhom tlieta fis-sena. Grazi

Saviour Dimech (Ġenitur)

Ivan Farrugia

Ivan Farrugia is a state registered Podiatrist. He studied at the University of Malta where he obtained a Diploma in Podiatry back in 1998. Ivan also had the position as President of the Association of Podiatrist of Malta from 2006 till 2009. From 2009, Ivan holds the role as Podiatry representative in the Council for Professions Complementary to Medicine.

He got his Pg Certificate in Podopaediatrics and did his thesis on Pedal Pathologies in Children. Ivan has a post as a Specialist in Podopaediatrics within the Health Department and runs a clinic at the Podiatry Department, Birkirkara Health Centre.

This service is offered to children aged from birth till the 16th Birthday. In this clinic all children are examined and treated according to their needs.



Recently I had the occasion to take part in the foot screening program organised by the Malta Special Olympics Committee and I must say that on the day I met the friendliest people in the country. In my experience of a Podopaediatric Specialist, only few times I had the opportunity to examine feet of Down syndrome children.

Hypermobility was the first thing I noticed in most of the children. Unfortunately an abnormal collagen development exists in these children and affects skin, bones, muscles and joints. Thus, it is of utmost importance that special care is given to these children not only from us podiatrist but also from a multidisciplinary team whom can work together to give a special service these children truly deserve.

Down syndrome children usually present with broad feet and short toes. Some of them may in addition present with a larger than normal space between the first and the second toe. One might consider these features as not medically problematic but type of footwear and walking can exacerbate these conditions and create further harm.

The most common foot condition amongst these children is Pes Planus (Flat Feet). Pes planus may present itself both ways, with neutral gait or severe pronation. In neutral gait one can notice that there is no excessive flattening of the arch while in severe pronation one can see a flattened feet most of the time caused by the hypotonia (Low muscle tone). Either case, one must consider to seek further advice by a podiatrist to discuss any possibilities of an orthotic or custom insert for the shoes that can support the flattening of the foot against any shear, torsion, pressure or friction that can occur due to flat feet. Also, this will ease fatigue and allow the child to remain active and more involved in sports and leisure activities.

A poor fitting shoe is another issue. One must always ask a shoe shop for a shoe measurement device to check the width and length of each foot and if the child has orthotics, these must be put in the new shoes before it is purchased.

Another condition is Metatarsus Adductus. In simple words is when having the mid part of foot behind the toes bends towards the inside of the foot. This also can lead to

an aching prominence to the inside of the 1st metatarsal (within the great toe bone) and may predispose to a bunion deformity. If this is diagnosed at an early stage this can be accommodated with orthotics or splints. In a later stage, these cases may require surgical correction.

Callus formation is also a common condition which is caused either by collagen changes in the skin, bad footwear, bony prominences or just the walking pattern.

Basic treatment for these calluses is to apply an emollient daily to keep the skin soft as much as possible but it is advisable to seek a Podiatrist.

After going through these conditions, one can clearly see the importance of Podiatric foot care in children with Down syndrome. Although, down syndromes' feet are a distinctive entity, they still can function and carry the individual through a pleasing life.

By Ivan Farrugia
D Pod SR Pod MPod A SR Ch UK MSc
Podiatry(Glasgow)
Podopaediatric Specialist

ETC Services for Persons with Disability

Application Process

To apply for the Registered Disabled Persons RDP register the applicant should have a recent medical certificate from his/her general practitioner that confirms his/her condition. After the application is completed, an appointment with ETC Doctor who confirms/not confirm the **application**.

All clients listed on the ETC register of disabled persons undergo an assessment from an occupational therapist so as to help in identifying the person's abilities. This strengthens the employment advisor's efforts in matching the client with the available vacancies. Persons with disability are classified into the following:

- intellectual disability
- physical disability &
- persons suffering from mental illnesses

Training Courses

Ad hoc training courses are organised to jobseekers with different disability. These courses are 'tailor made' to accommodate the particular needs of our clients. Furthermore, intellectually disabled clients and those suffering from mental illnesses can also benefit from specialised training through cooperative agreements the ETC has with both the Inspire and Richmond Foundations.

ikompli f'pagna 23



Il-President tal-Għaqda Ms Marthese Mugliette waqt il-prezentazzjoni tal-plakka, maħduma u sponsorjata mis-Sur Louis Galea, lis-Sinjuri Saami u Yusi flimkien mal-koordinatur is-Sur Markus Vahala.

Lill-KMPG li ta' kull sena jiverifikaw il-kotba u l-kontijiet finanzjarji.

Lit-Times of Malta li tirriklama b'xejn l-Assoċjazzjoni tagħna.

Lis-Sinjuri Mary Runza u Jessica Curmi u lill-grupp kollu għall-għajjnuna u s-sapport kontinwu tagħhom. Fiż-żmien tal-Milied dawn ġentilment ħadu ħsieb jagħmlu *fundraising* għall-Assoċjazzjoni tagħna.

Lill-Kumitat Qlub Ġenerużi fi ħdan il-Kumpanija Trelleborg Sealing Solutions Malta għall-ghotja finanzjarja tagħhom.

Lill-Middlesea Valletta Life Assurance Company Ltd li anke din is-sena komplet tagħtina l-appoġġ permezz ta' ħlas ta' polza tal-assigurazzjoni tagħna.

Lill-Commanderjay Music Entertainment għas-servizz li dejjem jagħtuna kull u meta jkollna b'żonn mingħajr ħlas.

Lill-Bank of Valletta plc, u lill-Radiographer Society għad-donazzjoni finanzjarja tagħhom.

Lill-familji Peel, Wetz, Stilon u Borg Cardona għall-għajjnuna finanzjarja tagħhom.

Lill-Paper Chase Stationery għall-ghotja ta' affarijiet li ta lill-Għaqda tagħna.

Lis-Sur Louis Galea li ħadem u sponsorja l-plakka sabiha li nghatat lill-partners tagħna mill-Fillandja fil-proġett *Youth in Action* tifkira tal-okkażjoni.

Christopher Diedo

Christopher boarded flight KM116 for Malta on 11th July of this year not fully appreciating what lay ahead in the form of his first one man photographic exhibition on the island. Although Chris and I had various display and design meetings with John Buttigieg, Marketing Executive at MSV Life, the firm meeting the cost of staging the exhibition, I don't think he actually understood what lay ahead until he stepped out of a taxi and into Auberge d'Italie on opening night! The pre-exhibition planning and visualising was probably all too abstract for Chris who's someone who better understands when he can see and touch for himself, much like when he takes a picture of someone and then approaches and talks to the person.

This is what Chris had to say in his opening exhibition speech given 20th July, 2012 before Mario Demarco, Minister of Tourism, Environment and Culture, David Curmi, CEO of MSV Life and invited guests:

Minister, Ladies and Gentlemen, I am Christopher Diedo from Dartford, Kent. Thank you for coming to see my photos. I hope you find them interesting. This is my first one man show in Malta but I have shown my pictures in galleries across London and in New York. Taking pictures has helped me to see more of my world. I take photos in different places and meet many interesting people. Sharing my world through my photos shows everyone what people



like me can do when people believe in us. My family always tell me to have a go. This is what I can do with my camera. I wonder what I'll try next? Thank you.

Speaking first that night, David Curmi as CEO told us that MSV Life had a long standing connection with the Eden Foundation now known as Inspire and that 13 years ago his firm started what it considered its most important community

programme. He said that since then, MSV Life had gone on to employ 14 young adults with special skills and had decided to sponsor Chris' exhibition because it wanted to highlight another side of the special skills possible but this time, on a creative level. David explained that Chris had agreed to make his photos available on a limited edition basis, giving the proceeds from the sale of the photographs to an NGO - Inspire!

Speaking next, Mario Demarco, the Minister for Tourism, the Environment and Culture, said in his inaugural speech that David hit it spot on when he referred to 'special skills'. Minister Demarco went on to say that everyone was there that night to celebrate the exhibition of an artist - that was the bottom line! He continued saying, that the photographs on display were those of an established and accomplished photographer with artistic talent who had managed to capture people in their true form, capturing a real feel for the people of Valletta.



Minister Demarco also congratulated Chris on the architectural element of his images, which he said he found, "Incredible!"

You may be asking, "Where did it all begin for Chris and what led to him holding his first exhibition?" I think the seeds were sown largely by example and by putting opportunities his way to handle a camera as a child. Whenever I wanted to be in a group picture myself or needed my picture taken, I would usually pass the camera to Chris who enjoyed being given the job. I'm a keen amateur photographer and Chris was often with me as a child and later as a young adult when I was out taking pictures of people and places. It wasn't until 2007 when Chris was 22 that I realised just how influenced he had been by my picture taking and his occasional use of my camera. At the time, I had enjoyed my first one man exhibition at The Mick Jagger Centre - 40 years of my photography! - and Chris had been in and out of the exhibition while it was on. When it ended, I took him with me to help take it down but Chris walked straight up to Nicola Bowden, the Centre manager and I heard him say to her, "What about me?" Her reply given without hesitation was, "Why not?" She could have said, "Bring some of your pictures in to show me and then we'll see," or "I'll need to discuss it with your dad first," but she didn't. Her confidence, trust and enthusiasm to give Chris the opportunity he asked for gave Chris the incentive he needed to show us all what he could do. She wasn't surprised by his request, I was! He spent the next two years enthusiastically building up a portfolio of pictures largely taken along the south east coast and in London. During this time I noticed that Chris wasn't holding his camera in the conventional horizontal or vertical way but instead at an angle to the horizon, I tried to correct this 'abnormality'

but soon came to appreciate this as a natural feature of his photography and so whilst not encouraging it, I now say nothing when he chooses to take pictures this way. He likes to isolate details which he sees in the landscapes and places around him but also takes wider shots. Although I've taught him how to hold and use a camera, it's his natural composition skills which are his strength. By the time the exhibition opened in 2009, he had 60 images ready to show the public, all of which he'd printed up himself in his bedroom. The exhibition was a great success with the public and even inspired pupils and staff of The Grammar School, Dartford, to take part in a creative writing competition organised by the Head of English, Ms. Lambert, based on Christopher's pictures. In July of that year, Chris gave a speech to 900 pupils and staff at the school and presented the winners with their prizes - the framed pictures they had written about. It was a very proud moment for me to see my son up there giving an inspirational speech to some of



the cleverest young minds in Dartford! The Headmaster, Mr. Oaks later told me that for him, it was one of the highlights of the school year.

Photography has helped Chris, who has speech and language problems, to convey what life is like for him. Sometimes people have difficulty understanding what Chris is saying to them, particularly strangers who aren't used to his speech patterns but his photographs transcend verbal language. His images give Chris the chance to show people some of the world he encounters through his camera without ever having to utter a word to them, instead speaking so eloquently through the lens of his camera!

Thankfully, Chris has never encountered any animosity from anyone when he's taken their picture which I'm sure has given him the confidence to approach strangers with his camera. However, he still sometimes looks to me for reassurance asking if they'd mind having their picture taken. In these cases, if it's a shot that would be lost in asking, I usually advise him to take his pictures first and ask them later! I know that Chris likes to engage with the people he photographs so I also encourage him to get close to his subjects and get to know them through polite conversation before raising his camera. Both styles work for Chris and have given him such exhibition pictures as those taken in Malta and in the UK.

This is what Chris sees as his hopes for the future as a photographer:
One day my dream is to photograph the 'Neighbours' cast in Australia. I also want to meet and photograph David Bowie and Mick Jagger. I want to have more exhibitions, maybe in Australia one day. I've already met some of the Eastenders cast at

awards ceremonies organised by Mencap and the Down syndrome Association so if I carry on taking pictures and doing well maybe I'll get to meet them all one day!

This is a list of some of the other things Chris does and also sees as important: I've been an altar server at St. Vincent's RC Church since I was 7 years old and I enjoy it, especially when I'm teaching younger servers what to do. I like swimming and keeping fit. I spend time in my room watching Neighbours and Eastenders, reading graphic novels and telling stories. I belong to DGSM Your Choice in Dartford where I attend a Stepping Stones class to help me learn more about handling money, standing up for myself, computer skills and lots of other things. I also take drama and zumba classes there, go on outings with my friends who also use the centre and I play the bongo drums in their band called Rush Hour.

One of our aims as a family in encouraging Chris' interest in photography and the exhibiting of his pictures, is to challenge and if possible change the public's attitudes towards people with Down syndrome. Many people still think that people who have DS live in institutionalised homes but this isn't always the case any more and certainly isn't the norm. People with DS exercise choice and where parents decide, go to mainstream schools - 20 years ago Chris became the first child with Down syndrome to be placed on the full time roll of a mainstream primary school in NW Kent. People with DS hold down full and part time jobs in the community - Chris did his work experience at John Lewis, Bluewater and at Pizza Hut, Dartford and is enrolled on a Stepping Stones programme to aid his transition to paid employment. With appropriately targeted support, people

with DS are increasingly going on to lead independent and semi independent lives - Chris has made it clear that he'll be leaving home when he's ready!

When Chris was born, we felt sorry for him and ourselves. We thought of all the things he'd never be able to do, of all the opportunities open to his brother and sister but not to him. It was only after we passed through this stage with support from family, friends, the DSA and Mencap that we changed from moving back in reverse gear to gradually moving forward and thinking positively, appreciating our son for the wonderful individual he is and believing in him every bit as much we do our other two children.

Hopefully, Christopher, who has exhibited his work around London, in Kent, New York and now in Valletta, Malta, has taken a big step in showing the public what people with Down syndrome can do when people believe in them and give them opportunities to show what they can do. We'd all do well to remember Nicola Bowden's response to

being asked by Chris if he could hold his own exhibition at The Mick Jagger Centre. It was her response of, "Why not!", which gave Chris his first break. It was David Curmi, CEO of MSV Life who reminded us, speaking before the Minister of Tourism inaugurated Christopher's exhibition in Malta, that we were there to celebrate a young man's special skills rather than his special needs. Proof indeed that attitudes are changing!

We've spent almost all of Christopher's life working at peeling away the label that some people stick on people with Down syndrome as a group, not seeing them as individuals but as a syndrome! Christopher is a person with Down syndrome and not a Down syndrome person! We have to look at the person first and not the syndrome so for that reason, he is an amateur photographer with Down syndrome and not a Down syndrome photographer!

Andrew Diedo
October, 2012

minn paġna 18

Job Coaching and Learning Support Assistance

This service can be offered to Registered Disabled Persons Jobseekers in case they need further assistance on the work place or during the training courses.

The **Bridging the Gap Scheme** offers the jobseeker a period of work exposure with an employer to enable him/her to demonstrate the skills needed for a particular job. Registered disabled persons can benefit from this scheme.

The **Community Work Scheme** provides the long-term unemployed the opportunity to undertake community work under the direction of Local Councils, NGOs and Government entities, with a view of enabling them to obtain further skills, and improving their employability and their chances of finding employment, on completion of such an experience through improving their work ethic.

For more information on how we can be of service to you, please visit the Inclusive Employment Services at ETC at Hal Far, or call us on 2220 1407 or send us an email at support.etc@gov.mt.

DISKORS AMMINISTRATTIV

tas-Segretarju Ġenerali – 29 ta' April 2012

Għaddew sentejn mill-ħatra ta' dan il-Kumitat. Dan ifisser li l-Għaqda tagħna qed terġa' tistedinkom halli turu interess f'dak kollu li qiegħed isir għall-Għaqda u fl-Għaqda tagħna mill-Kumitat. Din l-laqgħa għandha tliet għanijiet. Barra li nsiru nafu l-ħidma li saret is-sena li għaddiet u l-qagħda finanzjarja tal-Għaqda, ikollna l-opportunità li nitkellmu, nissuġġerixxu u nqajmu punti li għandhom x'jaqsmu mal-Għaqda. Din is-sena jerġa' jmiss li nivvutaw għall-membri ġodda fil-Kumitat biex immexxu l-Għaqda minħabba li t-terminu tal-Kumitat preżenti issa wasal fl-aħħar. Forsi naraw uċuh ġodda fil-Kumitat li jkun f'pożizzjoni li jikkontribwixxu ideat ġodda ta' ċertu valur għall-avvanż tal-Għaqda u gwadan għat-tfal tagħna li għandhom Down syndrome.

Biex inżommu l-Għaqda ħajja hemm bżonn l-impenn tal-membri kollha. Għalhekk kull sena nagħmlu appelli sabiex nies ġodda jersqu 'l quddiem, kemm jekk jaħsbu li jistgħu jagħtu kontribut fit-tmexxija tal-Kumitat kif ukoll biex joffru s-servizzi u l-għajnuna tagħhom meta jkun hemm bżonn.

Nagħmlu appell lill-membri kollha biex nuru aktar interess fl-Għaqda, nipparteċipaw aktar fi ħdanha u fl-okkażjonijiet li jkollna, biex b'hekk nagħtu kuraġġ akbar u rieda soda lill-Kumitat biex ikompli bil-ħidma tiegħu halli l-Għaqda tkompli timxi 'l quddiem. L-attendanza tagħkom tkun qed twassal messaġġ ta' inkuraġġiment biex inkomplu mmexxu l-bżonnijiet ta' wliedna 'l quddiem.

Konferenzi

Is-sena li għaddiet l-Għaqda tagħna fakkret it-tletin sena mit-twaqqif tagħha. Il-Kumitat ħaseb biex jiċċelebra dan l-anniversarju billi organizza żewġ konferenzi – waħda f'Malta u oħra f'Għawdex. Iż-żewġ konferenzi, li saru quddiem attendanza sabiħa ħafna trattaw

temi differenti li jolqtu lill-membri tagħna, lill-ġenituri u lill-familjari ta' persuni Down syndrome. Bħas-soltu dawn il-konferenzi kienu miftuħin għal kulhadd u bla ħlas. Fil-konferenza ta' Malta li saret is-Sibt 29 ta' Ottubru 2011 bit-tema 'Is-Saħħa u Persuni Down Syndrome' saret fil-lukanda 'The George Boutique' Paceville. Bħala kelliema ġiet mistiedna Dr Liz Marder mill-Ingilterra li taħdem fil-qasam tas-saħħa mat-tfal Down syndrome. L-informazzjoni li qasmet magħna fuq is-saħħa kien utili ħafna għal dawk preżenti fil-konferenza. Il-Professor Simon Attard Montalto tana stampa tas-sitwazzjoni f'Malta fir-rigward u wkoll, bħal Dr Marder, aċċenna fuq il-ħtieġa li jkun hemm moniteragġ tas-saħħa tal-persuni Down syndrome meta dawn isiru zghazagh u adulti.

Il-konferenza ġewwa Għawdex saret is-Sibt 5 ta' Novembru 2011 bit-tema 'Dak li jolqot lill-Persuni Down Syndrome'. Għall-konferenza f'Għawdex kellna tliet kelliema li indirizzaw il-konferenza fuq temi varji. Dr Isabella Borg, il-Konsulenta Ewlenija tal-Għaqda fuq is-saħħa tkellmet fuq is-saħħa tal-Persuni li għandhom Down syndrome. Dr Elena Tanti-Burlo tkellmet dwar 'L-Għeruq ta' Soċjetà Inklussiva' u r-riżultati pożittivi ta' soċjetà simili u Dr Jean Paul Grech ta informazzjoni dettaljata dwar il-qsim tal-beni tagħna lil ulied b'mod speċjali meta jkun hemm wild Down syndrome fil-parametri tal-liġi fil-pajjiż bħalissa.

Il-Kumitat kien kuntent ħafna bir-riżultat u bl-attendanza ta' dawn iż-żewġ konferenzi għalkemm wieħed irid jgħid li l-attendanza tal-membri tal-Għaqda kienet waħda fjakka. Irridu nsemmu wkoll li l-Għaqda, grazzi għan-National Lotteries Good Causes Fund, ibbilanċjat l-ispejjeż li għamlet biex saru dawn iż-żewġ konferenzi, wara li rċeviet kontribuzzjoni ta' tlett elef Ewro. Dan seta' jsir wara li ġew ipprezentati l-irċevuti fiskali kollha.

Programm għall-adulti

Minn meta kien waqaf il-programm 'Reach' li kien programm ta' tagħlim għall-adulti membri tal-Għaqda, il-Kumitat baqa' jaħdem biex jerġa' jibda programm ieħor simili. Il-President u membri oħra tal-Kumitat kellhom diversi laqgħat mal-awtoritajiet konċernati u kien ġie aċċettat il-prinċipju biex il-membri tagħna adulti li għandhom Down syndrome ikollhom l-opportunità li jkomplu bit-tagħlim tagħhom skont l-abilitajiet tagħhom fiċ-Ċentru tagħna bl-edukaturi pprovduti mill-awtoritajiet. Kienet saħansitra saret laqgħa tad-diskussjoni fiċ-Ċentru għall-membri u l-familji tagħhom mad-Direttur tal-Life Long Learning fil-preżenza tal-Kumitat biex jiġi spjegat x'kienu qed jippretendu minn dan il-programm il-ġenituri. Dan biex id-dipartiment ikollu linja gwida fit-tweqqif ta' dan il-programm. Għalkemm l-Għaqda baqgħet f'kuntatt mal-istess Dipartiment biex ninfurmaw rwieħna fir-rigward, minkejja li tajniehom l-informazzjoni li talbuna u minkejja li waqt il-laqgħa kienu pożittivi fir-rigward, jidher li għal xi raġuni, m'għadhomx daqshekk pożittivi. B'danakollu l-pressjoni tal-Għaqda għadha hemm għax verament nemmnu li ż-zghazagh tagħna għandhom dritt għall-Life Long Learning bħal kull żagħżuġ/a ieħor/oħra. L-għan tal-Kumitat huwa li dan il-programm isir realtà. Għalhekk il-kuntatti għadhom miftuħin u kwalunkwe informazzjoni mitluba mill-Għaqda nagħmlu mezz biex inkunu pronti biex nagħtuha lid-Direttur tal-Life Long Learning.

Youth in Action Project

Dan il-proġett seħħ bejn is-sittax u l-wieħed u għoxrin ta' Marzu 2012. Il-proġett kien ilu mfassal bħala idea li kellu jseħħ bil-fond tal-Unjoni Ewropea iżda kellu jieqaf meta l-fondi għall-proġetti kollha kienu ġew iffriżati nkluż l-applikazzjoni tal-Għaqda. Meta l-applikazzjonijiet għall-proġetti kienu reġġu fethu, l-Għaqda kellha terġa' timla l-applikazzjoni mill-ġdid biex tiġi kkunsidrata

u finalment aċċettat. Il-proġett jikkonsisti billi żewġ persuni b'nuqqas intellettuali minn Finlandja ġew Malta mal-assistenti tagħhom biex jiddiskutu magħna, juruna u jgħallmuna ħiliet u metodi ta' kif niżviluppaw attivitajiet għall-'media' għall-membri tagħna. L-għan tal-proġett huwa biex insaħħu kooperazzjoni bejn iż-żewġ organizzazzjonijiet u biex niżviluppaw stazzjonijiet ġurnalistiċi u attivitajiet fir-rigward għall-membri tagħna, kif hemm fil-Finlandja.

Jum Dinji tad-Down Syndrome

21 ta' Marzu - Din il-ġurnata hija ddedikat lid-Down Syndrome u rikonnoxxuta mad-dinja kollha. Din is-sena kienet is-sitt sena li l-Għaqda tagħna nqas ma' Għaqdiet oħra madwar id-dinja biex jifakkur dan il-jum. In-Nazzjonijiet Uniti kienet għaddiet riżoluzzjoni biex il-21 ta' Marzu jibda jittqies bħala l-Jum Dinji ddedikat lid-Down Syndrome. Minn din is-sena, il-UN stiednet lill-iStat Membri biex josservaw dan il-jum u biex iqajmu kuxjenza dwar din il-kundizzjoni.

Il-Kumitat ħaseb biex f'dan il-jum jorganizza disco ġewwa d-Dukes Disco Marina Hotel San Ġiljan, disco li tant huwa apprezzat u mixtieq mill-membri tagħna.

Servizz ta' Moniteragġ tas-saħħa għall-Adulti Down Syndrome

Wara 'l fuq minn sitt snin ta' ħidma, laqgħat u pressjoni u forsi grazzi għall-konferenza li għamilna għeluq it-tletin sena li trattat fuq is-saħħa, fl-aħħar l-għan tal-Kumitat saret fatt li kien sejjer jittwettaq. Għall-ewwel darba, l-Għaqda tagħna se tkun involuta direttament f'dan is-servizz li se jingħata lill-persuni adulti li għandhom Down Syndrome. Dan is-servizz ġie varjat il-Ħamis, 23 ta' Frar 2012 u sejjer jara l-bidu tiegħu għall-aħħar ta' Mejju. Bħalissa qiegħda ssir ħidma mit-Team Amministrattiv li qiegħed jaħdem bla heda biex ihejji halli jkollna servizz

professionali għall-benefiċċju tal-persuni kollha Down syndrome. Dan is-servizz seta' jsir possibli grazzi għall-interess u s-sapport tal-Ministru għas-Saħħa, l-Onor. Dr Joe Cassar. Dan il-Ministru għamel dak li għandu jsir f'kull qasam ta' bżonnijiet speċjali – involva direttament lill-Għaqda f'dak li għandu x'jaqsam mal-membri tagħna. Il-Ministru Cassar haqqu prosit u ringrazzjament mill-qalb.

Għall-fini tal-bidu ta' dan is-servizz li sejjer jingħata fil-*polyclinic* ta' B'Kara u li huwa indirizzat għal kull persuna li għandha Down syndrome minn sittax-il sena 'l fuq, l-Għaqda qiegħda titlob lill-membri u anke dawk li mhumiex, biex iċemplulna biex jirreġistraw l-interess tagħhom. Dr Dorothy Zammit hija t-tabiba li se tkun responsabbli minn din il-klinika. Hija ntgħazlet wara li saru *interviews* lil dawk it-tobba li kienu wrew interess. Permezz ta' dan is-servizz, fl-aħħar se nserrhu rasna li saħħet uliedna se tibqa' tiġi segwita matul hajjithom kollha biex jekk ikun hemm bidu ta' xi problema tinqabad minn kmieni ħalli b'hekk nikkurawha minn kmieni.

Hajja Indipendenti

L-Għaqda tagħna għandha fuq l-aġenda wkoll il-hajja indipendenti għall-persuni Down syndrome. L-Għaqda tixtieq issib l-aħjar soluzzjoni għal dan il-ħsieb li dejjem iberren fuq moħħna l-ġenituri. Biex aħna l-membri tal-Għaqda ninfurmaw rwieħna dwar dan is-suġġett u nkunu f'pożizzjoni aħjar biex naraw kif l-Għaqda tista' tindirizza dan il-bżonn, saret taħdita fit-13 ta' April 2012 fiċ-Ċentru tagħna mis-Sur Ronald Galea, l-Amministratur ta' Dar il-Wens fejn tkellem dwar x'irnexxielu jagħmel hu fir-rigward ma' persuni b'nuqqas intelletwali u kif qegħdin u għandhom jaħdmu residenzi simili.

MEUSAC

Fil-MEUSAC l-Għaqda hija rrapprezentanta minn Pio Fenech fil-Kumitat Settorjali għall-Impjiegi, Edukazzjoni u Saħħa.

Attivitajiet

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

Fuq talba ta' whud mill-membri, il-ħarġa tas-sajf reġgħet saret lis-Splash & Fun Park, Baħar iċ-Ċagħaq l-Erbgħa 3 ta' Awwissu 2011. Bhas-soltu l-prezz kien jinkludi dħul tal-faċilitajiet, burger, chips u xarba għal nofsinhar u te/kafè u *cake* għal ħin tat-te.

Bar-b-que organizza mill-Aġenzija Żgħażaġh għall-membri, familjari u ħbieb sar il-Ġimgħa 19 ta' Awwissu 2011 fil-Ġnien tal-Aġenzija Żgħażaġh, Sta Venera.

Bhas-snin l-imġhodidja ġiet organizzata l-attività tal-Milied. Din saret il-Fladd 18 ta' Diċembru 2011. Kien hemm ħafna ħidma biex jinsab post mhux tas-soltu, imma tajjeb għalina biex niċcelebraw dan iż-żmien ta' ferħ ma' xulxin. L-attività saret fir-Razzett tal-Ħbiberija Marsascalea. Barra l-ikel kien hemm ukoll il-mużika li kienet f'idejn Commanderjay Music Entertainment. L-Għaqda ma qassmitx rigali u minflok tat is-sussidju għall-ikla lill-membri Down Syndrome – l-Għaqda hallset l-ikla għal kull membru Down syndrome li attenda.

Attività oħra fiż-żminijiet tal-Milied u li tkun mistennija ħafna miż-żgħażaġh tagħna tkun id-disco. Din l-attività saret fid-29 ta' Diċembru 2011 fid-*disco club* tas-Suncrest Hotel il-Qawra. Barra d-disco kien hemm ukoll riċeviment żgħir u l-mużika waqt l-attività kienet f'idejn Commanderjay Music Entertainment.

Attività oħra li kienet ta' sorpiża għal kulħadd kienet l-Istedina li kellha l-Għaqda f'Lulju 2011. Grazzi għan-nominazzjoni ta' Ms Carley Barnes, is-Sur Dave McCarthy, Direttur Maniġerjali ta' *Sheffield United FC*, għamel kuntatt mal-President, biex jagħmlu attività mal-membri tagħna meta kellhom ikunu f'Malta f'dak ix-xahar stess. Din l-attività xejn mistennija ħabtet mas-sena li l-Għaqda kienet qed tiċcelebra t-30 anniversarju. Il-membri tagħna ħadu sehem f'taħriġ tal-ballun mal-*footballers* ta' *Sheffield United FC* fil-grounds tal-football f'Ta' Qali. It-team ta' *Sheffield* ipprezentaw lill-Għaqda *t-shirt* iffirmit mill-*players* kollha u li llum jinsab imdendel fiċ-Ċentru. Min-naħa l-oħra l-Għaqda pprezentat plakka tal-okkazzjoni li kienet saret mis-Sur Louis Galea mill-Furjana. Huwa taha bhala rigal lill-Għaqda.

Servizzi tal-Għaqda

Lezzjonijiet tal-Crafts, Aerobics u Computers: Dawn is-servizzi, minn persuni kwalifikati, qed jiġu offruti mill-membri tagħna bniet u subien u ssussidjati bil-bosta mill-Għaqda.

Quddies tal-Ewwel Ġimgħa tax-Xahar

Ma nistgħux ninsew il-quddiesa ta' kull l-ewwel Ġimgħa tax-xahar fiċ-Ċentru fejn wara wiehed ikun jista' jiehu l-kafè u l-pastizzi u jilgħab it-tombla.

Magazin

Il-magazin taht id-direzzjoni tal-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 ikollhom bżonn ta' xi għajnuna, il-membri tal-Kumitat ikunu lesti jgħinukom b'xi kitba u/jew intervista, jekk hemm bżonn fid-dar tagħkom stess.

Il-magazin qiegħed jiġi ppubblikat b'diffikultà kbira, anke finanzjarja. 50 fil-mija tan-nefqa għall-posta tingħata lura mill-Kummissjoni Nazzjonali Persuni b'Dizabilità wara applikazzjoni. Il-flus biex jithallas dan il-magazin iridu jiġu mill-ġbir ta' fondi, għax reklami, jew għajnuna diretta jew indiretta biex intaffu l-ispejjeż tiegħu m'għadniex insibu.

Laqgħat

Il-President tal-Għaqda, il-Viċi President u l-PRO ħadu sehem f'diversi laqgħat li kienu ta' interess jew importanza għall-Għaqda fosthom kien hemm:-

Laqgħa mal-Ministru Dolores Cristina fejn ġew diskussi: *Supported Employment, Life Long Learning* għal persuni Down syndrome, il-Bord tal-KNPD u nies b'nuqqas intelletwali.

Laqgħat mad-dipartimenti tal-artijiet bl-għan li l-Għaqda tiġi mogħtija xi proprjetà adekwata għall-bżonnijiet tal-Għaqda biex jinfetaħ Social Club għall-membri.

Laqgħat mad-dipartimenti tal-Life Long Learning u Supported Employment.

Barra minn dawn il-laqgħat u oħrajn, wiehed irid isemmi wkoll id-diversi programmi li ppartecipat fihom il-President tal-Għaqda fuq ir-radju u x-xandir fejn ġew trattati suġġetti u issues li jolqtu d-Down syndrome.

Konklużjoni

Hemm bżonn li membri b'ideat ġodda jsibu posthom fil-Kumitat, anke jkunu lesti jieħdu post il-membri tal-Kumitat li ilhom iservu għal bosta snin. Nies ġodda fi ħdan il-Kumitat ifisser ideat ġodda u dan huwa importanti ħafna biex l-Għaqda tad-Down Syndrome tkompli tikber, tiffjorixxi u tkompli tisemma u tagħmel isem tajjeb frott il-ħidma fejjieda tagħha għall-benefiċċju ta' wliedna.



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